

PROJECT

LIFECHAMPS: A Collective Intelligence Platform to Support Cancer Champions

GRANT AGREEMENT No.

875329

DELIVERABLE

D2.5 - End-user/stakeholder requirements – final version

CONTRACTUAL SUBMISSION DATE

31/01/2021

ACTUAL SUBMISSION DATE

31/01/2021

DELIVERABLE VERSION

3.0

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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	Emmanuelle Huck

DELIVERABLE DOCUMENTATION

Deliverable Title	D2.5 - End-user/stakeholder requirements – final version
Deliverable No.	D2.5
Deliverable Version	3.0
Deliverable Filename	LIFECHAMPS_D2.5_v3.0.docx
Nature of Deliverable	R (document, report)
Dissemination Level	PU (public)
Number of Pages	110
Related Work Package	WP2
Lead Beneficiary	UofG

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	06/01/2021	Contents page layout	Dr Grigorios Kotronoulas
V0.2	11/01/2021	Synthesis of results and draft report	Dr Rebecca Marshall-McKenna
V0.3	15/01/2021	Content review and edits	Dr Grigorios Kotronoulas
V0.4	16/01/2021	Added content to sections 5.4 and 6	Dr Grigorios Kotronoulas

V0.5	17/01/2021	Added content to sections 5.3	Dr Rebecca Marshall-McKenna
V0.6	18/01/2021	Edits and updated tables	Dr Rebecca Marshall-McKenna Sheena McGowan
V1.0	18/01/2021	Executive summary, final check and upgrade to V1.0 for submission	Dr Grigorios Kotronoulas
V1.1	25/01/2021	Amendments and updates following reviewers' feedback	Dr Rebecca Marshall-McKenna
V1.2	26/01/2021	Content reviewed	Sheena McGowan
V2.0	27/01/2021	Final check and upgrade to V2.0 for submission	Dr Grigorios Kotronoulas
V2.1	31/01/2021	Review of final comments	Dr Grigorios Kotronoulas
V3.0	31/01/2021	Upgraded to final version for EC submission	Prof. 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
PREM	Patient reported experience measures
PROM	Patient reported outcome measure
PUC	Pilot use case
RQ	Research Question
WHO	World Health Organization

1 EXECUTIVE SUMMARY

The goal of deliverable D2.5 is to provide a final report on the research methods employed within Task 2.2 and the results of our investigation of post-treatment experiences and healthcare requirements from the perspectives of middle-aged/older patients and family members/caregivers, as well as those of healthcare professionals and managers involved in their care. Secondly, we investigated expectations of these end-user groups and desired functionality of the developing LifeChamps platform. In this report, we provide details of a prospective mixed-methods study that was initiated at four partner sites by employing a descriptive and cross-sectional study design.

As identified in the initial report, a major challenge to setting up this study was the COVID-19 pandemic which was declared around the same time as our ethics applications were due for submission. After careful consideration that involved a formal risk assessment plan, we 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 delays we experienced. Our plan was successful. Ethical approvals at the partner sites were obtained on time, and recruitment started soon after. Despite the ongoing restrictions and the subsequent impact on recruitment, our methods allowed scope to merge modes of data collection and analyse data via thematic framework analysis.

Collectively, our rigorous work allowed for our recruitment goals to be achieved, and we surpassed the minimum recruitment target of 120 participants in total. At the end of November 2020, 155 end-users were recruited across groups and partners. The total sample included 70 patients, 23 family members/caregivers, 56 health professionals, and 6 health managers. At a country-specific level, accrual rates varied widely, which can be attributed to several influencing factors, including differences in recruitment start date among sites and differences in annual holiday periods, which affected availability of potential participants.

Our analysis offers varied insights into the perspectives of end-users in relation to post-treatment care for breast cancer, prostate cancer and melanoma, and the requirements for developing the LifeChamps system, that must be met, to provide the anticipated support in practice. Converging evidence suggests that key priorities and issues for middle-aged/older patients and their family members/caregivers in the post-treatment period are:

- Maintaining good physical and mental health, despite continuing physical problems. Management of physical symptoms such as fatigue, deconditioning and side effects of endocrine treatment were viewed as the main health needs.
- Tackling psychological and emotional needs that are prevalent and persistent, more so in 50-64 year age group. Advice on self-management strategies and management of fear of recurrence was key.
- Support from high-demand services of psycho-oncology, geriatrics, social work, physiotherapy, endocrinology and dermatology.
- Receiving practical and daily living advice. More in-depth information for patients and family members/caregivers is required about how to manage (instrumental) activities of daily living, possible side-effects, the disease itself, and the fluctuating needs for support.

- Receiving support that is individualised, multidisciplinary and that attends to such issues as functional decline due to aging, functional decline due to cancer, and burden of multimorbidity.
- Receiving care that is closer to home/community is required, also providing a network of support for social isolation and psychological support. Specialist cancer nurses are viewed as the best point of contact post-cancer treatment.
- The COVID-19 pandemic has had dramatic effects on older adults' experiences of health access to clinics and with daily living in the community. The fear of getting sick with the coronavirus and that hospitals may collapse are common concerns. Closer monitoring of patients during the pandemic to prevent social isolation and missed health care.

Key end-user expectations, desired functionality and implementation aspects related to the developing LifeChamps system are as follows:

Expected advantages: Potential improvements in monitoring multiple types of information; Speed of referral and care pathway; Easy health care access; Quick advice and help; Better patient-clinician communication; Enhanced clinician-clinician collaboration; and Identification of patients' unmet needs.

Anticipated challenges: Lack of comfort in using advanced technology (particularly older patients); Issues with personal data use; Falsely predicting issues that may not occur; Security risks; Restriction of physical contact; Issues with compatibility with existing healthcare systems; and Capacity in relation to time/workload and availability of personnel to address patient issues as they arise.

Desired functionality: Up-to-date and timely information to patients and their family members/caregivers. Regular information to health professionals about the physical and psychological status of the patient. Tailored clinical support based on each patient's data. Health professionals must be able to design a new treatment plan and re-define goals involving the patient's perspective. Careful attendance must be paid to system design, operability, integration, and accessibility to prevent additional workload to clinicians. Clinicians must be able to monitor clinical signs or alarming symptoms of cancer recurrence, as well as signs of patient depression and/or fear of recurrence.

Implementation aspects: Thorough training must be provided to end-users before the system is deployed. Information provided by the developing platform must be available on demand to accommodate varying clinical needs as they emerge and at the time of a patient's follow-up review. The information provided by the developing platform must be presented in the patient's electronic health record. To be implemented, the developing system must be compatible with the already existing patient electronic record and clinical portals. Close collaboration between end-users and IT support is crucial, complemented by adequate access, connectivity and hardware to enable smooth running. The system must be made available on demand on the patient's phone and be easy to access/use to involve even those who feel less comfortable with technology.

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 2020, 9.9 million new cases of cancer were registered in adults aged ≥ 65 years; that was 51.6% of the total number of new cancer cases worldwide [2]. 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 anticancer 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). 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).

To this end, the aim of Task 2.2 was 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, as well as their views, preferences and expectations from the developing LifeChamps platform. This report (D2.5) presents the aims set for Task 2.2, the research methods and procedures which included the flexible and adaptable plan to achieve our goals despite the impact of the COVID-19 pandemic, the analysis and interpretation of the results from the four partner sites and finally the conclusions of this task.

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 addressed were 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

This was a prospective mixed methods study, employing a descriptive and cross-sectional study design.

All research activities were planned to take place in accordance with the World Medical Association Declaration of Helsinki [4].

4.2 TARGET PARTICIPANTS

We used a strong engagement strategy to consult with relevant end-users (section 4.9.1), including:

- Middle-aged people (50-64 years) and older people (≥ 65 years) 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
<ul style="list-style-type: none"> • 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 (breast, prostate, or melanoma) and living beyond initial cancer treatment (curative/incurable) 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).

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

Eligibility Criteria

- Oncology consultants (specialists), 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 [5]. 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, we opted for data collection to be a combination of online surveys and telephone interviews (one to one or focus group where possible) with the goal 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 also orchestrated pilot use case (PUC) scenarios at their respective sites, i.e. APC (Sweden), AUTH (Greece), HULAFE (Spain) and UofG (UK).

Surveys and interviews ran in parallel at the four partner countries. Interviews complemented survey data and allowed for exploration of opinions/issues following a guided script.

The online surveys were set up via the EU Survey tool². This is an established online tool for the management of global surveys offering maximum data protection, confidentiality and translation into multiple languages. See Appendix 8.5 for screenshots of the EU Survey tool.

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

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 and family members/caregivers)

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)

(For health professionals/health managers)

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

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 were 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 were asked to participate in 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).

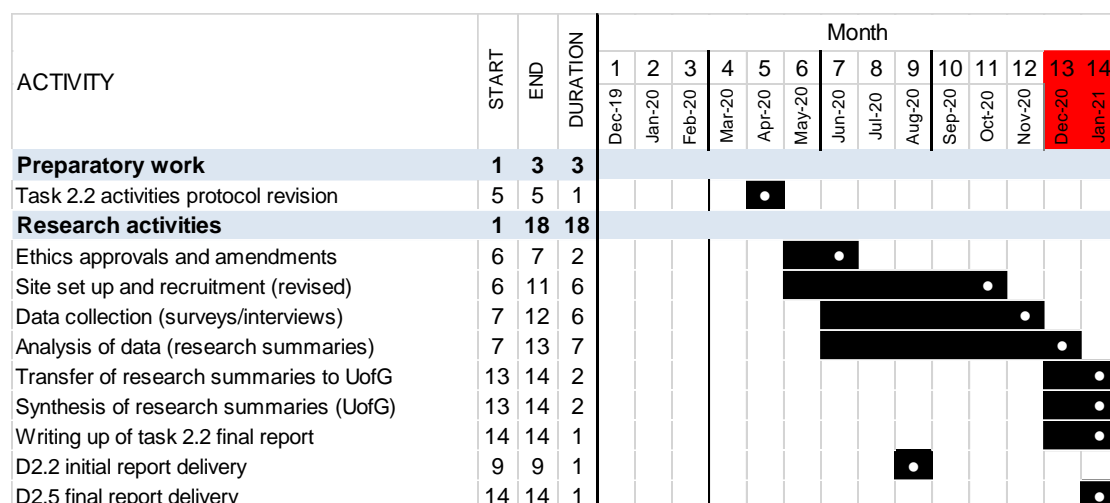


FIGURE 1 GANTT CHART OF TASK 2.2 TIMELINES (REVISED FOR COVID-19)

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

For online surveys, 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 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 4. 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 [5].

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, 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 $0.75 \times 0.75 = 0.56$ 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 [5].

Table 4 shows 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 3 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 4 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 agreed 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 had 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 had 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 snowball sampling, whereby we invited 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 were 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 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.

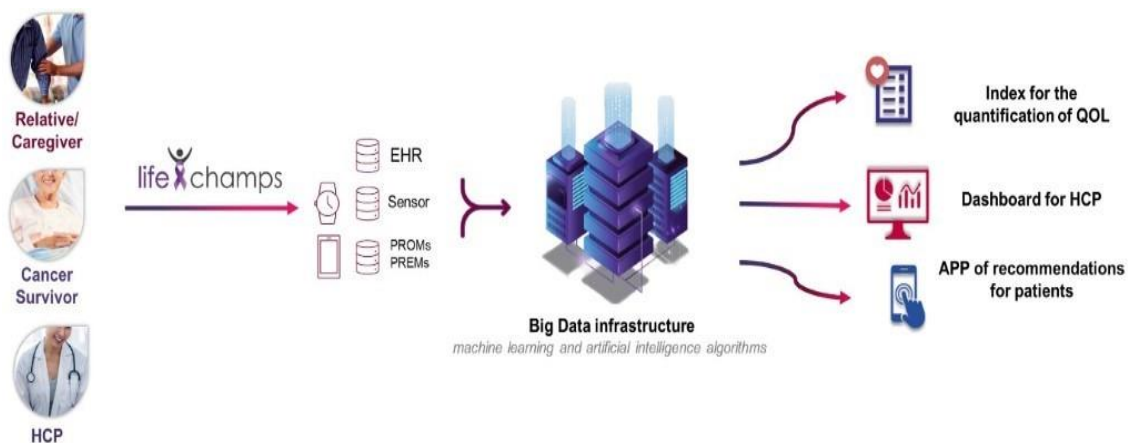


FIGURE 2 DIAGRAM OF LOW FIDELITY PROTOTYPE

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 8.2). 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.

4.7 DATA MANAGEMENT AND ANALYSIS

Research participants' personal data (i.e. names, home/work/email addresses, phone numbers) were set to be securely destroyed within 3 months after the end of Task 2.2. Once personal data are 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 have supplied in the course of the surveys/interviews were set to 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 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. 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 the analysis of their own raw research data as generated at their respective sites/countries. Specific instructions for the analysis of research data were provided in a data analysis scheme appearing in Appendix 8.3. Each partner created a 'Summary of Findings' (see Appendix 8.4) containing processed (but no raw) and fully anonymised research data written in English for subsequent evidence synthesis purposes.

4.8 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 5 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)	Swedish Ethical Review Authority	Aristotle University of Thessaloniki Ethics Committee
Date of ethics application	2 nd week in April 2020	2 nd week in April 2020	2 nd week in April 2020	2 nd 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 5 SUMMARY OF SITE ETHICS APPROVALS AND START DATES

4.9 EFFICIENCY OF RECRUITMENT MODES

We closely followed our revised recruitment plan. For group 1 and 2 end-users, we engaged with health professionals and personnel employed at local charitable organisations and hospitals, who indeed provided potential participants with information about the study via text or email. However, due to the continued disruptions caused by the pandemic the majority of charitable organisations and

regular routes of recruitment had limited services, thus the priority was on providing support to patients, not to research.

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 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 [6]. Thus, for those who contacted the researchers directly for information regarding the study we would send a reminder after several days via email (if provided). In the UK, even a prize draw for shopping vouchers has been implemented to offer a small honorarium to compensate them for their time on the study without increasing the risk for undue coercion [7]. We had 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 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 actively employed our referral technique, asking clinicians to also invite other colleagues to consider participation. This technique helped us widen the pool of potential participants.

5 RESULTS

5.1 ACCRUAL RATES

At the end of Month 12, a total of 155 end-users had been recruited across groups and partners. Collectively, the total accrual rates surpassed the minimum recruitment target of 80 participants for end-user groups 1 and 2 (n=93 patients and family carers) for surveys/interviews, and that of 40 participants for end-user groups 3 and 4 (n=62 health professionals and health managers) for surveys/interviews. A total of 135 end-users completed the online survey, while 20 end-users took part in a telephone/online interview.

On a partner level, accrual rates varied widely (Table 6), which can be attributed to several influencing factors. All were engaged in numerous methods of promoting recruitment at each site (Appendix 8.1), differences in recruitment start date among sites and annual holiday periods (July for some countries, August for others) and the continuing impact of COVID-19 on members of the public. Charitable organisations were facing redundancy of staff, limited resources and were understandably prioritising patient support. Moreover, health professionals have continued to experience increased pressure and workloads due to infection, re-distribution, or furlough, all of which 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 or interviews	Cancer Patients	20-65	35	215%	9	70%	7	35%	19	145%	80-260	70	116%
	Family / Friends / Carers		8		5		0		10			23	
	Health Professionals	10-35	22	230%	3	30%	12	130%	19	230%	40-140	56	155%
	Health Managers		1		0		1		4			6	
	Total target n per partner	30-100	66	220%	17	57%	20	67%	52	173%	120-400	155	129%

¹Accrual rate = (Actual n / minimum Target n) x100.

TABLE 6 SUMMARY OF TOTAL AND COUNTRY ACCRUAL RATES

5.2 DESCRIPTION OF THE SAMPLE

5.2.1 PATIENTS

Collectively, we recruited 70 patient participants, of which 59 completed the online survey and 11 undertook the telephone/online interview. Most patients who completed the survey were treated for breast cancer (67%); there was less engagement from patients with prostate cancer or melanoma across the partner sites (23%).

Almost half the patients who participated were below the age of 60 years (47%) and 34% were between 60 and 69 years. Thirty-three per cent of our sample was aged 65 and above. As age inclined there were fewer participants with only two participants in the 80-84 age group.

The time since completion of treatment varied across partners. Most patients completed treatment over 25 months ago (54%) and 29% within the last 12 months. 50% of patients had at least one comorbidity and hypertension was the most frequently reported (33%) (Table 7). The data revealed 65% of patients had a comorbidity before they were diagnosed with cancer and whilst 35% reported their comorbidity/comorbidities had deteriorated, 65% reported their status had remained the same. Only one participant reported having six comorbidities.

Variables	Responses	n (%)
Gender	Female	49 (70)
	Male	21 (30)
Age (years)	55-59	20 (28.8)
	50-54	13 (18.6)
	60-64	13 (18.6)
	65-69	11 (15.7)
	70-74	6 (8.6)
	75-79	4 (5.7)
	80-84	2 (2.9)
	85-89	0
	90+	0
	Unknown	1 (1.4)
Type of cancer	Breast cancer	47 (67.1)
	Prostate cancer	16 (22.9)
	Skin cancer	7 (10)

Time since end of treatment (months)	25+	38 (54.3)
	7-12	12 (17.1)
	1-6	8 (11.4)
	13-18	6 (8.6)
	19-24	5 (7.1)
	less than one	1 (1.4)
Number comorbidities	1-2	35 (50)
	0	30 (42.9)
	3-5	3 (4.3)
	6-10	1 (1.4)
	Unknown	1 (1.4)
Name of comorbidities	Hypertension (Cardiovascular)	13 (32.5)
	Osteoporosis (Musculoskeletal)	4 (10)
	Asthma (Respiratory)	3 (7.5)
	Diabetes (Endocrine, metabolic and nutrition)	3 (7.5)
	Heart Disease (Cardiovascular)	3 (7.5)
	Hypothyroidism (Endocrine)	2 (5)
	Osteoarthritis (Musculoskeletal)	2 (5)
	Fibromyalgia (Musculoskeletal)	2 (5)
	Lymphoedema (Blood and lymphatics)	2 (5)
	COPD (Respiratory)	2 (5)
	Cirrhosis (Digestive system)	1 (2.5)
	Aortic Stenosis (Cardiovascular)	1 (2.5)
	Atrial Fibrillation (Cardiovascular)	1 (2.5)
	Bladder cancer (non-pulmonary cancer)	1 (2.5)
	Osteopenia (Musculoskeletal)	1 (2.5)
	Melanoma (non-pulmonary cancer)	1 (2.5)
	Chronic Bronchitis (Respiratory)	1 (2.5)
	Interstitial Lung Disease (Respiratory)	1 (2.5)
	Poliomyelitis (Neurological)	1 (2.5)
	Loss of one eye (Eye and Ear)	1 (2.5)
Neuropathy (other-General)	1 (2.5)	
Retrocecal cystic hamartomas (other – General)	1 (2.5)	
Crohn's Disease (Other-general)	1 (2.5)	
Meniere's disease (Other – general)	1 (2.5)	

	Pulmonary embolism (Other – Respiratory)	1 (2.5)
	Adrenal insufficiency (Other – immune system)	1 (2.5)
	Aortic Aneurysm (other-General)	1 (2.5)
	Thrombophilia (other – Blood and Lymphatics)	1 (2.5)
	Intestinal Polyps (other – Digestive)	1 (2.5)
Timing of comorbidities diagnosis	Before Cancer	26 (65)
	Post Cancer	11 (27.5)
	side effect of cancer treatment	7 (17.5)
	During Cancer	4 (40)
	No information	9 (22.5)
Current status of comorbidities	Stayed same	26 (65)
	Got worse	14 (35)
	No information	14 (35)
	Got better	3 (7.5)

TABLE 7 SUMMARY OF PATIENT CHARACTERISTICS ACROSS PARTNER SITES

5.2.2 FAMILY MEMBERS / CAREGIVERS

Across partner sites we recruited a total of 23 caregivers of which, 20 completed the online survey and three participated in a telephone/online interview (Table 8). Most participating family members / caregivers were female (83%) and were the daughters of patients with breast cancer (44%). Only one son had been recruited by AUTH. Three participants did not disclose their relationship to the patient with cancer. Two caregivers provided care to patients with melanoma.

Practical aspects of care were the main areas of support provided by caregivers. Similar to the data collected from patients (Section 5.2.1), caregivers had provided support to patients who had ended their treatment over 25 months ago (43.5%). However, there were almost an equal number of caregivers who had provided support within the last six months (39%) from the date they were involved in Task 2.2. Over half of the caregivers had no comorbidities (65%), and only one caregiver reported that their comorbidity status had got worse since providing support to a patient with cancer.

However, 61% of patients being supported by family/caregiver's had at least one comorbidity, of which 17% had reported having between three and five comorbidities. Yet, most comorbidities were diagnosed before cancer (54%) and from the caregiver's perspective their patient's health status (comorbidity) had stayed the same since the diagnosis of cancer (46%). Despite 52% of caregiver's not being a direct relative (e.g., wife/partner), there was a similarity between the patients they were supporting in the top four comorbidities (hypertension, diabetes, osteoporosis and heart disease).

Variables	Responses	n (%)
Gender	Female	19 (82.6)
	Male	4 (17.4)
Age of caregiver (years)	50-54	10 (43.5)
	35-49	5 (21.7)
	18-34	4 (17.4)
	65-69	3 (13)
	Unknown	1 (4.3)
Patient's type of cancer	Breast cancer	13 (56.5)
	Prostate cancer	8 (34.8)
	Skin cancer	2 (8.7)
Age of patient with cancer (years)	Unknown	8 (34.8)
	65-69	4 (17.4)
	60-64	4 (17.4)
	50-54	3 (13.0)
	80-84	3 (13.0)
	85-89	2 (8.7)
	70-74	1 (4.3)
	55-59	1 (4.3)
	75-79	0
	90+	0
Relationship to patient	Daughter	10 (43.5)
	Wife / Partner	5 (21.7)
	Husband / Partner	3 (13)
	Other	3 (13)
	Sister-in-law	1 (4.3)
	Son	1 (4.3)
Support to patient	Practical	15 (65.2)
	Emotional	4 (17.4)
	Both	2 (8.6)
	No information	2 (8.6)
Time since patient's end of treatment (months)	25+	10 (43.5)
	1-6	9 (39.1)
	19-24	2 (8.7)

	13-18	1 (4.3)
	7-12	1 (4.3)
	less than one	0
Number of Caregiver comorbidities	0	15 (65.2)
	1-2	7 (30.4)
	3-5	1 (4.3)
Name of caregiver comorbidities	Hypertension (Cardiovascular)	13 (32.5)
	Osteoporosis (Musculoskeletal)	4 (10)
	Diabetes (Endocrine, metabolic and nutrition)	1 (12.5)
	Heart Disease (Cardiovascular)	1 (12.5)
	Osteoarthritis (Musculoskeletal)	1 (12.5)
	Fibromyalgia (Musculoskeletal)	1 (12.5)
	Hypertension (Cardiovascular)	1 (12.5)
	Uterus Cancer (non-pulmonary cancer)	1 (12.5)
	Diverticular Disease (Digestive system)	1 (12.5)
	Atrial Fibrillation (Cardiovascular)	1 (12.5)
	Thyroid Hashimoto (Endocrine, metabolic and nutrition)	1 (12.5)
	Hiatal hernia (Digestive)	1 (12.5)
	Trigeminal neuralgia (other-neurological)	1 (12.5)
	Tinnitus (other-general)	1 (12.5)
Timing of Caregiver comorbidities diagnosis	No information	17 (65.3)
	Before caring for patient	5 (19.2)
	At same time caring for patient	2 (7.7)
	After caring for patient	2 (7.7)
Current status of caregiver's comorbidities	No information	16 (61.5)
	Stayed same	6 (23.1)
	Got better	3 (11.5)
	Got worse	1 (3.9)
Number of patient's comorbidities	1-2	10 (43.5)
	0	9 (39.1)
	3-5	4 (17.4)
Name of patient's comorbidities	Diabetes (Endocrine, metabolic and nutrition)	7 (25)
	Osteoporosis (Musculoskeletal)	5 (17.9)
	Hypertension (Cardiovascular)	4 (14.3)

	Heart Disease (Cardiovascular)	2 (7.1)
	Migraine Headache (Neurological)	1 (3.6)
	Arthralgia (Musculoskeletal)	1 (3.6)
	Osteoporosis (Musculoskeletal)	1 (3.6)
	COPD (Respiratory)	1 (3.6)
	Asthma (Respiratory)	1 (3.6)
	Atypical Angina (other)	1 (3.6)
	Pulmonary embolism (Other)	1 (3.6)
	Hypotension (other)	1 (3.6)
	Brain Degeneration (Other)	1 (3.6)
	Chronic Fatigue Syndrome (other)	1 (3.6)
Timing of patient's comorbidities in relation to cancer diagnosis	Before Cancer	15 (53.6)
	No information	5 (17.9)
	During Cancer treatment	4 (14.3)
	Post-cancer treatment	4 (14.3)
Patient current status of comorbidities	Stayed same	13 (46.4)
	No information	8 (28.6)
	Got worse	4 (14.3)
	Got better	3 (10.7)

TABLE 8 SUMMARY OF CAREGIVER CHARACTERISTICS ACROSS PARTNER SITES

5.2.3 HEALTHCARE PROFESSIONALS / HEALTH MANAGERS

The pandemic affected staffing resources as clinicians were redistributed, furloughed or were facing increased clinical pressures across all partner sites. Despite this, we were able to recruit 57 healthcare professionals, of which 53 clinicians participated via the online survey and four via telephone/online interviews.

Most healthcare professionals were female (72%) (Table 9). The most prevalent clinical role was General Practitioner (25%) followed by Clinical Nurse Specialists (19%). We were able to gather data from the perspectives of multidisciplinary professionals involved directly with the care and treatment of patients/families with cancer at different junctions within their journey thus providing rich data. This was reflected in the range of clinical roles and the duration of time specifically working in cancer as 50% of healthcare professionals had more than 11 years of experience. Regarding cancer type, the most prevalent area of specialty was prostate cancer (26%), closely followed by General Medicine / Practice (all cancers) (25%) and breast cancer (21%).

Variables	Responses	n (%)
Gender	Female	41 (71.9)
	Male	15 (26.3)
	Prefer not to say	1 (1.8)
HCP role	General Practitioner	14 (24.6)
	Clinical Nurse Specialist	11 (19.3)
	Clinical Oncologist	8 (14)
	Urologist	7 (12.3)
	Physiotherapist	5 (8.8)
	Medical Oncologist	4 (7)
	General / Community/ District Nurse	3 (5.3)
	Psychologist	2 (3.5)
	Specialist Radiographer	1 (1.8)
	Dermatologist	1 (1.8)
	Dietician	1 (1.8)
Time working specifically in cancer (years)	21+	10 (17.5)
	11 – 15	10 (17.5)
	16 – 20	9 (15.8)
	1 – 5	9 (15.8)
	6 – 10	8 (14)
	Less than 1 year	8 (14)
	Other	3 (5.2)
Time working in current role (years)	1 – 5	24 (42.1)
	6 – 10	19 (33.3)
	11-15	12 (21.1)
	21+	2 (3.5)
Area of specialty	Other*	28
	Prostate	15 (26.3)
	Breast	12 (21.1)
	Melanoma	4 (7)
	*General Medicine / Practice (all cancers)	14 (24.6)
	*No further information	4 (7)
	*Chemotherapy	3 (5.3)

	*Nursing / Palliative care / lymphoedema	2 (3.5)
	*Psychology	2 (3.5)
	*Haematology (all cancers)	1 (1.8)
	*Hospice (all cancers)	1 (1.8)
	*General musculoskeletal (all cancers)	1 (1.8)

TABLE 9 SUMMARY OF HEALTHCARE PROFESSIONALS ACROSS PARTNER SITES

Across all partner sites Health Managers were the hardest end-users to engage, possibly due to the added responsibilities of managing staff in these unprecedented times. However, AUTH recruited four Health Managers with backgrounds in clinical oncology (40%), plastic surgery (20%) and urology (20%). UofG recruited one Health Manager who is the lead for Allied Health Professionals with a background in rehabilitation (20%) and APC also recruited one Health Manager (Table 10). The Health Manager at APC responded to the survey by their role as a clinician and consequently, their responses counted in the group of clinicians. Therefore, due to the small numbers and overlapping roles the data collected was merged with health professionals in the reporting of the results (section 5.3.3).

Health managers' areas of specialities were varied and the most prevalent was Melanoma (40%). Most participants had substantial experience with 40% having at least six years of experience as Health Managers and 60% working specifically in cancer for 16 years or more.

Variables	Responses	n (%)
Gender	Female	3 (71.9)
	Male	2 (26.3)
Health Manager Role	Allied Health Professional Team Lead	1 (20)
	Clinical Oncologist	2 (40)
	Plastic Surgeon	1 (20)
	Urologist	1 (20)
Time working specifically in cancer (years)	16 – 20	2 (40)
	21+	1 (20)
	11 – 15	1 (20)
	6 – 10	1 (20)
Time working in current role (years)	1 – 5	3 (60)
	6 – 10	1 (20)

	11-15	1 (20)
Area of specialty	Melanoma	2 (40)
	Prostate	1 (20)
	Breast	1 (20)
	Rehabilitation	1 (20)
	Chemotherapy	1 (20)
	Lung cancer	1 (20)

TABLE 10 SUMMARY OF HEALTH MANAGERS ACROSS PARTNER SITES

5.3 PERSPECTIVES ON POST-TREATMENT CARE

5.3.1 PATIENTS

Across partners, patients most frequently identified 'finding a new normal' as their priority in life as the consequences of cancer had a varying degree of impact on patients' lives (Table 11). Many described continuing physical limitations and problems such as muscle aches or general body pain as part of their 'new' life. However, some patients reported they had happily resumed their usual activities, which may reflect those with less burdensome issues post-treatment (Thematic category one).

The two main areas of need identified were physical or symptom-related and psychological/emotional, for patients both below and above the age of 65 years (Thematic category 4 and 6). Similar shared concerns were largely due to the fear of cancer recurrence, and in relation to side effects of medication and bone health ("*aching bones*," "*bone density*"). The need for psychological support was more evident in the 50-64-year-old group. Furthermore, the possible interactions between these two identified areas of need ("*poor sleep*," "*pain/stiffness*," "*stress*," "*anxiety*") may be especially important for those patients who are still requiring employment as one patient described, "*I am no longer efficient in my work.*"

Similarly, patients identified that psychological/emotional support and the need for information were the two most important areas of concern between finishing treatment and all the follow-up appointments (Thematic category 11). Patients wanted information available to them at the right time and from factual and reliable sources that covered a range of concerns (healthy eating, mental well-being, updates on cancer treatments). The lack of clear communication and direction of where to go for help was described as "*fear*" or "*worry*" and the possible reluctance in contacting their GP. Patients described more information and psychological support was available through sharing experiences with other patients and patient/charity support groups than their healthcare professionals.

Across the partners there were very few needs identified for the support of patients' families. This may be due to most of the participants having finished their treatment

25 months earlier ("*after so long I think we have quite overcome the bad times*"). This may be also due to individual circumstances as some lived alone. Family-related concerns were most common at the UofG which suggested that there was need for support to help with adjustment, especially as there maybe more than one person in the family going through cancer treatment (Thematic category 13). Information for the family about the patient's situation was also an identified need by AUTH.

In relation to the current pandemic, patients described the practical aspects of treatment such as "delays" and "more telephone or video consultations" as their most common concern (UofG, APC, AUTH) (Thematic category 8). However, psychological/emotional concerns were also identified at the UofG. Patients described feeling "*unsupported*" or, their preference to die from COVID-19 rather than cancer. This reflects how the pandemic has severely affected some patients more than others which may reflect differences across countries, the number of participants and/or stage of cancer.

Subsequently, across countries there was a varied response to what was perceived as the ideal health services (Thematic category 16). This was a key concept which highlighted the complex needs of older adults with cancer. Patients had described 'other' health services such as those that offer specific support in areas such as a nurse-led skin clinic (APC); and diet, counselling, and massages (UofG). Similar areas of support were suggested for psychology, physiotherapy, and physical activity (AUTH, HULAFE), although the service responsible differed (Hospital, Primary Care), there was agreement that it should be provided free of charge. This type of service could be interpreted as a 'holistic', or rather a service where "*post-cancer patients are fully monitored*". Thus, providing the rationale for setting up specific health care services to address these identified needs.

Across partners, the ideal type of advice identified by patients was the need for practical / day to day living (Thematic Category 17). Patient expectations were to have information/advice that reflected realistic concerns regarding how to prepare for life post treatment such as what are 'normal feelings', how to cope with returning to work (forgetfulness, noise) and type of diet. Self-management reflected the need for tools that may aid with relaxation and give patients a sense of control over side effects such as sleep disturbance.

Thematic Category 1 - *Priorities in life after cancer treatment*

Finding a 'new normal'

"I can't crouch down anymore, I can't do anything like that, since I've had the chemotherapy, I would say that I'm even struggling with that" (UofG28)

Life since cancer has totally changed, will never be able to return to previous activities. Feel 83 not 53." (UofG23)

"I suppose it's more about not stressing over the little things anymore "I've got a new norm really because I get very tired. So,

	<p>yeah, I have got a new norm and I get muscle aches and things, yeah, so it's different" (<i>UofG61</i>)</p> <p>"returned to normal life although with much more awareness of my health and well-being" (<i>APCUK2</i>)</p> <p>"not experiencing 'normal life 'yet" (<i>APCUK3</i>)</p> <p>"accept the new normal." (<i>APCSW2</i>)</p> <p>"It's a new normal for erectile dysfunction and a bit of urinary incontinence." (<i>HULAFESP5</i>)</p> <p>"After treatment, I was able to return to my previous activities without any added problems, except for general pain all over my body and dental problems that arose after the chemo treatment." (<i>HULAFESP7</i>)</p>
Going back to previous activities	<p>"I am currently working normally with some minimal sequelae from the treatment that I must take for five years." (<i>HULAFESP3</i>)</p> <p>"Since the surgery I have practically resumed all my activities normally." (<i>HULAFESP6</i>)</p> <p>"I returned to my work and soon" (<i>AUTHGR0001</i>)</p> <p>"I continue my life normally" (<i>AUTHGR1005</i>)</p>
Living life to the full	<p>"now my priority is to live calmly and try to be happy" (<i>HULAFESP1</i>)</p> <p>"enjoy the life" (<i>HULAFESP2</i>)</p> <p>"I did not return to work. I had to find another job, to fill my day." (<i>AUTHGR1003</i>)</p>
Family	"Family, companionship, friendships" (<i>AUTHGR1012</i>)
Thematic Category 4 – Concerns/needs 50 - 64 years	
Physical/symptom	<p>"My mobility is restricted as I tire easily and am pretty much house bound." (<i>UofG58</i>)</p> <p>"Medication side effects, and its effects on my bone density particularly" (<i>UofG68</i>)</p> <p>"Poor sleep is huge issue - due to night sweats and hot flashes which wake me every night multiple times still" (<i>UofG57</i>)</p> <p>"Stay healthy" (<i>HULAFESP1</i>)</p> <p>"The medication sometimes causes me muscle aches, although they are bearable." (<i>HULAFESP3</i>)</p> <p>"Pain and risk of fractures, recurrence, metastasis" (<i>HULAFESP4</i>)</p> <p>"I am worried about whether the side effects of the hormone therapy injection (back pain, stiffness, fatigue, depression) will continue. I am no longer so efficient in my work, due to constant fatigue." (<i>AUTHGR1014</i>)</p>

<p>Psychological-emotional</p>	<p>"Side effects and worry about cancer returning." (UofG56)</p> <p>"Since I had a cancer diagnosis, you do then worry about every single other thing that you get, is this going to be secondary cancer? Is this going to be, you know, something else that could turn my life upside down and so it's difficult to try and just maybe put that to one side." (UofG53)</p> <p>"There is very little support for the patient too once you have survived for 5 years, you are regarded as a success by NHS and get signed off all support services." (UofG57)</p> <p>"Mental fatigue, stress" (APCSW1)</p> <p>"Fear of recurrence" (APCUK1)</p> <p>"the possibility that there might be a recurrence...mild anxiety about being in the sun" (APCUK3)</p> <p>"What made it difficult for me was the emotional-psychological part" (AUTHGR0001)</p>
<p>Thematic Category 6 – Concerns/needs 65+ years</p>	
<p>Physical/symptom</p>	<p>"UK hospitals and doctors try to make you believe problems are "due to your age" and get annoyed when you say you want such-and-such treatment." (UofG24)</p> <p>"Side effects of medication" (UofG48)</p> <p>"suffer aching bones and some back pain which if I believe are from taking Letrozole" (UofG22)</p> <p>"Improve the aforementioned side effects." (HULAFESP5)</p> <p>"As a result of the treatment, I lost my taste in many foods." (HULAFESP8)</p> <p>"If cancer and unresolved urination problems return." (AUTHGR1008)</p>
<p>Psychological-emotional</p>	<p>"I have also suffered from continuous depression since I was diagnosed with cancer" (HULAFESP7)</p> <p>"Lead a normal life as always." (HULAFESP9)</p> <p>"a man who can do nothing ceases to be what he was psychologically" (AUTHGR0002)</p> <p>"I do not know how long I will continue [hormone therapy] and this creates a psychological state for me" (AUTHGR0003)</p>
<p>Thematic Category 8 – COVID-19 concerns/needs</p>	
<p>Psychological-emotional</p>	<p>"I felt a bit abandoned and unsupported." (UofG35)</p> <p>"I am not too worried about getting COVID-19 19, sometimes I think it would be better to die of COVID-19 than cancer" (UofG52)</p>

	"Having survived cancer, I don't want to catch COVID-19 and die from the virus." (UofG68)
Practical/treatment	<p>"I am concerned should the cancer return and treatment delayed due to the focus on covid 19 in the NHS." (UofG26)</p> <p>"Postponement of annual mammogram and bone density scan" (UofG48)</p> <p>"Oncology appt moved 4 times since Aug. GP sent me for a CT scan as I have shortness of breath. Small area on scan they have put down to covid - it was a small blurry area which was cancer before." (UofG50)</p> <p>"worried by delays in treatment" (APCUK1)</p> <p>"the treatments are very much restricted" (APCUK2)</p> <p>"less face to face and more telephone or video consultations" (APCUK3)</p> <p>"Delays in scheduled exams" (AUTHGR1011)</p>
Other	<p>"Nothing has changed." (HULAFESP6)</p> <p>"I think my concerns are no different from someone my age without cancer" (HULAFESP5)</p> <p>"I am very careful. I only go out for emergencies" (AUTHGR1015)</p>
Social	"Anxiety about my family, myself, the people I love, the sick (intubated or not) and the need for personal relationships" (AUTHGR1012)
Thematic Category 11 - Experience since end of treatment	
Information needs	<p>"Information at the right time and stop people googling for information, which may not have been proven. There is lots of false information there." (UofG27)</p> <p>"It is important that you are informed of next follow up, how you will be followed up. Sometimes the process is not explained clearly, and you are left thinking is that it??" (UofG35)</p> <p>"My local hospital does not operate follow up appointments after the end of active treatment (chemo or rads) you are pushed back to your GP or told to go to charity support groups" (UofG37)</p> <p>"I would have liked to have written information about what type of melanoma according to the scales and subtypes I had" (APCSV4)</p> <p>"more detailed information" (APCSV2)</p> <p>"updates on cancer treatments" (APCUK2)</p> <p>"Advice and support from healthcare personnel" (HULAFESP2)</p> <p>"From doctors little information, more information through patient associations" (HULAFESP4)</p>

	<p>"Information regarding healthy eating and mental well-being" (AUTHGR1011)</p> <p>"Basically, for me the A and the Z is for the patient to know exactly what he has to face, (...), that is, I do not want the truth to be hidden" (AUTHGR0001)</p>
Psychological-emotional	<p>"I want to talk about it, I want to say I feel like screaming, but when I do start...not that anybody every asks me but I think people avoid it." (UofG28)</p> <p>"I accessed an online weekly session with a small group of women in the same position as myself. I realised my feelings and experiences were normal, and I was able to share with women who were in my position as all hospital appointments were very much isolated." (UofG35)</p> <p>"I think there might be a fear out there amongst some men about what might...the future might hold. One of the things about cancer is you do worry about contacting your GP and discussing things" (UofG33)</p> <p>"Psychological support" (APCSW3)</p> <p>"to be in touch with people with a similar experience" (APCUK3)</p> <p>"Hope - of survival" (APCUK1)</p> <p>"I needed psychotherapy for a while to accept the situation and overcome it as well as the fears I had for a possible metastasis." (AUTHGR1010)</p>
Physical / symptom-related	<p>"Only urinary incontinence problems" (AUTHGR1008)</p>
Thematic Category 13 - Current needs for family/support	
Family-related concerns	<p>"I've changed and they find it hard to understand why when cancer gone." (UofG21)</p> <p>"They are fine but if I went to stage 4 they would need support." (UofG49)</p> <p>"My husband is having cancer treatment in the same cancer hospital, which I was treated in, so I can't escape cancer at the moment" (UofG68)</p>
Other	<p>"I am alone" (APCSW1)</p> <p>"None" (APCSW3)</p> <p>"None" (APCSW4)</p> <p>"After so long I think we have quite overcome the bad times" (HULAFESP1)</p> <p>"At this moment and once overcome they do not need help" (HULAFESP7)</p>

Psychological-emotional	"Counselling, psychological." (AUTHGR1012)
Information	"Full information from doctors." (AUTHGR1014) "More detailed explanation of the situation" (AUTHGR1009)
Thematic Category 16 - Ideal health Services	
Other services	"Something similar to the French system, where post-cancer patients are fully monitored." (UofG24) "Counselling; healthy diet (dietician); massages; Reiki" (UofG58) "The NHS service is brilliant at dealing with the physical treatment, but useless at any psychological support" (UofG68) "A nurse led skin/ lymph gland check clinic, 6 mthly?" (APCUK1) "It would be easier to contact with a contract nurse and chat, send photos, make question with an easy-to-use app" (APCSW1) "To be called for annual control." (APCSW4)
Hospital services	"Physiotherapy, dermatology" (HULAFESP4) "Psychological Support" (HULAFESP8) "To have all the structures of the examinations that need to be gathered in one place, together with the psychological counseling and of course to be provided free of charge for all the patients !!" (AUTHGR1014)
Primary care services	"Immediate access to doctors when necessary, physiotherapy by specialists, mental health, free physical activity services (exercise should be included in health services)." (AUTHGR1012)
Thematic Category 17 - Ideal type of advice	
Practical /day-to-day living	"Details about what support was out there in the community. Help with return to work - I had an occupational health interview before returning to work...tiredness, forgetfulness, being overwhelmed by the noise" (UofG30) "I feel worse than going through treatment, as you have time to process what's happened, but this is normal" (UofG68) "It would have been helpful for someone to say, look, you know, you don't have to go vegan if you've had a cancer diagnosis, these are different options and this is what a healthy diet looks like and just a bit more, kind of, practical help and support really." (UofG53) "Practical recommendations" (HULAFESP4) "Information about diet and possible new tumours, to be able to solve them." (HULAFESP3)

	"Communication should not be impersonal, (...), there is no time to communicate with the patient [the doctor] even half an hour" (AUTHGR0001)
Psychological support	"be prepared for depression, as you feel so alone" (UofG15) "solution-focused therapy, cognitive behavioural therapy or just somebody listening to me, saying how I feel, or I felt, at the end of it." (UofG28) "More psychological support for breast cancer, more tailor made follow up by type and characteristics. One size does not fit all." (UofG50)
Self-management	"Preparation for the side-effects" (APCSW1) "More information.... the more I know the better I can manage my illness" (APCSW2) "How to relax and cope with worries especially those that destroy sleep." (APCUK1) "I would like to know from the beginning of the treatment the ways to protect myself from lymphedema so that at this stage I continue to rely only on my own strengths and of course not to be financially burdened by the required regular sessions and the high cost of purchase every 8 months of suitable compression garments (sleeve + glove)." (AUTHGR1012)
Management of physical symptoms	"Clear prognosis for the course of my health and coverage of the side effects of the treatment" (AUTHGR1011)

TABLE 11 PATIENTS PERSPECTIVES OF POST-TREATMENT CARE

5.3.2 FAMILY MEMBERS/CAREGIVERS

In this section, we present the findings that explored the caregiver's perspectives on the patient's they were supporting, and their own personal experiences (Table 12). Caregivers' perspectives on their patient's priorities varied across the three partners (UofG, AUTH, HULAFE), with most describing that patients were back to their previous activities or living life to the full (Thematic category 3). However, for some patients due to the consequences of cancer treatment they had to find meaning to their daily lives as they had "*been adapted*" so much due to the side effects and medications.

In relation to post-treatment care, caregivers for both age groups (50-64yrs, 65+yrs) described the same areas of concern which were for practical treatment, psychological/emotional and physical/symptom-related needs (Thematic category 5 and 7). However, caregivers provided insight into their experiences of patients who were older and may need a "*little more help*" but did "*not want to become a burden*."

Due to COVID-19 (Thematic category 9), most caregivers viewed their patients as requiring emotional support and described them as being *"frightened"*, *"depressed"* or feeling *"vulnerable"* due to myelosuppression. Caregivers also described patient concerns about *"getting sick"* from the virus. Conversely, caregivers had identified more social unease and were being *"precautionary"* and also concern for possible *"lack of healthcare services for any other disease"* during the current pandemic (Thematic category 10).

Irrespective of the current pandemic, caregiver's perspectives were that psychological/emotional support was still a current concern for some patient's post-cancer treatment (Thematic category 15). Patients having to come to terms with treatment related side-effects, acceptance of life changes and increased practical support with instrumental activities of daily living (bathing) were some of the issues described.

An insight into caregiver's own priorities in life since their patient had finished cancer treatment revealed whilst some had returned to enjoying and appreciating normal family life, others were still providing aspects of care by continuing to support them emotionally (Thematic category 2). Thus, most caregivers had identified they needed psychological/emotional support themselves at this stage (Thematic category 12), or for their partner (Thematic category 14), especially if the patients they were caring for had non-curative cancer. Furthermore, caregivers who were being kept informed about their patient's treatment and health may feel some sense of control with better awareness of their patient's symptoms (Thematic category 12-AUTHGR1016).

Finally, caregivers were asked to provide their views on an ideal health service (Thematic Category 18), and ideal type of advice/information (Thematic Category 19) for patient's post-treatment. However, due to the small number of participants/responses an overall interpretation was collated and presented here; caregivers suggested they wanted more follow-up (*"annual check-up generally the way forward"* -UofG69), and support to access services (*"Who is now there to help you on how to access services easily"*-UofG3, *"Counselling"* -UofG2, *"Mental health services. How to adjust to a new normal?"* -UofG1). One participant plainly stated *"GP of your choice every time, in order to build a relationship with them. Real life – is not the ideal!"* (UofG41).

Thematic Category 2 - Caregiver's priorities in life	
Going back to previous activities	"I continue with the same life that I had during the treatment, as she is an older person I have to continue with her care" (HULAFESP2) "normal life" (HULAFESP4)
Family	"My priorities are first to care and support for my husband" (UofG41) "To appreciate time spent as a family" (UofG2) "Normal family life, continue to support mother emotionally" (UofG69)

	<p>"My priority is my mother who I take care of because she has not yet finished with the side effects of her surgery" (AUTHGR1018)</p> <p>"Due to the fact that the patient's condition is aggravated and has not returned from the chemo, my priority remains to take care of her." (AUTHGR1019)</p>
Finding a 'new normal'	"I reconcile with the new everyday life. In general a normal life" (AUTHGR1021)
Thematic Category 3 - Caregiver's perspective on patient priorities	
Going back to previous activities	<p>"we have been able to resume our lives as they were before the diagnosis" (HULAFESP4)</p> <p>"After 10 years, we have all resumed our lives" (HULAFESP5)</p> <p>"at first he was a little tired and was at home, but then he started his life normally again" (AUTHGR0005)</p>
Finding meaning	<p>"Because of the depression caused by having cancer, her emotional life is very sad (she never wants to do anything) and she is always (almost) depressed" (HULAFESP2)</p> <p>"She has no priorities in life" (HULAFESP3)</p> <p>"My patient's life definitely goes on with many changes, since now his whole daily life has been adapted to the program around his medication and his visits to the hospital." (AUTHGR1016)</p>
Living life to the full	<p>"just to enjoy what he's got. I mean, he's got lots of friends,.. and they take him places when he's well, you know. He's got people in high places he knows. He gets taken to nice places and he gets boxes at the football" (UofG34)</p> <p>"Living each day and not taking anything for granted" (UofG2)</p> <p>"Stay mentally and physically strong" (UofG1)</p>
Family	"The first concern is communication with people close to you and socializing as much as possible." (AUTHGR1017)
Thematic Category - 5 Caregiver's perspective on patients concerns relating to age (50-64yrs) since end of cancer treatment	
Practical/treatment	"Do not worsen health and side effects of subsequent medication." (HULAFESP1)
Psychological/emotional	"He needs ongoing emotional support, both for his own recovery and even more particularly given my diagnosis. He has been referred for NHS counselling, for which we are grateful, but the waiting time is very long." (UofG41)

Physical/ symptom- related	"Not to relapse" (<i>AUTHGR1020</i>)
Thematic Category – 7 Caregiver's perspective on patients concerns relating to age (65+yrs) since end of cancer treatment	
Psychologica l/ emotional	"Feeling comfortable with her body after a mastectomy" (<i>UofG65</i>) "Readjusting to life" (<i>UofG1</i>) "She is afraid of cancer recurrence" (<i>HULAFESP3</i>)
Practical/ treatment	"She needs a little more help" (<i>HULAFESP4</i>)
Physical/ symptom- related	"To survive" (<i>AUTHGR1017</i>)
Family- related	"not to become a burden" (<i>AUTHGR1023</i>)
Thematic Category 9 - Caregiver's perspective on patients during COVID-19	
Psychologica l/ emotional	"we are extremely frightened of getting the virus" (<i>UofG41</i>) "depression" (<i>UofG2</i>) "need for connection, emotional support" (<i>UofG69</i>) "he is afraid, he does not leave the house" (<i>AUTHGR0005</i>)
Other	"Needs the same. Concerns, not getting sick from coronavirus." (<i>HULAFESP3</i>) "We try not to get infected by going out on the street" (<i>HULFESP5</i>)
Physical/ symptom- related	"the fear of coronavirus due to the vulnerable immune system" (<i>AUTHGR1019</i>) "Not to get sick" (<i>AUTHGR1018</i>)
Thematic Category 10 - Caregiver's COVID-19 experiences	
Physical/ symptom- related	"To not pass a germ to my mother" (<i>AUTHGR1018</i>) "To not get sick of course and to not transmit the virus" (<i>AUTHGR1021</i>)
Other	"I am concerned about the lack of healthcare for any disease other than coronavirus" (<i>HULAFESP2</i>) "Don't get sick" (<i>HULAFESP5</i>)
Physical/ symptom- related	"he is afraid, he does not leave the house" (<i>AUTHGR0005</i>)

Thematic Category 12 - Caregiver's experience since end of patient treatment	
Psychological/ I/ emotional	<p>"the counselling support for my husband is in the pipeline." (UofG41)</p> <p>"somebody to talk through my experience with so I felt less alone" (UofG2)</p> <p>"We know that we may have to take John back, because I would not want John to be on his own. That is a concern. That is, definitely, a concern." (UofG34)</p> <p>"Psychological support" (AUTH GR1020)</p>
Other	<p>"None" (HULAFESP3)</p> <p>"I don't need any information at the moment" (HULAFESP4)</p>
Physical/ symptom- related	<p>"I was informed about the treatment he is receiving and the state of his health due to diabetes in combination with cancer." (AUTHGR1016)</p>
Thematic Category 14 - Caregiver's current needs for support for their family/partner	
Psychological/ I/ emotional	<p>"emotional support need is ongoing" (UofG41)</p> <p>"Reassurance that my partner is still beautiful despite her surgery" (UofG67)</p> <p>"It's a worry for us. I mean, obviously, for any...my husband, it's his brother, he's got cancer and he seems well. Every time he goes for treatment, you worry, you know" (UofG34)</p>
Thematic Category 15 - Caregiver's perspectives on patient current needs for support	
Psychological/ I/ emotional	<p>"emotional support need is ongoing." (UofG41)</p> <p>"Ongoing" [reassurance on body image] (UofG65)</p> <p>"This is a mental health issue, and another one that's very rarely talked about, the mental health to help him, to allow other people to help him with this would be good" (UofG34)</p> <p>"Psychological and group support" (HULAFESP3)</p> <p>"courage and desire to live" (HULAFESP4)</p> <p>"Definitely psychological to accept the change he is experiencing and the limitations he now has in his life." (AUTHGR1016)</p>
Physical/ symptom- related	<p>"had to deal with incontinence with pelvic floor exercises" (AUTHGR0006)</p> <p>"Medical" (AUTHGR1018)</p>
Practical treatment	<p>"needs help with his daily needs (food, bath, etc.) to offer him his medical coverage (to talk to the doctors, to go to the hospital to get his prescriptions, to the pharmacy, etc.)" (AUTHGR1022)</p>

TABLE 12 FAMILY MEMBER/CAREGIVERS' PERSPECTIVES POST-TREATMENT CARE OF PATIENT

5.3.3 HEALTH PROFESSIONALS/MANAGERS

Across partners, most of the health professionals/managers who participated were involved in the medical management of older adults during/post cancer treatment, or till death for those with incurable disease (Table 13; Thematic category 1). The management of a patient's physical symptoms was viewed as the main health need post-treatment, and specific issues described were "fatigue", "pain" and "loss of fitness" (Thematic category 2). Psychological issues were also viewed as important with patient concerns over the fear of cancer relapse, mood changes and increased sleep disturbance, which was similarly described by patients (section 5.3.1).

Overwhelmingly, professionals' priority was to provide the best supportive care, which varied according to the patient's diagnosis, their individual priorities and the support structure at each site (Thematic category 3). Frequent monitoring was described at AUTH and the emphasis was on survival at HULAFE. Interestingly, across all sites there was little reference to the importance of communication with patient's post-treatment, especially as the lack of communication during this period had been identified by patients (section 5.3.1). Although one clinician did acknowledge that *"often patients do not take in or remember all the information they are given at hospital"*.

However, clinicians across all partner sites identified the need for support in many key areas such as practical and day-to-day living such as managing fatigue and increasing physical activity (UofG). Time to provide 'information' and to explain *"adverse effects that the patient may not be aware of because they are not treatment related"* (HULAFE). Gaps were also identified in the continuation of the monitoring progress, especially in older adults (AUTH) (Thematic category 4).

The views on what type of health service may be more or less useful was mainly in primary services, which may reflect the number of GP's involved in this task and the need for improvement of services offered, especially in the community. Specialised services in the community or closer to home may be more of an issue in some countries due to logistics (Thematic category 5). Hospital follow up services described more of a need for a specialised onco-geriatric service involving a multi-disciplinary team (HULAFE). Flexible and remote monitoring with a contact oncology nurse was seen as a priority for patients (APC). To summarise, there was an overall agreeance that a health service which combined of a range of specialities that could *"collaborate"* and *"focus on the patient"* closer to home would be beneficial to older patients.

Clinicians were asked to identify Patient-Reported Outcome Measures (PROMs) or Patient-Reported Experience Measures (PREMs) currently utilised or would be most important to measure post-cancer treatment (Thematic Category 6). Most health professionals did not comment on the importance of these measures (APC, UofG). The clinicians who responded were mainly supportive of the use of PROM's and mentioned measures used locally and internationally such as EQ-5D-5L, FACT and the Distress Thermometer (UofG/AUTH). There was agreeance that the benefits of using PROMs and/or PREMs was to provide *"better treatment of the individual patient"* in areas such as physical activity, fatigue, diet and quality of sleep. This type of measurement could

help both patients and clinicians when considering other aspects of the patient's life other than specifically cancer.

Finally, in relation to the current pandemic (Thematic Category 7), most health professionals/managers described that older adults were experiencing concerns with access to health services. This was contributed to "anxiety", "delays" in appointments, issues with new methods of consultations and "fear of visiting hospitals." However, this was closely followed by problems with daily living and community care as some patients were experiencing psychological effects such as "feeling lonely" and "isolated". Issues with follow up services were more pronounced in some countries as "non-compliance" to appointments and visits were described (AUTH). Moreover, health managers described the greatest impact of COVID-19 was on the psychological and physical wellbeing of older patients with cancer at post-treatment.

Thematic category 1 - <i>Involvement in patient care</i>	
Medical management	<p>"Assess, consent, treat and monitor patients with early and metastatic breast cancer (radiotherapy and systemic therapy)." (UofGHP21)</p> <p>"I see patients with new breast cancer diagnosis, advise regarding treatment, review during treatment and see again on completion of treatment advising about ongoing endocrine treatment and management of any associated symptoms. I am not involved in longer term follow up of early breast cancer which is undertaken by breast surgical team. I also see patients with metastatic breast cancer and am involved in care and management until death." (UofGHP11)</p> <p>"supporting patients and their families through their oncological treatment both psychologically and with side effects of treatment, managing end of life care in partnership with community nursing teams." (UofGHP34)</p> <p>"coordinator and nurse of trials, in the protocols to be followed for many of them," (HULAFESP1)</p> <p>"In the consultation we are dedicated to guiding the patient and the family about the different treatment options, we carry out the surgical and / or medical treatment ourselves and handle the complications thereof." (HULAFESP2)</p> <p>"Direct involvement in the treatment of the patient and I try to know what the family situation is and the deficiencies to put them in contact with the social worker to advise them." (HULAFESP3)</p> <p>"Investigation, diagnosis, sometimes treatment, follow-up" (APCSW12)</p> <p>"diagnosing and taking care of" (APCSW8)</p> <p>"family doctor." (APCSW9)</p>

	"therapeutic plan proposal" (AUTHGR1042)
Treatment Administration	"post op care of trauma" (APCSW6) "taking care of Picc-line" (APCSW7) "operation." (APCSW13)
Pharmacy	"My role is to properly inject the chemotherapy. All the service of the patient from the moment he enters the field of healthcare until his discharge." (AUTHGR1026)
Physiotherapy	"Responsible Physiotherapist" (AUTHGR1027)
Thematic category 2 - <i>Perspectives on patient's post-treatment health needs</i>	
Psychological support	"Middle-aged patients (...) frequently, alterations in mood." (HULAFESP3) "sleep disturbance. Worry and stress" (APCSW11) "the patients are worried to relapse" (APCSW6) "disfiguration is a continuing reminder of the undergone illness" (APCSW6) "lack of sociability, fear of commentary, psychological, sociability" (AUTHGR1029) "[They] experience anxiety and distress for possible relapse, need for support and understanding that the situation is under control" (AUTHGR1042)
Management of physical symptoms	"Fatigue, muscle atrophy, deconditioning, diminished balance control" (UofGHP1) "Support to help regained fitness or energy after treatment." (UofGHP3) "...joint project (Improving Cancer Journey Team) by Macmillan and Glasgow City Council, kind of tied in with the Macmillan long term conditions team and some of the allied support networks, they basically offer a holistic health needs assessment whenever it's requested. ...it can be done at the end of treatment or at any point in the future." (UofGHP4) "Many of them (usually over 65 years old) had fragility and loss of autonomy due to insecurity as well as physical and mental limitations," (HULAFESP1) "Middle-aged patients (...) Sometimes they also report chronic osteoarticular pain" (HULAFESP3) "loss of sensation - disturbance in feet" (APCSW7) "rehabilitation at home after treatment" (APCSW8) "side effects" (APCSW5)

	<p>"Need to relieve post-cancer pain, other complications and desire to return to daily activities." (AUTHGR1027)</p> <p>"fatigue, treatment of side effects" (AUTHGR1041)</p>
Self-management	"mostly problems of the patient [as] "I cannot self-care" (AUTHGR0009)
Other	"are mainly interested in not burdening their environment, they put their life in the background (patients with metastatic cancer) treatments that we may do as much as possible so that they can see their environment, their grandchildren, their children (women with breast cancer)" (AUTHGR0010)
Thematic category 3 - Professional priorities	
Best supportive care	<p>"Function, symptom management, fitness / stamina affects meaningful activity, identifying meaningful goals" (UofGHP12)</p> <p>"advice about diagnosis, management and follow up. Ensure that planned follow up takes place in a timely fashion. Often patients do not take in or remember all the information they are given at hospital." (UofGHP14)</p> <p>"to empower them to return to functional meaningful day to day life if their state of health allows that." (UofGHP34)</p> <p>"priorities are driven from individual's limitations in function-structure, activities-participation" (APCSW11)</p> <p>"psychological support" (APCSW1)</p> <p>"easy to access, everyday help" (APCSW8)</p> <p>"Treatment of treatment complications, close monitoring of the disease for possible relapses, interdisciplinary discussions in difficult-complicated cases." (AUTHGR1032)</p> <p>"Facilitation with appropriate arrangements of visits, effort to negotiate with colleagues to avoid unnecessary travel" (AUTHGR1040)</p> <p>"My team includes a psychologist and a nutritionist, so we try to give them at least 2 of the 3 factors related to lifestyle nutrition and psychology, the exercise part is missing. Clearly trying to keep reassuring them that this is a chronic illness that no one has to deal with like other chronic illnesses. The effort to adapt the observation to the personality of everyone. (...) put them in a holistic monitoring program" (AUTHGR0010)</p>
Frequent monitoring, follow up and communication	<p>"to be careful and to pay attention even to slight symptoms that may have relation to cancer-recurrence" (APCSW10)</p> <p>"to identify sign for new tumor or recurrence" (APCSW13)</p> <p>"availability important" (APCSW2)</p>

	"Continuous monitoring of the patient's clinical picture and examinations." (AUTHGR1026)
Survival	<p>"The priority is to know the level of quality of life and perception of their health and to verify that there is no alteration." (HULAFESP1)</p> <p>"The priority in the middle-aged patient is to cure him and secondly to avoid the comorbidity of the treatment." (HULAFESP2)</p> <p>"In the case of the elderly (...) our objective is to offer the treatment that best adapts to their state of health and therefore offers the best life expectancy with the highest possible quality of life. " (HULAFESP3)</p>
Thematic category 4 - Support or information needed by patients and family members/caregivers at post-treatment	
Practical and day-to-day living	<p>"I would like to see a reduction in assuming the patients are aware of the role and benefits of increasing PA and being part of their rehab." (UofGHP1)</p> <p>"People always seem to struggle with managing fatigue and want information" (UofGHP12)</p> <p>"Need better access to exercise programs and to look at other lifestyle changes that could promote physical and emotional wellbeing." (UofGHP21)</p> <p>"Carer support, lifestyle education including fatigue management/managing breathlessness/cognitive rehab, advice re keeping fit and active" (UofGHM10)</p>
Psychological support	<p>"emotional support, attention to minimizing changes in body image produced by the treatment, aids for progressive return to work" (HULAFESP3)</p> <p>"Those patients who came to post-treatment control and came to coincide with them (which were very few), the support was psycho-social knowing that you can count on the healthcare team whenever you need" (HULAFESP1)</p> <p>"follow up...psychologically important" (APCSW8)</p> <p>"To listen and show understanding". (APCSW6)</p> <p>"need can be both physical and psychological" (APCSW1)</p>
Management of physical symptoms	<p>"to come earlier for rehab in order to avoid patient's loss of movement, physical condition and strength" (APCSW11)</p> <p>"Contact nurse with possibility to contact in case of suspicion, concern or reassurance" (APCSW13)</p> <p>"need can be both physical and psychological" (APCSW1)</p>
Information	"The support that was offered to those included in post-treatment follow-up, was the total connection in case of needing

	<p>information. For example: in the covid period, many patients in the EoS period called to find out if they were at risk or not and if they could go to work quietly." (HULAFESP1)</p> <p>"In both middle-aged and elderly patients, we need time to be able to clearly explain the effects of the treatment and its expectations, to be able to investigate those adverse effects that the patient may not be aware of because they are not related to the treatment." (HULAFESP2)</p> <p>"they have a lot of questions, they have information gaps for the continuation of their monitoring too, especially the older people" (AUTHGR0008)</p> <p>"Proper information about possible complications after surgery and subsequent radiotherapy or chemotherapy." (AUTHGR1027)</p>
Other	"nutritional" (AUTHGR1042)
Thematic category 5 - Views on health services at post-treatment	
Primary care services	<p>"Community teams to provide practical support and assist in maintaining independence." (UofGHP3)</p> <p>"Specialist cancer care nurses are undoubtedly the best contact for both patients, relatives and primary care." (UofGHP22)</p> <p>"A holistic provision of health care addressing not only physical issues like medication side effects and disease symptoms but assessing emotional and social needs. This should be close to the patient in their community and linked with their primary care provider" (UofGHP34)</p> <p>"primary health care near their place of residence, instead of hospital care and treatment." (AUTHGR1025)</p> <p>"regular monitoring by a support team, which will detect the possible progression of the disease and will refer accordingly that there is a certain health professional who monitors the observance of the monitoring protocol" (AUTHGR1042)</p>
Hospital follow up services	<p>"psycho-oncology, a liaison nurse with a social worker and home care unit," (HULAFESP1)</p> <p>"nurses, primary care doctors, geriatrician in the case of older patients, physiotherapists, psychologists and the specialist in charge of their cancer," (HULAFESP2)</p> <p>"psychological care, rehabilitation or physical therapy, endocrinology" (HULAFESP3)</p> <p>"specialized holistic care center" (AUTHGR1041)</p>
Remote monitoring services	"telephone number that they can ring to their oncologist-cancer nurse" (APCSW8)

	<p>"contact nurse with feasibility to flexible telephone hours" (APCSW12) "Contact nurse first priority" (APCSW13)</p> <p>"There must be flexibility. Some do not need anything. Some people need someone to help them with even the simplest things (bathroom, toilet)" (AUTHGR1037)</p>
Patient support groups	"An organized department of health professionals specializing in the management of cancer and its complications, consisting of different specialties that talk and collaborate with a focus on the patient." (AUTHGR1027)
Home care services	"home help, health guests, home monitoring by post-care teams" (AUTHGR1040)
Thematic category 6 - Views on important PROMs or PREMs	
PROMs	<p>"Most PROMS we have experience of are designed for clinical trials and not to benefit the patients. Their primary aim is to establish cost of a QALY for health economic analysis. FACT scores seem good in that they are shorter and focus on function." (UofGHP21)</p> <p>"EQ-5D-5L and Godin Leisure Time Exercise questionnaire." (UofGHP1)</p> <p>"DASH" (self-report outcome measure of upper limb symptoms and function questionnaire) "Fatigue - Macmillan CaPASEF outcome measures" (Cancer Physical Activity Standard Evaluation Framework) (UofGHP37)</p> <p>"MyCaw (My Concerns and Wellbeing Checklist), Godin Leisure-Time Exercise Questionnaire, EQ-5D-5L health questionnaire, FACIT Fatigue Scale. Locally developed Patient and Carer Experience (PACE) surveys are also regularly completed, and clinician feedback gathered." (UofGHM10)</p> <p>"activity, lack of pain, quality of sleep, diet" (AUTHGR1029)</p> <p>"The key is the evaluation of the quality of life, which is often what is required. Also effects that concern in addition to the disease the patient's daily life such as symptoms or anxiety" (AUTHGR1032)</p> <p>"The scale related to discomfort, the scale that has to do with pain" (AUTHGR0010)</p>
PREMs	<p>"patient's participation in social life compared before and after illness/psychological prosperity" (APCSW11)</p> <p>"Patient experience varies depending on the patient. All the care the patient receives in the health care system is what concerns them many times..." (AUTHGR1026)</p>
Both	"It is fundamental to listen to the patient, so both PROMS and PREMS should be systematized in our usual practice because I believe that it would result in a better treatment of the individual patient. Sometimes we forget that we treat a patient with a

	<p>personal situation and an own experience, so we only consider that it is a patient with a cancer with a specific stage and that we must treat it with the appropriate treatment." (HULAFESP2)</p> <p>"I see it important to computerize the health system, since there is a lot of information that is lost, as the patient does not write it down, so he/she does not comment on it to the health system and the overworked health worker cannot concentrate on writing down everything necessary to notify good PROMs and PREMs " (HULAFESP1)</p>
Thematic category 7 - Views on patients' experiences due to COVID	
Experiences with health access	<p>"dramatic reductions in elderly patients attending clinics and having treatment" (UofGHP3)</p> <p>"Levels of support are less, especially face to face support. Older people are less able to use video consultations and may not hear well on the telephone. Communication can be more challenging." (UofGHP14)</p> <p>"anxiety about attending hospital and their increased risk of contracting COVID-19" (UofGHP30)</p> <p>"In addition, the collapse in the clinical hospital in the area of diagnostic imaging did not help, because many of our requests for CT, mammography, nuclear medicine and ultrasound were postponed or canceled by covid (many times without notifying the patient or the nurse of the patient." (HULAFESP1)</p> <p>"extra-long waiting time when visit postponed because of infection symptoms of the patient or clinician" (APCSW12)</p> <p>"important decisions such as chemotherapy have been taking through telephone" (APCSW10)</p> <p>"delayed diagnosis." (APCSW13)</p> <p>"fear of visiting hospitals resulting in inadequate monitoring and non-compliance with appropriate protocols" (AUTHGR1042)</p>
Experiences with daily living and community care	<p>"Increased deconditioning and significant loss of muscle strength and exercise tolerance, lack of confidence, increased anxiety, increased fatigue, significant psychological impact of shielding." (UofGHM10)</p> <p>"More lonely" (APCSW9)</p> <p>"Worried to meet their relatives. More remote contacts" (APCSW10)</p> <p>"patients with undergoing cancer rehabilitation are maybe extra careful." (APCSW11)"Isolated, feeling helpless, away from doctors and scared as a high-risk group" (AUTHGR1036)</p>
Experiences with follow up services	<p>"Yes, in general the elderly patient has stopped coming for consultations, has lost follow-up, has delayed treatment, has not</p>

	<p>manifested his discomfort and his health condition has worsened." (HULAFESP2)</p> <p>"Fear and non-compliance with follow-up visits and follow-up examinations." (AUTHGR1033)</p> <p>"There are patients who delay attending the doctor, or skip visits or postpone surgeries for fear of COVID-19 in hospitals" (AUTHGR1040)</p>
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TABLE 13 HEALTH PROFESSIONALS PERSPECTIVES ON PATIENTS POST-TREATMENT CARE

5.4 DESIRED FUNCTIONALITY OF THE DEVELOPING PLATFORM

5.4.1 PATIENTS

Most patients' views on the proposed LifeChamps system were positive and in support, especially in the form of a phone app as it is to provide easy access and information when they required it and timely support when they needed it (Thematic category 20; Table 14). Patients regard the LifeChamps system as a good opportunity to help the healthcare system work better by filling gaps in the current delivery of care, either through better prevention or by offloading the work of primary care or by helping with follow-up of the cases. Patient participants diagnosed with secondary breast or prostate cancer expressed the opinion that the type of support being developed would be more applicable after secondary diagnosis. Others felt that the system would be useful for both patients and their caregivers, considering the personalised support the system can offer.

Naturally, there was some critique on the system, but this was largely in the method of how information would be presented, for example: "...*whatever it is, must be detailed, scientifically accurate and not patronising.*" Some patients appeared rather sceptical, mentioning that only researchers could benefit from the use of such system in practice as clinical practice would probably run as normal regardless.

Regarding frequency of predictions (Thematic category 21), patients' views were not very specific. There were variable suggestions of 3-monthly, 6-monthly or annual predictions depending on the needs of the person, which on reflection could also have been coded as 'on demand'.

Patients clearly wanted to see improved communication between themselves and healthcare professionals in response to the developing platform (Thematic category 22). As evident throughout this task there was a sense of frustration with the lack of follow-up services. As such, patients thought that the system could help improve patient-clinician communication. Patients would like clinicians to use the system to discuss their data with them and tailor clinical decisions to each patient's own needs. There was also an expressed expectation that the system would facilitate better collaboration and communication of the different health professionals involved in the patient's care.

Finally, most patient participants reported general comfort in using technology such as smartphones and fitness trackers (Thematic category 23). However, some patients felt they were not very comfortable using technology, and that they would prefer "face-to-face" care rather than through a device. A few patients reported that they did not know how to use a smart device and feared that using such a system might be the cause of additional stress in their lives.

Thematic Category 20 - Views of the LifeChamps system	
Praise / advantages	<p>"I think with an app you can go onto it any time you feel actually, I need a wee bit of support here. I think an app would be quite good, actually.... "But if somebody would just tell me that or somebody would suggest it to me from the NHS" (UofGP28)</p> <p>"I wonder is there still a concern that people of my age, men of my age, how they respond to the electronic message but there will be people within a family that do respond to the electronic message. I think we are more prepared for hearing about or getting information about coping strategies" (UofGP33)</p> <p>"The sort of support you are considering would be much more applicable after my secondary cancer diagnosis, given that there is no cure." (UofGP52)</p> <p>"It is very interesting because at the moment there are only voluntary programs and clubs, such as Alma [Zois] (...), but you will do something more I hope, that is, you will have medical advice timely." (AUTHP001)</p> <p>"I consider the personalized counselling as an advantage as it will offer a better quality of life to the patient" (AUTHP1012)</p> <p>"speed of referral for physical symptoms" (APCUK1)</p> <p>"Very positive" (APCSW2)</p> <p>"In principle it sounds good...advantage that someone can whenever they will to log in and get advice and help. Very positive". (APCSW4)</p> <p>"I see it quite useful especially for prevention" (HULAFEP1)</p> <p>"This infrastructure can help you a lot to download primary medicine" (HULAFEP2)</p> <p>"It would be an ideal system for the follow-up of cancer patients." (HULAFEP3)</p>
Critique / disadvantages	<p>"Only the researchers would have an advantage and not the patient" (AUTHP1006)</p> <p>"disadvantage is the application in practice" (AUTHP1004)</p> <p>"Where are the data saved? Who owns the data? Can they be sold? A disadvantage can be that I do not feel I am getting something new and it will just take space in my phone." (APCSW1)</p> <p>"disadvantage: very general" (APCSW2)</p>

	"person feels like a person and not an identifier for a computer" (APCUK1)
Thematic Category 21 – Frequency of Predictions	
Daily	"I would not mind advice coming as often as possible" (AUTHP0001)
Weekly	"Often enough. Per week." (AUTHP1014)
Other	<p>"It would depend on the overall health of the person or needs of their support system at the outset, so for most people annually but maybe 6 monthly for others." (UofGP21)</p> <p>"It depends how accurate they are and how I would benefit from this information." (UofGP37)</p> <p>"At the end of treatment, with occasional perhaps every 3 months" (UofGP36)</p> <p>"6-monthly" (APCUK3)</p> <p>"When something changes" (APCSW1)</p> <p>"I do not know. Let's say 2 times per year." (APCSW4)</p> <p>"Once a month or quarter, depending on the need" (HULAFEP2)</p> <p>"As often as the patient requires." (HULAFEP8)</p> <p>"I think that it is more important that the advice reaches people who are starting treatment, to avoid losing their strength and the desire to continue." (HULAFEP9)</p>
Thematic Category 22 - Health professional actions	
Communicate with and inform the patient / family	<p>"Actually find time to read them, and talk to me as to what concerns me and will help me." (UofGP24)</p> <p>"offer practical and timely support...currently the system relies on whether I keep up with results from clinical trials reporting and whether I take action to follow up." (UofGP57)</p> <p>"be available for an in-depth discussion rather than be fobbed off with a 10 min appointment" (UofGP39)</p> <p>"Better communication" (HULAFEP4)</p> <p>"To collaborate by evaluating them and encouraging their use if they consider them appropriate." (HULAFEP5)</p>
Adjust follow up care	<p>"To discuss with me and adapt the data to my own health problem." (AUTHP1010)</p> <p>"Provide an appointment and examination" (APCUK1)</p> <p>"To use for assessment and treatment" (APCSW4)</p> <p>"Meet face to face" (APCUK3)</p>
Share information with other treating health professionals	"the various medical specialties to collaborate with each other and exchange their knowledge and experiences, listen to the other specialty. Doctors should "listen" to both physiotherapists and nurses." (AUTHP1014)
Thematic Category 23 – Comfort using technology	

General competency reported	<p>"I am comfortable using most devices, some of the finer points maybe escape me but I have a savvy 9-year-old granddaughter for that!" (UofGP22)</p> <p>"smartphone and fitness tracker are fine, I use them routinely." (UofGP36)</p> <p>"feel comfortable. Using my I phone right now!" (UofGP63)</p> <p>"Very comfortable" (AUTHP1003)</p> <p>"quite comfortable" (APCUK3)</p> <p>"very" (APCSW2)</p> <p>"comfortable" (APCSW4)</p> <p>"Very well, I'm used to use it" (HULAFEP4)</p> <p>"Very comfortable" (HULAFEP2)</p>
Low competency or barriers reported	<p>"I have not learned to send an SMS for so many years that I have a mobile phone... Maybe it adds some stress to me, I do not know, and I do not want to know." (AUTHP0003)</p> <p>"I am not comfortable. I only know how to use my mobile phone to make calls (my daughter is helping me with this survey)" (HULAFEP7)</p> <p>"I don't usually use them, better personalized attention" (HULAFEP8)</p>
Thematic Category 24 - Additional comments	
Practical/treatment	<p>"I am concerned that I am now 5 years post diagnosis and checks will now cease. I am concerned that something may be missed." (UofGP46)</p> <p>"Should this go to GP as well. A more community approach? If there is anything we've learnt from COVID-19 is a local level approach is more appropriate for health." (UofGP49)</p>

TABLE 14 PATIENTS' PERSPECTIVES OF POST-TREATMENT CARE

5.4.2 FAMILY MEMBERS/CAREGIVERS

Family member/caregiver participants perceived the development of the system as advantageous (Thematic Category 20; Table 15) and able to constantly support patients, although it could interfere with the human connection between patients and their clinicians. Family members emphasised that all support provided to the patient can be well received as long as a personalised treatment is maintained, and the necessary information is provided. An interesting opinion was offered that the system may predict issues that may never actually occur, pointing to potential risk of unnecessary heightened anxiety.

Regarding the frequency of predictions from the LifeChamps system (Thematic Category 21), family members considered that having a regular update on the patient's situation is acceptable. Same as with patients, wide variability in responses was noted,

which pointed to the direction of regular updates provided at least a couple of months apart (if not longer).

In relation to health professional actions, such a system could drive (Thematic Category 22) family members towards expected goals set by health professionals. Simultaneously, they could provide a realistic insight and a better understanding of the physical and mental health of their patients. This would involve a range of proactive actions being enabled, whereby clinicians would alert patients and family members if they detected a problem via system data, as well as provide advice about possible future issues.

Finally, the vast majority of family members were rather comfortable with everyday use of technology (Thematic Category 23), although uncertainty about the actual use of such a system was raised by one participant. Of note, a suggestion was made that, if the patient was very old, the system could be better and more easily used if the actual end-user was the family member or caregiver and not the patient.

Thematic Category 20 - Views of the LifeChamps system	
Praise / advantages	<p>"Continuous psychological and physical support of both the patient and those involved in such a condition is important. So, we need a system that constantly supports the citizens." (AUTHC1016)</p> <p>"Extra support is always good" (HULAFEC3)</p> <p>"speed in diagnoses and possible treatments." (HULAFEC1)</p> <p>"Immediacy and Effectiveness for data management by doctors." (HULAFEC1)</p>
Critique / disadvantages	<p>"the disadvantage is that the system is not anthropocentric." (AUTHC1023)</p> <p>"The danger of treating ourselves as numbers, cattle, etc." (HULAFEC1)</p> <p>"Being too aware of data about your health (hypochondria)" (HULAFEC1)</p> <p>"for older people it would be better if the system worked through caregivers." (HULAFEC2)</p> <p>"Could predict issues that may not occur" (UofG3)</p> <p>"Security risk is disadvantage" (UofGC1)</p>
Thematic Category 21 – Frequency of Predictions	
Weekly	"Even once a week I do not mind" (AUTHC0005)
Monthly	"Monthly" (UofGC2)
Other	<p>"Regularly to be constantly updated on the situation" AUTHC1016</p> <p>"To the extent that it can affect the patient" (HULAFEC2)</p> <p>"As often as each patient requires" (HULAFEC5)</p> <p>"Annually" (UofGC65)</p> <p>"Annually, better 6-monthly" (UofGC41)</p>

	<p>"Quarterly or maybe every couple of weeks" (UofGC3)</p> <p>"No need if filtered through a health care professional" (UofGC1)</p>
Thematic Category 22 - Health professional actions	
Communicate with and inform the patient / family	"a deep understanding of what is going on in the patient's mind and body. Emphasis on parity and the inclusive open procedure between doctor and patient" (AUTHC1023)
Adjust follow up care	<p>"and immediate action in the event of a problem in this regard." (HULAFEC1)</p> <p>"Use them and not remain as a mere report" (HULAFEC2)</p> <p>"To speak with the patient to advise treatment and a way of life." (HULAFEC3)</p>
Thematic Category 23 – Comfort using technology	
General competency reported	<p>"Absolutely familiar" (AUTHC1021)</p> <p>"Overall comfortable" (HULAFEC1)</p> <p>"Very good, I use them every day" (HULAFEC2)</p> <p>"I don't usually have problems with these devices" (HULAFEC5)</p> <p>"I use my phone for everything, but it used to be computers for everything, and my iPad, I hardly ever open now, it's the phone because it's there all the time." (UofGC34)</p>
Low competency or barriers reported	"not at all because I do not know, others serve me to do this" (AUTHC1022)

TABLE 15 FAMILY MEMBERS'/CAREGIVERS' PERSPECTIVES OF POST-TREATMENT CARE

5.4.3 HEALTH PROFESSIONALS/MANAGERS

Owing to close similarity in data gleaned from health professionals and health managers, these were aggregated and presented in combination for both groups (Table 16).

Feedback from both groups was positive overall and supportive towards the "*proactive*" effects the proposed technology could have on monitoring older patients' health status. Participants felt that LifeChamps could help identify, specify and quantify patients' needs that are currently not being taken into account, flag patients at risk for declined health status, and do so in an objective and tangible way (Thematic Category 8).

Almost equally there was critique on how the system could be managed, safely accessed, or communicated within the existing healthcare system infrastructure. Impact on workload and issues around patient safety such as frequency, and timely actioning of patient feedback was also mentioned (Thematic category 10-12), which are essential points to be considered when implementing the system in practice. Some health professionals/managers also emphasised that system accessibility would be an

important aspect for consideration from a patient point of view, given that LifeChamps is intended to be used to assist older people.

When health professionals/managers were asked about the type of information required from the system or what they would like monitored (Thematic category 9), their responses touched upon managing specific symptoms such as the endocrine treatment side-effects, activity at night, exercise and nutrition, and patient functioning. Other health professionals/managers hoped that the system would help monitor (a) physical indicators such as accidental falls, weight, physical activity; (b) indicators of cancer recurrence; (c) mental health status, specifically depression; and (d) adherence to medical advice or prescribed medications.

Despite variability in responses around the frequency of information becoming available to health professionals (Thematic category 10), most participants felt that on-demand information before every patient visit, or every 3-4 months approximately, would be reasonable to provide an update on a patient's health status.

Regarding the presentation of information (Thematic category 11), a summary report was suggested as useful to provide health professionals with details necessary to evaluate each patient case individually and over time. However, many stressed the necessity for compatibility of this information with the electronic health record. For the LifeChamps system to be implemented (through mobile applications, the medical record system or online), health professionals involved in this task foresee that a collaboration between the different stakeholders (doctors, patients, etc.) is necessary, on top of investment in time and technology.

In Thematic category 12, the health professionals/managers emphasised the need for clear pathways about who acts upon the information from the system, the need for adequate IT support in the everyday use of the system, user-friendliness, accessibility, and involvement of the wider multidisciplinary team to tackle known workload and human resources barriers. Automation and technological compatibility were cited as aspects to consider in order to tackle infrastructure barriers, whereas adequate time for training of the involved staff could facilitate a buy-in process.

Thematic Category 8 - Perceptions on system benefits and drawbacks

Praise / advantages

"I would be very interested in using this kind of technology it is the way forward. I think we could record patient's activity very easily and this would encourage patients to improve their activity." (UofGHP3)

"Definitely need more work to look at needs of older patients. The use of multiple types of information and combining them could be good. Technology that does not rely on the user to gather data e.g., motion sensors could provide additional info." (UofGHP21)

"it could also enable patients themselves to be proactive in terms of accessing services or having a centralised or even personalised suggestions of how to address and how to improve their own quality of life. I think that would certainly be an advantage to try and get people more IT" (UofGHP4)

	<p>"Particularly useful - It will fill a huge gap in the most common cancer in men. To evaluate and discover the needs of patients!" (AUTHHP1036)</p> <p>"will probably help to highlight the patients who need more attention. It is interesting to note the use of impersonal mass media to produce a personalized approach" (AUTHHM1042)</p> <p>"to identify patients with greater need and type of need" (APCHP13)</p> <p>"to bring to surface and make visible needs from a patient group that is not common (for rehabilitation)" (APCHP11)</p> <p>"to improve healthcare through systematically observe and quantify the needs that exist" (APCHP2)</p> <p>"auspicious for the purpose of developing such services" (APCHP13)</p> <p>"to identify the unmet needs of the patient or family member that are as important as the pathology being treated, since in the end what we try to give the patient is a good state of health." (HULAFEHP2)</p> <p>"The great advantage is that it allows quantifying things that seem intangible and can allow early intervention." (HULAFEHP3)</p>
<p>Critique / disadvantages</p>	<p>"There are many patients who still find IT technology difficult to management. At present the IT service within the health service is very outdated. To adapt to new technology improvements would need to be carried out" (UofGHP23)</p> <p>"Need to reassure everyone that data was secure and obviously some folk may not have access to IT. Needs to be free for patients using mobiles (probs in past where calls are charged at premium rates for some NHS services)" (UofGHP22)</p> <p>"its not gonna work. We need better follow up and care of patients, not a software to predict a failure that we will not have capacity to act upon. The NHS is already cluttered with multiple pieces of software that don't communicate." (UofGHP29)</p> <p>"Every patient is different. You can hardly categorize them. We need almost as many categories as patients." (AUTHHP1037)</p> <p>"too many elderly patients do not have the ability, the electronic familiarity to be able to participate in such procedures [...] The doctor does not have much time to be able to have this communication with the patient, it is impossible for the doctor to run it alone (...) maybe I will add users and trained secretaries [...] so it should be done in such a way so that non-doctors can handle it" (AUTHHM0010)</p> <p>"I am considering if this can replace the complexity of the personal contact" (APCHP10)</p> <p>"If the IT-system is not compatible it will be time consuming, ineffective, frustrating and can be unsafe for patient" (APCHP12)</p> <p>"unnecessary" (APCHP8)</p> <p>"the older patient may be need more support to precisely express that information" (HULAFEHP2)</p>

	"As a disadvantage I think it will be to see if the accessibility is generalized." (HULAFEHP3)
Thematic Category 9 – Required information and monitoring	
Physical symptoms	<p>"to be able to quickly get the measurement [e.g.] of bone mass from the radiology laboratory and the lipid measurements. If you add in this now the part of generic blood [exams] [...] you have automatically reached a very good point for the rough stuff. An oximeter that measures oxygenation which should also give you the beats [...] and the oximeter data to be inserted [in the app] automatically" (AUTHHM0010)</p> <p>"early indications" (APCHP8)</p> <p>"alarm for suspected new tumor or recurrence" (APCHP13)</p> <p>"Own suspicion for recurrence?" (APCHP12)</p> <p>"Early indicators of: Lower urinary tract symptoms [and] Adverse effects of treatment" (HULAFEHP2)</p> <p>"accidental falls, weight, physical activity" (HULAFEHP3)</p>
Emotional / psychological symptoms	<p>"How they translate their own psychic world, their phobias, their anxieties, their sadness" (AUTHHP0007)</p> <p>"to catch up signs for depression" (APCHP2)</p> <p>"depressive factors" (APCHP10)</p> <p>"Fear, depression? Need for support?" (APCHP12)</p> <p>"and perception of health and quality of life." (HULAFEHP1)</p> <p>"Changes in health status and / or quality of life related to the pathology treated and or the treatment given" (HULAFEHP2)</p>
Performance status and functioning	<p>"clinical, laboratory and imaging monitoring depending on the type of tumour" (AUTHHP1038)</p> <p>"It would analyze the lifestyle" (HULAFEHP1)</p> <p>"sincerity in compliance with the recommendations" (HULAFEHP1)</p> <p>"Degree of completion of the recommendations given" (HULAFEHP2)</p> <p>"number of drugs taken by patients" (HULAFEHP3)</p>
Practical and daily living	<p>"exercise and collecting dietary information would be valuable. activity overnight would be helpful in providing care needs at home." (UofGHP3)</p> <p>"For patients the biggest things they will want to report/get answers to quickly is menopausal symptoms and strategies to manage these." (UofGHP11)</p> <p>"how they are managing the essential daily tasks of their lives depending on their ability - early indicators of these things becoming a struggle would allow intervention before they became impossible" (UofGHP34)</p> <p>"Information that would be beneficial include changes in function and QoL, awareness of who is (or isn't) utilising self-management advice and implementing behavioural changes relating to preventative strategies." (UofGHM10)</p>

	<p>"recording patient expectations, realistic goal setting, monitoring progress, designing a new treatment plan, redefining goals" (AUTHHM1042)</p>
Thematic Category 10 – Frequency of information	
Weekly	<p>"Once a week I would like a communication with him" (AUTHHP0008)</p>
Monthly	<p>"Monthly" (AUTHHP1029)</p>
On demand	<p>"Every time I evaluate a new patient" (AUTHHP1027)</p> <p>"depends on the parameter... there are people who are very good in health and I do not need to zoom (in time), there are people who are fragile (...) they would be interested at some point to zoom" (AUTHHM0010)</p>
Other	<p>"When the patient is due their clinical review (varies according to their diagnosis etc). There is not time to be looking at these scores and assessments outside of the current review times" (UofGHP21)</p> <p>"This would depend if patient is still being followed up in hospital setting. Most patients are discharged at 5 years. Most of ongoing care should be shared with community." (UofGHP23)</p> <p>"as soon as available - means info is available in "real time" for clinicians instead of a weekly or monthly "dump" (UofGHP22)</p> <p>"It would depend on what we were doing with this information - it would be impossible to receive this information for every patient we see as we do not have the ability to keep patients on our caseloads indefinitely." (UofGHM10)</p> <p>"once every 3 months" (AUTHHM1042)</p> <p>"3-4 times in the first year, 2-4 times the second year." (APCHP13)</p> <p>"in predefined time according to specific agreement" (APCHP12)</p> <p>"when I see the patient?" (APCHP10)</p> <p>"I would say that between control visits (if they are every 6 months, then after 3 months have a telephone control through a socio-psycho-physical-emotional assessment survey)." (HULAFEHP1)</p> <p>"before each patient visit" (HULAFEHP3)</p>
Thematic Category 11 – Presentation of information	
Summary report notification	<p>"there could be a summary of what is considered important" (AUTHHP0009)</p>
Graph or chart notification	<p>"a general overview" (AUTHHP0007)</p> <p>"It is best to have these recorded so that your doctor can see the entire chart so that he/she has a much safer picture of how you spent the [last] 6 months." (AUTHHM0010)</p>
Other	<p>"Linked into Clinical Portal so it can be viewed by all involved in their care." (UofGHP1)</p>

	<p>"Ideally electronically either via email or through one of the patient records systems that exist - would ideally not want to open another platform" (UofGHP21)</p> <p>"The idea of an online dashboard looks great. Would need to integrate smoothly with existing clinical systems." (UofGHP40)</p> <p>"it must synchronize with the already existing journal system" (APCHP12)</p> <p>"through the normal channel which is the journal" (APCHP10)</p> <p>"the best would be in patient's electronic journal" (APCHP2)</p> <p>"Have access to the developed platform." (HULAFEHP1)</p> <p>"Mobile application." (HULAFEHP2)</p> <p>"through the computerized medical record, or in an online platform with easy and fast access." (HULAFEHP3)</p>
Thematic Category 12 – Requirements for system implementation	
<p>Tackle workload / human resource barriers</p>	<p>"Someone to help with follow up to use the data appropriately and ensure follow up care to help use the data productively" (UofGHP9)</p> <p>"Time (always time) to address this new "portal" and deal with what coming through it. Would need to work out who addressed these issues as for early breast cancer patients/survivors this is not usually oncologists but is often breast care nurses. For metastatic patients (and I am not sure if you are suggesting this system for met patients) it would be oncology BCNs and oncologists." (UofGHP11)</p> <p>"As everywhere, workloads are stretched - if this system is burdensome it unfortunately will not be well used. Main thing would be ease of use, support, info that is beneficial to patient assessment" (UofGHP30)</p> <p>"Significant increase in the provision of AHP interventions within cancer services." (UofGHM10)</p> <p>"Automation so that it is not time consuming" (AUTHHP1036)</p> <p>"workload" (AUTHHP1032)</p> <p>"we will have to see how these people who will do this work will be rewarded, because you will have to hire someone if you do it to enough people" (AUTHHM0010)</p> <p>"Involvement by all components (patients, health workers, etc ...)" (HULAFEHP1)</p> <p>"Having time to be able to provide us with the information, have access to information platforms, have prepared hardware and enable us to handle it seem important requirements to me. " (HULAFEHP2)</p>
<p>Tackle infrastructure barriers</p>	<p>"existence of infrastructure, each patient to be registered in a specific care unit and to follow the individualized follow-up plan" (AUTHHM1042)</p> <p>"If the IT-system is not compatible it will be time consuming, ineffective, frustrating and can be unsafe for patients" (APCHP12)</p>

	"a demanding journal system needs to be developed" (APCHP11) "the data should be able to get transferred automatic" (APCHP9)
Buy-in process	"training of staff who will use it" (AUTHHP0008)

TABLE 16 HEALTH PROFESSIONALS'/MANAGERS' PERSPECTIVES OF POST-TREATMENT CARE

6 CONCLUSIONS

In sum, we have adopted a flexible yet robust approach to the research methods employed in task 2.2. The extended timelines allowed us adequate time to approach and recruit at least the minimum required number of end-users and maintain the quality of the outcomes. Our analysis offers varied insights into the perspectives of end-users in relation to post-treatment care for breast cancer, prostate cancer and melanoma, and the requirements for developing the LifeChamps system must meet to provide the anticipated support in practice. An overview of the main messages and concluding key points is provided below (6.2).

6.1 LIMITATIONS

The main limitations with Task 2.2 included the necessary amendments to the original methodology with a view to absorbing the impact of the COVID-19 pandemic. All end-users, across all partners, have had their lifestyles affected and this was reflected in the number of participants recruited. Our recruitment was largely reliant upon end-users 1 and 2 (members of the public) via online routes, which may have biased the sample to reflect only those who were already accessing information online. Reduced services and the opportunity to recruit face-to-face from local support/charity groups may have resulted in missed perspectives from older adults who were not familiar with using technology. Furthermore, no data was collected to identify participants literacy or income deprivation, which may relate to the degree of comfort some participants have with using the proposed technology. Last, COVID-19 hindered the recruitment of specialists within the health services due to limited time and stretched resources faced within real-time clinical environments.

6.2 OVERVIEW OF END-USER PERSPECTIVES OF POST-TREATMENT CARE

Converging evidence from the three partner sites (AUTH, HULAFE, UofG) suggests that key priorities and issues for middle-aged/older patients with breast or prostate cancer and their family members/caregivers in the post-treatment period are as follows:

- Patients and family members/caregivers try to maintain good physical and mental health.
- Patients still describe physical problems as part of their 'new' life with concerns in relation to their bone health.

- Psychological and emotional needs are prevalent and continue longer than expected, more so in 50-64 year age group.
- The services of psycho-oncology, geriatrics, social work, physiotherapy and endocrinology and dermatology are on high demand among these end-users.
- Good information and professional support, as well as follow-up, is highly valued.
- Patients identified 'ideal advice' as psychological support and information on practical day-to-day living.
- Practical and daily living advice is the support that caregivers need to help support their patients.
- Vulnerability and physical and mental health challenges are common in this population in the post-treatment period according to health professionals.
- Management of physical symptoms such as fatigue, deconditioning and side effects of endocrine treatment were viewed as the main health needs.
- Health professionals/managers identified the need for support and information for practical day-to-day living for older patients at post-treatment.
- Professional priorities were to provide best supportive care and empower patients to resume or adapt to meaningful goals and life activity.
- Caregivers feel that more continuing psychological and emotional support was needed for both patients and often the caregiver.
- Psychological support is needed to help patients and family members/caregivers cope with the changes that cancer has brought into their lives.
- More in-depth information for patients and family members/caregivers is required about how to manage (instrumental) activities of daily living, possible side-effects, the disease itself, and the fluctuating needs for support.
- Better support for patients and family members/caregivers is required in relation to follow-up health care services, e.g. monitoring the patients' physical and psychological condition, tests, medication adherence/effectiveness.
- Support must be individualised and attend to such issues as functional decline due to aging, functional decline due to cancer, and burden of multimorbidity.
- A more holistic approach to patients' healthcare needs is required and this should be multidisciplinary to address the key domains of older patients' well-being, for example psychological concerns, functional status, falls, cognition, geriatric syndromes, nutrition and comorbidities.
- Care that is closer to home/community is required, also providing a network of support for social isolation and psychological support.
- Specialist cancer care nurses are viewed as the best point of contact post-cancer treatment.

- Primary care is the type of health service that could be improved by providing more practical and emotional support for older adult's post-cancer treatment.
- The COVID-19 pandemic has had dramatic effects on older adults' experiences of health access to clinics and with daily living in the community. The fear of getting sick with the coronavirus and that hospitals may collapse are common concerns. Closer monitoring of patients during the pandemic to prevent social isolation and missed health care.

Evidence from APC suggests that key priorities and issues for middle-aged/older patients with melanoma in the post-treatment period are as follows:

- Melanoma survivors try to adapt to the new normal, however they have increased psychological needs, especially regarding fear of recurrence, stress, anxiety, depression and sleep disturbances.
- Physical needs after treatment include rehabilitation and signs of melanoma recurrence, such as new lesions and abnormal lymph nodes.
- Melanoma survivors require information regarding their illness, such as melanoma stage, prognosis and treatment updates.
- They need advice regarding self-management strategies and management of fear of recurrence.
- Access to healthcare services is important to melanoma survivors.
- Frequent follow-up is demanding for early identification of recurrence.
- During the COVID-19 pandemic, melanoma survivors have experienced decreased healthcare access, delays in treatment and follow up that can affect the prognosis of the disease.
- Melanoma survivors might experience loneliness, anxiety and social isolation because of the COVID-19 pandemic.
- At post-treatment, clinicians must monitor psychological markers of melanoma survivors' status, indicating depression, anxiety and sleep disturbance.
- Clinicians must monitor melanoma survivors' physical functioning and signs of recurrence.
- The ideal post-treatment health service for melanoma survivors is a contact oncology nurse with easy access to achieve frequent monitoring, physical follow up and provision of information.

6.3 OVERVIEW OF END-USER DESIRED FUNCTIONALITY OF THE DEVELOPING PLATFORM

Converging evidence from all four partner sites (APC, AUTH, HULAFE, UofG) suggests that key end-user expectations, desired functionality and implementation aspects related to the developing LifeChamps system are as follows:

Expectations:

- Expected advantages:
 - Potential improvement in monitoring multiple types of information,
 - Speed of referral and care pathway,
 - Easy health care access,
 - Quick advice and help,
 - Better patient-clinician communication,
 - Enhanced clinician-clinician collaboration, and
 - Identification of patients' unmet needs.
- Anticipated challenges:
 - Lack of comfort in using advanced technology (particularly older patients),
 - Issues with personal data use,
 - Falsely predicting issues that may not occur,
 - Security risks,
 - Restriction of physical contact,
 - Issues with compatibility with existing healthcare systems, and
 - Capacity in relation to time/workload and availability of personnel to address patient issues as they arise.

Desired functionality:

- Up-to-date and timely information to patients and their family members/caregivers.
- Regular information to health professionals about the physical and psychological status of the patient.
- Tailored clinical support based on each patient's data.
- Health professionals must be able to design a new treatment plan and re-define goals involving the patient's perspective.
- Careful attendance must be paid to system design, operability, integration, and accessibility to prevent additional workload to clinicians.
- Clinicians must be able to monitor clinical signs or alarming symptoms of cancer recurrence.
- Clinicians must be able to monitor signs of patient depression and/or fear of recurrence.

Implementation aspects:

- Provide thorough training to end-users before the system is deployed.

- Information provided by the developing platform must be available on demand to accommodate varying clinical needs as they emerge and at the time of a patient's follow-up review.
- The information provided by the developing platform must be presented in the patient's electronic health record.
- To be implemented, the developing system must be compatible with the already existing patient electronic record and clinical portals.
- Close collaboration between end-users and IT support is crucial, complemented by adequate access, connectivity and hardware to enable smooth running.
- Make the system available on demand on the patient's phone and easy to access/use to involve even those who feel less comfortable with technology.

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8 APPENDIX

8.1 LOCAL RECRUITMENT PROCEDURES FOR PARTNER SITES

University of Glasgow (Family members/caregivers)

This task opened for recruitment at the University of Glasgow (UofG) on 6th July 2020 and closed 30th November 2020. Recruitment for members of the public affected by breast or prostate cancer and/or caregivers was advertised via our Call for participants advert in the UK [<https://www.callforparticipants.com/study/DW7R5/what-are-the-health-needs-of-middle-aged-and-older-people-with-cancer>]. This link provided brief information regarding the requirements to participation and directed the individual to contact the UofG for the full study information (patient information sheet and privacy notice). This method allowed us to monitor accrual and to generate follow up reminder emails, if required.

This link was advertised on the LifeChamps website, via the European Cancer Patient Collaboration [ECPC] who sent a generic email to all partners covering 'all types' of cancer in the UK, of which, one was breast specific (Breast Cancer Now) and four prostate-specific (Prostate Cancer Network, Prostate Cancer Support Association, Prostate Cancer Support Foundation, Tackle Prostate Cancer) on the 23rd July 2020. Locally, we had been in correspondence to Maggie's Glasgow (Cancer support Centre), unfortunately they were unable to help due to the pandemic. Therefore, to increase awareness we had two half-page newspaper advertisements in the Glasgow Times [Wednesday 19th August and Wednesday 16th September] and via 200,000 digital ad impressions running on www.glasgowtimes.co.uk between the 24th August and the 21st September. Direct emails from the UofG followed up the generic emails sent to ECPC UK partners in October. Breast Cancer Now responded to the direct email and we went through the internal peer review process which permitted our call for participants to be advertised on their research forum till the 30th November and this was also included on their mail outs (posted 27th November).

Due to a poor response from any members of the public affected by prostate cancer we directly emailed several smaller support groups around the UK, Cancer Support Scotland, Prostate Cancer Federation UK, Prostate Cancer UK, Prostate Scotland several times. We received a reply from Prostate Scotland on the 13th November apologising for the delay, understandably patients and families were their priority due to resources and research capacity being severely stretched in the current pandemic. Although our deadline was 30th November a patient with prostate cancer contacted us the 9th December after he received an email on the 8th December from Prostate Scotland. This patient agreed to participate in the survey.

Therefore, despite these challenging times we received 67 emails of interest and if necessary, follow-up emails were sent a maximum of three times. This resulted in 43 (64%) members of the public being enrolled. Only one member of the public provided a reason for not participating (optional), which was "I am just too overwhelmed at the moment", the remaining 23 participants did not respond. Thus, the UofG surpassed the minimum target set per partner (n = 20 patient/family members) and achieved 215%.

University of Glasgow (Health professionals)

The pandemic affected staffing resources as clinicians were redistributed, furloughed or were facing increased clinical pressures. At UofG, we directly emailed the study information to 55 clinicians; 21 never responded and one declined. The actual number of clinicians notified via email through the clinical networks or snowball techniques was not traceable. Overall, we involved 23 clinicians (Table 7), which also surpassed the minimum target (n=10 per partner) and achieved 230%.

Two clinicians participated in the telephone interview and 21 clinicians via the online survey. Health professionals (HP) were recruited from secondary (n=14) and primary care (n=8). Only one health manager (HM) was recruited from the Beatson West of Scotland Cancer Centre and her role was clinical, thus, our results of HP and HM were merged. In this task, we recruited five Clinical Nurse Specialists, three were involved in breast cancer and one in prostate cancer. Similarly, we were able to recruit two medics with expertise in prostatectomy and prostate clinical oncology; this increased our understanding of local variables in relation to the development of the LifeChamps technology.

HULAFE (Family members/caregivers)

During the period between July 23, 2020 and December 15, 2020, HULAFE carried out the task of distributing the surveys through different media, thus obtaining the collaboration of 14 end-users of the patients and family members group.

The means used for distribution were:

- Social networks of La Fe Hospital and La Fe Health Research Institute of Valencia (LinkedIn, Facebook, Twitter ...)
- Social networks of the ECPC organization (with the help of Charis Girvalaki)
- Social networks of the LifeChamps project
- Email contact with 4 cancer patient associations:
 - Foundation Against Cancer (FEFOC)
 - Spanish Group of Cancer Patients (GEPAC)
 - Grup Àgata
 - Spanish Association Against Cancer (AECC)
- Distribution through family and friends
- Direct contact via twitter to patient profiles with many followers

Despite this distribution work, the task has been concluded with a low participation in these surveys, HULAFE believes that it may be due to COVID-19, which has saturated all the patient organizations and citizens.

HULAFE (Health professionals)

During the period July 23, 2020 to December 15, 2020, HULAFE carried out the task of distributing the surveys through different media, thus obtaining the collaboration of 3 end-users of the health care professionals' group.

The means used for survey distribution were:

- Social networks of La Fe Hospital and La Fe Health Research Institute of Valencia (LinkedIn, Facebook, Twitter)
- Social networks of the LifeChamps project
- Distribution through family and friends
- Distribution through hospital clinicians

Despite all efforts, participation levels were low and can perhaps be explained as follows: (1) recruitment started in the summer (which was the first holiday period for healthcare professionals after the first wave of COVID-19), and (2) COVID-19 had saturated hospitals and sapped the energies of many health professionals, thus preventing them from displaying a willingness to take part when in normal circumstances they may well have opted to participate.

APC (Family members/caregivers)

For the recruitment of patients and family members early contact was made with the patient association for Melanoma in Sweden (Melanomföreningen) during March 3rd, 2020. After additional emails from APC partner directly, but also contact through ECPC (LifeChamps partner), a connection and collaboration with Melanomföreningen was established in late July – early August 2020. From that point Melanomföreningen assisted further in disseminating the advertisement and the call for participants for the EU survey through direct mailing with their own members, but also through several announcements and posting of the recruitment details on their Facebook member page feed. Later, during October 2020, contact was made through UoG (LifeChamps partner) with the Scottish patient association for melanoma (MASScot), who also assisted in disseminating an English version of the EU survey within their member mailing list. Additionally, the team of APC created a digital poster/information sheet with the LifeChamps graphical design and dissemination material, that contained a short description of the call for participants in the EU Survey. This material was disseminated through the help of ECPC (LifeChamps partner) and through the coordinator of LifeChamps (AUTH) through posts in the respective partners Facebook page feed. Printed posters were put up as well on selected health care centres in each waiting room. The duration of recruitment was between July 8th – November 30th, 2020 (for Melanomföreningen) and October 15th – November 30th, 2020 (for MASScot). Representatives and contact persons from both patient organisations received all necessary material for dissemination in due time before the official recruitment period, with detailed instructions for the patient and caregiver survey outline, the access to the Participant Information Sheet (PIS) and details about the electronic informed consent. Follow ups and reminders were made subsequently during the recruitment period via email communication with both patient organisations. In order to boost the recruitment of caregiver participation, both patient organisations were made aware of the possibility that responding patients could share the same EU survey link and PIS to one of their caregivers (family, close friend, etc.). Even though repeated efforts were made, no responses from melanoma patient caregivers were collected during the recruitment period.

APC (Health professionals)

The accrual and response rates of physicians cannot be calculated because of the indirect recruitment processes. Most physicians were invited to participate in our study via the clinical managers of the primary care centre, with the exception of dermatologists and physiotherapists. Thirteen clinicians participated in our study. All participants chose to answer the survey and no one chose to participate in the interview. Although two health managers answered our survey, both responded via their role as clinicians and, as a consequence, their responses were counted in the group of clinicians.

AUTH (Family members/caregivers)

The recruitment phase lasted for 4 months, from the 29th of July 2020 to the 30th of November 2020. To engage participants, we disseminated a call to action through the following recruitment channels: -

- Social media posts to Facebook, and twitter through the official accounts of the project
- email invitations to major Greek NGOs about cancer patients through the European Cancer Patient Coalition (ECPC)
- Personal engagement of patients, their family members through the Hellenic Federation of Cancer (ELL.O.K)
- Announcement of the survey, through a webinar, that was hosted by the NGO Alma Zois
- Personal engagement of patients, their family members through the NGO Alma Zois
- Local engagement and referral of patients, their family members through their personal oncologist and urologist clinicians.

AUTH (Health professionals)

The recruitment phase lasted for 4 months, from the 29th of July 2020 to the 30th of November 2020. To engage participants, we disseminated a call of action through the following recruitment channels: -

- Social media posts to Facebook, and twitter through the official accounts of the project and the Laboratory of Medical Physics
- email invitations to oncologists through the Hellenic Society of Medical Oncology (HeSMO)
- email invitations to the healthcare professionals (e.g. oncologists, urologist, psychologist, nurses, dietician) that participated in our initial workshops for WP 2.1
- email invitations to urologists through the Institute for the Study of Urologic Diseases (<http://www.imop.gr/en>)
- local engagement through our network of associated partners (see [LLM Care EIPonAHA Reference Site](#)),

In total, 17 healthcare professionals and 2 healthcare managers answered the online survey, while 2 healthcare professionals and 2 healthcare managers participated in online interviews. Accrual rates, for healthcare professionals and managers, were $(23/10) = 230\%$. The main reason some healthcare professionals did not respond positively to our invitation was due to limited time available. Increase of on job duties because of the pandemic seemed to be the main bottleneck that made their participation not feasible.

8.2 INTERVIEW GUIDES

Patients with Cancer

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

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 <u>health services</u> would have been useful to you at the end of cancer treatment?	
10. In an ideal world, what type of <u>advice or information</u> 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
<p>Prior to interview: Access the contact template form, clarify the relationship to the cancer patient, age of cancer patient and type of cancer diagnosed.</p> <p><i>Opener Question:</i></p> <p>1. Do you have a reason or interest for participating in this project?</p>	
<p>2. People provide varying levels of care to cancer patients, some may need more help than others.</p>	<p>Think about daily activities, help in evenings, additional needs, living arrangements</p>

In general, what kind of activities or support were you providing?	
3. How many <u>months</u> has it been since the patient you take care of finished his/her treatment for cancer?	
<p>4. Has the patient you take care of been diagnosed with any other health condition by a doctor or healthcare professional?</p> <p><i>(If NO, move on the Question 5)</i></p> <p>When were they diagnosed? (months)</p> <p>How are these health conditions now since the patient you take care of has finished his/her cancer treatment?</p>	<p>E.g., Diabetes, high blood pressure, osteoporosis. <i>Remember to address EACH health condition mentioned!</i></p> <p>(was it before cancer, same time, since your treatment finished)</p> <p>(Got worse/ stayed the same / got better)</p>
<p>5. Have <u>you personally</u> been diagnosed with any other health condition by a doctor or healthcare professional?</p> <p><i>(If NO, move on the Question 6)</i></p> <p>When were you diagnosed? (years/months)</p> <p>How are these health conditions now since the patient you take care of has finished his/her cancer treatment?</p>	<p>E.g., Diabetes, high blood pressure, osteoporosis. <i>Remember to address EACH health condition mentioned!</i></p> <p>(was it before cancer, same time, since your treatment finished)</p> <p>(Got worse/ stayed the same / got better)</p>
<p>6. What are <u>your priorities in life</u> now that the patient you take care of moves beyond cancer and cancer treatment?</p>	<p>What is life like now.</p> <p>How do you feel, have you returned to you usual routine/life</p>
<p>7. Thinking about the patient you were taking care of, what do think his/her priorities are in life <u>now</u> for moving beyond cancer and cancer treatment?</p>	<p>What is life like now.</p> <p>Have they resumed life as it was before cancer, have they had to make any adjustments.</p>
<p>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?</p>	<p>Think about the conversations you've had, whether more help is needed.</p>
<p>9. In general, due <u>to coronavirus</u> and after the patient you take care of has received treatment for cancer, what do you think are his/her experiences, need or concerns?</p>	
<p>10. In general, due <u>to coronavirus</u> what are <u>your own</u> experiences, needs or concerns?</p>	

11. What kind of support or information did <u>you need</u> after the patient you take care of finished his/her cancer treatment?	
12. What kind of support do <u>your feel your</u> 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 <u>health services</u> would have been useful <u>to you</u> at the end of his/her treatment?	
15. After taking care of a cancer patient, in an ideal world, what type of <u>advice or information</u> would have been useful <u>to you</u> 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?	<i>Conversations with colleagues, persistent problems/symptoms, psychological support, reduced mobility, fatigue, frailty, what do patients find more difficult during this period.</i>
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 <u>support or information</u> do you think middle-aged or older patients, and their families, might need post treatment?	<i>what you have experienced, where are the gaps, the duration between follow up appoints, what would be useful</i>
10. What type of <u>health services</u> might be more or less useful, for middle-aged or older patients and their families post treatment?	<i>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.</i>
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 <i>differently</i> post cancer treatment and during the follow up periods?	<i>Think about your conversations, your experience and observation</i>
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?	<i>From your perspective, what advantages or disadvantages do you foresee, would you feel comfortable using this technology.</i>
15. What information would you be looking for and/or what do we need to monitor in middle aged or older patients?	<i>From your clinical perspective, ideally what would you want to know e.g. early indicators, any preventative strategies, specific changes in QoL.</i>
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?	<i>workload, infrastructure</i>
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?	

8.3 DATA ANALYSIS SCHEME

Analysis of demographic/clinical data

Basic 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. If 25+ months enter duration in “actual time since Rx (months)”.
#06. Comorbidities - number	Code as: 0; 1-2; 3-5; 6-10; 11+. Present n, % in descending order of frequency.
#07. Comorbidities – names on list	Code all entries using the list in this link . If not on the list, code as ‘Other: XX’, and type in comorbidity name in next column. Present n, % in descending order of frequency. If none, enter N/A (not applicable).
#08. Comorbidities – when was this diagnosed in relation to cancer.	Code as: before cancer/same time/after cancer Rx. If stated it was a side effect of cancer treatment code as ‘side effect of Rx’. If none, enter N/A (not applicable). Code as ‘no information’, if no information provided. Present n, % in descending order of frequency.
#09. Comorbidities - current status	Code as: ‘got worse’; ‘stayed the same’; ‘got better’. Code as ‘N/A’ (not applicable), if none. Code as ‘no information’, if no information provided on comorbidity status. 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 of caregiver (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. Age of patient with cancer	Code as: 50-54y; 55-59y; 60-64y; 65-69y; 70-74y; 75-79y; 80-84y; 85-89y; 90+y. Code as 'unknown', if age not known. Present n, % in descending order of frequency.
#15. Relationship to patient	Code all entries (see template). Present n, % in descending order of frequency.
#16. Support to patient	Code as: 'emotional support', 'practical support'. Categories aren't mutually exclusive. Present n, % in descending order of frequency.
#17. Time since patient's end of treatment (months)	Code as: 1-6m; 7-12m; 13-18m; 19-24m; 25+m. If 25+ months enter duration in "actual time since Rx (months)" Present n, % in descending order of frequency.
#18. Caregiver comorbidities - number	Code as: 0; 1-2; 3-5; 6-10; 11+. Present n, % in descending order of frequency.
#19. Caregiver comorbidities - name list	Code all entries using the list in this link . If not on the list, code as 'Other: XX', and type in comorbidity name in next column. If none, enter N/A (not applicable). Present n, % in descending order of frequency.
#20. Caregiver comorbidities – timing of diagnosis	Code as: before caring for patient with cancer/ at same time/or after. If none, enter 'N/A' (not applicable). Code as 'no information', if no information provided. Present n, % in descending order of frequency.
#21. Caregiver comorbidities - current status	Code as: 'got worse'; 'stayed the same'; 'got better'. If none, enter N/A (not applicable). Present n, % in descending order of frequency.
#22. Patient comorbidities - number of	Code as: 0; 1-2; 3-5; 6-10; 11+. Present n, % in descending order of frequency.
#23. Patient comorbidities - name list	Code all entries using the list in this link . If not on the list, code as 'Other: XX', and type in comorbidity name in next column. If none, enter N/A (not applicable). Present n, % in descending order of frequency.
#24. Patient comorbidities - time since diagnosis	Code as: before cancer/same time/after cancer Rx. If stated it was a side effect of cancer treatment code as 'side effect of Rx'. If none, enter N/A (not applicable). Code as 'no information', if no information provided. Present n, % in descending order of frequency.
#25. Patient comorbidities - current status	Code as: 'got worse'; 'stayed the same'; 'got better'. If none, enter N/A (not applicable). Code as 'no

	information', if no information provided on comorbidity status. Present n, % in descending order of frequency.
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C. Health professional data	
Variables	Output
#26. Health professional - specify role	Code all entries (see template) Present n, % in descending order of frequency.
#27. Time working in cancer	Code as: <1y; 1-5y; 6-10y; 11-15y; 16-20y; 21+y. Present n, % in descending order of frequency.
#28. Time working in current role	Code as: <1y; 1-5y; 6-10y; 11-15y; 16-20y; 21+y. Present n, % in descending order of frequency.
#29. Area of specialty	Code all entries (see template). If other, please specify. Present n, % in descending order of frequency.
#30. Gender	Present n, % in descending order of frequency.

D. Health manager data	
Variables	Output
#31. Health manager - specify role	Present n, % in descending order of frequency.
#32. Time working in cancer	Code as: 1-5y; 6-10y; 11-15y; 16-20y; 21+y. Present n, % in descending order of frequency.
#33. Time working in current role	Code as: 1-5y; 6-10y; 11-15y; 16-20y; 21+y. Present n, % in descending order of frequency.
#34. Area of specialty	Code all entries. Present n, % in descending order of frequency.
#35. 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 [8] 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	<ul style="list-style-type: none"> a. <i>Going back to previous activities</i> b. <i>Living life to its full</i> c. <i>Family</i> d. <i>Finding meaning</i> e. <i>Finding a 'new normal'</i> 	4.1. <i>What are your priorities in life now that you move beyond cancer and cancer treatment?</i>
#02 - Caregiver's priorities in life after patient's cancer treatment - caregiver's perspective	<ul style="list-style-type: none"> a. <i>Going back to previous activities</i> b. <i>Living life to its full</i> c. <i>Family</i> d. <i>Finding meaning</i> e. <i>Finding a 'new normal'</i> 	4.2. <i>What are your priorities in life now that the patient you have taken care of moves beyond cancer and cancer treatment?</i>
#03 - Patient's priorities in life after cancer treatment - caregiver's perspective	<ul style="list-style-type: none"> a. <i>Going back to previous activities</i> b. <i>Living life to its full</i> c. <i>Family</i> d. <i>Finding meaning</i> e. <i>Finding a 'new normal'</i> 	4.3. <i>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?</i>
#04 - 50-64y/o patient concerns or needs - patient's perspective	<ul style="list-style-type: none"> a. <i>Physical/symptom-related concerns or needs</i> b. <i>Psychological/emotional concerns or needs</i> c. <i>Social concerns or needs</i> d. <i>Practical/treatment concerns or needs (e.g. transportation, finances)</i> e. <i>Family-related concerns or needs</i> f. <i>Information needs</i> g. <i>Other</i> 	4.4. <i>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?</i>
#05 - 50-64y/o patient concerns or needs - caregiver's perspective	<ul style="list-style-type: none"> a. <i>Physical/symptom-related concerns or needs</i> b. <i>Psychological/emotional concerns or needs</i> c. <i>Social concerns or needs</i> d. <i>Practical/treatment concerns or needs (e.g. transportation, finances)</i> 	4.5. <i>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?</i>

ANALYTICAL FRAMEWORK A -- PATIENTS/CAREGIVERS		
THEMATIC CATEGORY	CODING	CORRESPONDING QUESTION
	<ul style="list-style-type: none"> <i>e. Family-related concerns or needs</i> <i>f. Information needs</i> <i>g. Other</i> 	
#06 - 65+y/o patient concerns or needs - patient's perspective	<ul style="list-style-type: none"> <i>a. Physical/symptom-related concerns or needs</i> <i>b. Psychological/emotional concerns or needs</i> <i>c. Social concerns or needs</i> <i>d. Practical/treatment concerns or needs (e.g. transportation, finances)</i> <i>e. Family-related concerns or needs</i> <i>f. Information needs</i> <i>g. Other</i> 	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	<ul style="list-style-type: none"> <i>a. Physical/symptom-related concerns or needs</i> <i>b. Psychological/emotional concerns or needs</i> <i>c. Social concerns or needs</i> <i>d. Practical/treatment concerns or needs (e.g. transportation, finances)</i> <i>e. Family-related concerns or needs</i> <i>f. Information needs</i> <i>g. Other</i> 	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	<ul style="list-style-type: none"> <i>a. Physical/symptom-related concerns, needs or experiences</i> <i>b. Psychological/emotional concerns, needs or experiences</i> <i>c. Social concerns, needs or experiences</i> <i>d. Practical/treatment concerns, needs or experiences (e.g. transportation, finances)</i> <i>e. Family-related concerns, needs or experiences</i> 	4.8. In general, due to the coronavirus and after having treatment for cancer, what are your experiences, needs or concerns?

ANALYTICAL FRAMEWORK A -- PATIENTS/CAREGIVERS		
THEMATIC CATEGORY	CODING	CORRESPONDING QUESTION
	<ul style="list-style-type: none"> <i>f. Information needs</i> <i>g. Other</i> 	
#09 - Patient COVID needs or concerns - caregiver's perspective	<ul style="list-style-type: none"> <i>a. Physical/symptom-related concerns or needs</i> <i>b. Psychological/emotional concerns or needs</i> <i>c. Social concerns or needs</i> <i>d. Practical/treatment concerns or needs (e.g. transportation, finances)</i> <i>e. Family-related concerns or needs</i> <i>f. Information needs</i> <i>g. Other</i> 	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	<ul style="list-style-type: none"> <i>a. Physical/symptom-related concerns, needs or experiences</i> <i>b. Psychological/emotional concerns, needs or experiences</i> <i>c. Social concerns, needs or experiences</i> <i>d. Practical/treatment concerns, needs or experiences (e.g. transportation, finances)</i> <i>e. Family-related concerns, needs or experiences</i> <i>f. Information needs</i> <i>g. Other</i> 	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	<p>Support with:</p> <ul style="list-style-type: none"> <i>a. Physical/symptom-related concerns, needs or experiences</i> <i>b. Psychological/emotional concerns, needs or experiences</i> <i>c. Social concerns, needs or experiences</i> <i>d. Practical/treatment concerns, needs or</i> 	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?

ANALYTICAL FRAMEWORK A -- PATIENTS/CAREGIVERS		
THEMATIC CATEGORY	CODING	CORRESPONDING QUESTION
	<p><i>experiences (e.g. transportation, finances)</i></p> <p><i>e. Family-related concerns, needs or experiences</i></p> <p><i>f. Information needs</i></p> <p><i>g. Other needs</i></p>	
<p>#12 - Caregiver experiences of support or information since treatment - caregiver's perspective</p>	<p><i>Support with:</i></p> <p><i>a. Physical/symptom-related concerns, needs or experiences</i></p> <p><i>b. Psychological/emotional concerns, needs or experiences</i></p> <p><i>c. Social concerns, needs or experiences</i></p> <p><i>d. Practical/treatment concerns, needs or experiences (e.g. transportation, finances)</i></p> <p><i>e. Family-related concerns, needs or experiences</i></p> <p><i>f. Information needs</i></p> <p><i>g. Other needs</i></p>	<p>4.12 What kind of support or information did you need after the patient you were taking care of finished their cancer treatment?</p>
<p>#13 - current needs for support for family/partner - patient's perspective</p>	<p><i>Support with:</i></p> <p><i>a. Physical/symptom-related concerns, needs or experiences</i></p> <p><i>b. Psychological/emotional concerns, needs or experiences</i></p> <p><i>c. Social concerns, needs or experiences</i></p> <p><i>d. Practical/treatment concerns, needs or experiences (e.g. transportation, finances)</i></p> <p><i>e. Family-related concerns, needs or experiences</i></p> <p><i>f. Information needs</i></p> <p><i>g. Other needs</i></p>	<p>4.13 What kind of support do you feel your family or partner might need right now?</p>

ANALYTICAL FRAMEWORK A -- PATIENTS/CAREGIVERS		
THEMATIC CATEGORY	CODING	CORRESPONDING QUESTION
#14 – current needs for support for family/partner – caregiver’s perspective	<p><i>Support with:</i></p> <ul style="list-style-type: none"> <i>a. Physical/symptom-related concerns, needs or experiences</i> <i>b. Psychological/emotional concerns, needs or experiences</i> <i>c. Social concerns, needs or experiences</i> <i>d. Practical/treatment concerns, needs or experiences (e.g. transportation, finances)</i> <i>e. Family-related concerns, needs or experiences</i> <i>f. Information needs</i> <i>g. Other needs</i> 	4.13 <i>What kind of support do you feel your family or partner might need right now?</i>
#15 - Patient current needs for support - caregiver’s perspective	<p><i>Support with:</i></p> <ul style="list-style-type: none"> <i>a. Physical/symptom-related concerns, needs or experiences</i> <i>b. Psychological/emotional concerns, needs or experiences</i> <i>c. Social concerns, needs or experiences</i> <i>d. Practical/treatment concerns, needs or experiences (e.g. transportation, finances)</i> <i>e. Family-related concerns, needs or experiences</i> <i>f. Information needs</i> <i>g. Other needs</i> 	4.14 <i>What kind of support do you feel the patient you were taking care of may need right now?</i>
#16 - Ideal health services - patient’s perspective	<ul style="list-style-type: none"> <i>a. Hospital services</i> <i>b. Primary care services</i> <i>c. Community services</i> <i>d. Home care services</i> <i>e. Other services</i> 	4.15 <i>In an ideal world, what type of health services would have been useful to you at the end of cancer treatment?</i>
#17 - Ideal type of advice or information - patient’s perspective	<ul style="list-style-type: none"> <i>a. Practical and day-to-day living</i> <i>b. Management of physical symptoms</i> 	4.16 <i>In an ideal world, what type of advice or information would have been useful to</i>

ANALYTICAL FRAMEWORK A -- PATIENTS/CAREGIVERS		
THEMATIC CATEGORY	CODING	CORRESPONDING QUESTION
	<i>c. Psychological support d. Self-management</i>	<i>you at the end of cancer treatment?</i>
#18 - Ideal health services - caregiver's perspective	<i>a. Hospital services b. Primary care services c. Community services d. Home care services e. Other services</i>	<i>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?</i>
#19 - Ideal type of advice or information - caregiver's perspective	<i>a. Practical and day-to-day living b. Management of physical symptoms c. Psychological support d. Self-management</i>	<i>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?</i>
#20 - Perceptions on system benefits and drawbacks	<i>a. Praise/advantages- patient b. Critique/disadvantages - patient c. Praise/advantages - caregiver d. Critique/disadvantages - caregiver</i>	<i>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?</i>
#21 - Frequency of predictions	<i>a. Daily b. Weekly c. Monthly d. On demand e. Other</i>	<i>5.3 How often would you want predictions and advice like this sent to you, or your family?</i>
#22 - Health professional actions	<i>a. Communicate with and inform the patient/family b. Adjust follow up care c. Share information with other treating health professionals</i>	<i>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?</i>
#23 - Comfort using technology	<i>a. General competency reported b. Low competency or barriers reported</i>	<i>5.5 In general, how comfortable do you feel using technology?</i>
<i>Not applicable.</i>	<i>Use coding from previous questions to code responses in this question</i>	<i>5.6 Finally, is there anything else you would like to add?</i>

ANALYTICAL FRAMEWORK B -- HEALTH PROFESSIONALS / MANAGERS		
THEMATIC CATEGORY	CODING	CORRESPONDING QUESTION
#01 - HP/HM involvement in patient care	<i>a. Medical management b. Treatment administration c. Psychological support d. Community care</i>	<i>4.1 What involvement do you have with treatment, advice, support or caring for</i>

ANALYTICAL FRAMEWORK B -- HEALTH PROFESSIONALS / MANAGERS		
THEMATIC CATEGORY	CODING	CORRESPONDING QUESTION
	<ul style="list-style-type: none"> e. Pharmacy f. Physiotherapy g. Other 	<p>older patients and their families?</p> <p>4.2 What type of health services for older patients with cancer are you responsible for?</p>
#02 - Patient's post-treatment health needs - HP/HM's perspective	<ul style="list-style-type: none"> 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?
#03 - HP/HM professional priorities	<ul style="list-style-type: none"> a. Survival b. Best supportive care c. 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 support/information patients need at post-treatment	<ul style="list-style-type: none"> a. Practical and day-to-day living b. Management of physical symptoms c. Psychological support d. Self-management e. Information f. Other 	4.5 What kind of support or information do you think middle-aged or older patients, and their families, might need post treatment?
#05 - HP/HM views on health services at post-treatment	<ul style="list-style-type: none"> 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?
#06 - HP/HM views on important PROMs or PREMs	<ul style="list-style-type: none"> 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?
#07 - HP/HM views on patients' experiences due to COVID	<ul style="list-style-type: none"> a. Experiences with symptom management b. Experiences with health access 	4.8 COVID-19-19 has caused many changes, what do you think older patients are experiencing differently post cancer

ANALYTICAL FRAMEWORK B -- HEALTH PROFESSIONALS / MANAGERS		
THEMATIC CATEGORY	CODING	CORRESPONDING QUESTION
	<ul style="list-style-type: none"> c. Experiences with follow up services d. Experiences with daily living and community care 	treatment and during the follow up periods?
#08 - Perceptions on system benefits and drawbacks	<ul style="list-style-type: none"> a. Praise/advantages - HP b. Critique/disadvantages - HP c. Praise/advantages - HM d. Critique/disadvantages - HM 	<p>5.1 What do you think about a system like this?</p> <p>5.2 What is the potential of this service?</p>
#09 - Required information and monitoring	<ul style="list-style-type: none"> 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?
#10 - Frequency of information	<ul style="list-style-type: none"> 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?
#11 - Presentation of information	<ul style="list-style-type: none"> 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?
#12 - Requirements for system implementation	<ul style="list-style-type: none"> 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 entered into **Step 1 Matrix** for each thematic category using Microsoft Excel. The matrix will comprise one row per participant, insert all quotes linked to codes see example below. **Step 1 Matrix** will also help to identify most common codes in response to the question.

STEP 1 MATRIX (see updated template 27.11.20)

HP/HM	Thematic Category 1			
	(a) Medical management	(b) Rx administration	(c) Psychological support	(d) Community support
Participant 1	Quotes linked to codes	Quotes linked to codes	Quotes linked to codes	Quotes linked to code
Participant 2	Quotes linked to codes	Quotes linked to codes	Quotes linked to codes	Quotes linked to codes

Subsequently, the data will then be summarised for each thematic category using **Step 2 Matrix**. This will require the analyst (at each partner site) to be reflective and interpretative of each participant's survey and select the relevant code(s) and quote(s) (text) representative for each theme. The matrix will comprise one row per participant and one column per thematic category. To summarise the evidence, look at each thematic category over ALL participants. It maybe that one code is most common so use three quotes to support or, if two codes are the most common use six quotes. This will be for each thematic category for inclusion into each partner's 'Summary of

Findings' document will be sent to the University of Glasgow for inclusion in the final report for task 2.2.

STEP 2 MATRIX (see updated Template 27.11.20)

HP/HM	Thematic category 1		Thematic category 2		Thematic category 3		Thematic category 4	
Participant 1	code	Quote from most relevant text	code	Quote most relevant text	code	Quote most relevant text	code	Quote most relevant text
Participant 2	code	Quote from most relevant text	code	Quote most relevant text	code	Quote most relevant text	code	Quote most relevant text
Summary	<i>Summarised evidence</i>		<i>Summarised evidence</i>		<i>Summarised evidence</i>		<i>Summarised evidence</i>	

A separate sheet will be used for patients, carers and health professionals/managers. As per task 2.2 activities protocol, **Task 2.2 partners will be responsible for the analysis of their own raw research data as generated at their respective sites/countries.**

8.4 'SUMMARY OF FINDINGS' TEMPLATE

Summary of Findings template

Task 2.2 partner: [enter partner acronym here]

Reporting of partner findings will be according to headings provided below.

1. End-user groups 1 & 2 (patients and family members)

1.1. Summary of local recruitment procedures

Please provide an account of recruitment procedures at your site, including duration of recruitment.

Suggested word-count: 300-400 words.

1.2. Summary of accrual and participant characteristics

Please provide an account of accrual rates, response rates, reasons for refusal, total number of participants, numbers of participants taking the survey v. being interviewed.

Please provide an account of participant background characteristics. Please make use of Tables 1 and 2 below.

Suggested word-count: 300-400 words (excluding Tables).

Table 1. Patient characteristics		
Variables	Responses	n (%)
Gender	Female Male	
Age (years)	55-59 50-54 60-64 65-69 70-74 80-84 75-79 85-89 90+	
Type of cancer	Breast cancer Prostate cancer Skin cancer	
Time since end of treatment (months)	25+ 1-6 7-12 19-24 13-18 less than one	

Table 1. Patient characteristics		
Variables	Responses	n (%)
Comorbidities - number	1-2 0 6-10	
Name of co-morbidities	<i>Add a list here as appropriate based on local data.</i>	
Timing of co-morbidities diagnosis	Before Cancer Post Cancer side effect of cancer treatment During Cancer No information	
Current status of co-morbidities	Stayed same Got worse No information Got better	

Table 2. Family member characteristics		
Variables	Responses	n (%)
Gender	Female Male	
Age of caregiver	50-64 65-79 35-49 18-34	
Type of cancer	Breast Prostate Skin cancer	
Age of patient	60-64 65-69 unknown 55-59	
Relationship to patient	Daughter Husband/ Partner Wife/ Partner Sister-in-law	
Support to patient	practical emotional	
Time since end of treatment (months)	25+ 1-6 19-24	
Caregiver co-morbidities - number	0 1-2 3-5	
Name of caregiver co-morbidities	<i>Add a list here as appropriate based on local data.</i>	
Timing of caregiver co-morbidities diagnosis	Before caring for patient At same time caring for patient	
Current status of caregiver co-morbidities	Stayed same Same time	
Patient co-morbidities - number	0 1-2 3-5	
Name of patient co-morbidities	<i>Add a list here as appropriate based on local data.</i>	
Timing of patient co-morbidities diagnosis	Before Cancer During Cancer treatment	
Current status of patient co-morbidities	Stayed Same Got better	

1.3. Summaries of end-user experiences of post-treatment care

1.3.1. *Patient perspectives*

Please provide a detailed account of findings, combining data from the corresponding thematic categories.

Please present thematic categories, corresponding codes and representative quotes per thematic category, using Table 3 below.

Suggested word-count: 500-1000 words (excluding Table 3).

Table 3. Patients' experiences of post-treatment care	
Thematic Category 1 - Priorities in life after cancer treatment	
<i>Insert corresponding code here. Please use one row per code.</i>	<i>Insert representative corresponding quotes in quotation marks here. Each quote must be followed by the participant's local ID (e.g. UK12, SP12, GR12, SW12). Please limit representative quotes to 2-3 per code.</i>
Thematic Category 4 – Concerns/needs 50 - 64 years	
<i>Insert corresponding code here. Please use one row per code.</i>	<i>Insert representative corresponding quotes in quotation marks here. Each quote must be followed by the participant's local ID (e.g. UK12, SP12, GR12, SW12). Please limit representative quotes to 2-3 per code.</i>
Thematic Category 6 – Concerns/needs 65+ years	
<i>Insert corresponding code here. Please use one row per code.</i>	<i>Insert representative corresponding quotes in quotation marks here. Each quote must be followed by the participant's local ID (e.g. UK12, SP12, GR12, SW12). Please limit representative quotes to 2-3 per code.</i>
Thematic Category 8 – COVID-19 concerns/needs	
<i>Insert corresponding code here. Please use one row per code.</i>	<i>Insert representative corresponding quotes in quotation marks here. Each quote must be followed by the participant's local ID (e.g. UK12, SP12, GR12, SW12). Please limit representative quotes to 2-3 per code.</i>
Thematic Category 11 - Experience since end of treatment	

Table 3. Patients' experiences of post-treatment care	
<i>Insert corresponding code here. Please use one row per code.</i>	<i>Insert representative corresponding quotes in quotation marks here. Each quote must be followed by the participant's local ID (e.g. UK12, SP12, GR12, SW12). Please limit representative quotes to 2-3 per code.</i>
Thematic Category 13 - Current needs for family/support	
<i>Insert corresponding code here. Please use one row per code.</i>	<i>Insert representative corresponding quotes in quotation marks here. Each quote must be followed by the participant's local ID (e.g. UK12, SP12, GR12, SW12). Please limit representative quotes to 2-3 per code.</i>
Thematic Category 16 - Ideal health Services	
<i>Insert corresponding code here. Please use one row per code.</i>	<i>Insert representative corresponding quotes in quotation marks here. Each quote must be followed by the participant's local ID (e.g. UK12, SP12, GR12, SW12). Please limit representative quotes to 2-3 per code.</i>
Thematic Category 17 - Ideal type of advice	
<i>Insert corresponding code here. Please use one row per code.</i>	<i>Insert representative corresponding quotes in quotation marks here. Each quote must be followed by the participant's local ID (e.g. UK12, SP12, GR12, SW12). Please limit representative quotes to 2-3 per code.</i>

1.3.2. Family member perspectives

Please provide a detailed account of findings, combining data from the corresponding thematic categories.

Please present thematic categories, corresponding codes and representative quotes per thematic category, using Tables 4 and 5 below.

Suggested word-count: 500-1000 words (excluding Tables).

If no family members were recruited, please delete this section.

Table 4. Family members' perspectives on patients post treatment care	
Thematic Category 3 - Caregiver's perspective on patient priorities	
<i>Insert corresponding code here. Please use one row per code.</i>	<i>Insert representative corresponding quotes in quotation marks here. Each quote must be followed by the participant's local ID (e.g. UK12, SP12, GR12, SW12). Please limit representative quotes to 2-3 per code.</i>
Thematic Category - 5 & 7 Caregiver's perspective on patients concerns relating to age since end of cancer treatment	
<i>Insert corresponding code here. Please use one row per code.</i>	<i>Insert representative corresponding quotes in quotation marks here. Each quote must be followed by the participant's local ID (e.g. UK12, SP12, GR12, SW12). Please limit representative quotes to 2-3 per code.</i>
Thematic Category 9 - Caregiver's perspective on patients during COVID-19	
<i>Insert corresponding code here. Please use one row per code.</i>	<i>Insert representative corresponding quotes in quotation marks here. Each quote must be followed by the participant's local ID (e.g. UK12, SP12, GR12, SW12). Please limit representative quotes to 2-3 per code.</i>
Thematic Category 15 - Caregiver's perspectives on patient current needs for support	
<i>Insert corresponding code here. Please use one row per code.</i>	<i>Insert representative corresponding quotes in quotation marks here. Each quote must be followed by the participant's local ID (e.g. UK12, SP12, GR12, SW12). Please limit representative quotes to 2-3 per code.</i>

Table 5. Family members' own experiences of care

Thematic Category 2 - Caregiver's priorities in life

Table 5. Family members' own experiences of care	
<i>Insert corresponding code here. Please use one row per code.</i>	<i>Insert representative corresponding quotes in quotation marks here. Each quote must be followed by the participant's local ID (e.g. UK12, SP12, GR12, SW12). Please limit representative quotes to 2-3 per code.</i>
Thematic Category 10 - Caregiver's COVID-19 experiences	
<i>Insert corresponding code here. Please use one row per code.</i>	<i>Insert representative corresponding quotes in quotation marks here. Each quote must be followed by the participant's local ID (e.g. UK12, SP12, GR12, SW12). Please limit representative quotes to 2-3 per code.</i>
Thematic Category 12 - Caregiver's experience since end of patient treatment	
<i>Insert corresponding code here. Please use one row per code.</i>	<i>Insert representative corresponding quotes in quotation marks here. Each quote must be followed by the participant's local ID (e.g. UK12, SP12, GR12, SW12). Please limit representative quotes to 2-3 per code.</i>
Thematic Category 14 - Caregiver's current needs for support for their family/partner	
<i>Insert corresponding code here. Please use one row per code.</i>	<i>Insert representative corresponding quotes in quotation marks here. Each quote must be followed by the participant's local ID (e.g. UK12, SP12, GR12, SW12). Please limit representative quotes to 2-3 per code.</i>

1.4. Summaries of end-user desired functionality of the developing platform

1.4.1. Patient perspectives

Please provide a detailed account of findings, combining data from the corresponding thematic categories.

Please present thematic categories, corresponding codes and representative quotes per thematic category, using Table 6 below.

Suggested word-count: 300-500 words (excluding Table 6).

Table 6. Patients' desired functionality of the system	
Thematic Category 20 - Views of the LifeChamps system	
<i>Insert corresponding code here. Please use one row per code.</i>	<i>Insert representative corresponding quotes in quotation marks here. Each quote must be followed by the participant's local ID (e.g. UK12, SP12, GR12, SW12). Please limit representative quotes to 2-3 per code.</i>
Thematic Category 21 – Frequency of predictions	
<i>Insert corresponding code here. Please use one row per code.</i>	<i>Insert representative corresponding quotes in quotation marks here. Each quote must be followed by the participant's local ID (e.g. UK12, SP12, GR12, SW12). Please limit representative quotes to 2-3 per code.</i>
Thematic Category 22 - Health professional actions	
<i>Insert corresponding code here. Please use one row per code.</i>	<i>Insert representative corresponding quotes in quotation marks here. Each quote must be followed by the participant's local ID (e.g. UK12, SP12, GR12, SW12). Please limit representative quotes to 2-3 per code.</i>
Thematic Category 23 – Comfort using technology	
<i>Insert corresponding code here. Please use one row per code.</i>	<i>Insert representative corresponding quotes in quotation marks here. Each quote must be followed by the participant's local ID (e.g. UK12, SP12, GR12, SW12). Please limit representative quotes to 2-3 per code.</i>

1.4.2. Family members perspectives

Please provide a detailed account of findings, combining data from the corresponding thematic categories.

Please present thematic categories, corresponding codes and representative quotes per thematic category, using Table 7 below.

Suggested word-count: 300-500 words (excluding Table 7).

If no family members were recruited, please delete this section.

Table 7. Family members' desired functionality of the system	
Thematic Category 20 - Views of the LifeChamps system	
<i>Insert corresponding code here. Please use one row per code.</i>	<i>Insert representative corresponding quotes in quotation marks here. Each quote must be followed by the participant's local ID (e.g. UK12, SP12, GR12, SW12). Please limit representative quotes to 2-3 per code.</i>
Thematic Category 21 – Frequency of predictions	
<i>Insert corresponding code here. Please use one row per code.</i>	<i>Insert representative corresponding quotes in quotation marks here. Each quote must be followed by the participant's local ID (e.g. UK12, SP12, GR12, SW12). Please limit representative quotes to 2-3 per code.</i>
Thematic Category 22 - Health professional actions	
<i>Insert corresponding code here. Please use one row per code.</i>	<i>Insert representative corresponding quotes in quotation marks here. Each quote must be followed by the participant's local ID (e.g. UK12, SP12, GR12, SW12). Please limit representative quotes to 2-3 per code.</i>
Thematic Category 23 – Comfort using technology	
<i>Insert corresponding code here. Please use one row per code.</i>	<i>Insert representative corresponding quotes in quotation marks here. Each quote must be followed by the participant's local ID (e.g. UK12, SP12, GR12, SW12). Please limit representative quotes to 2-3 per code.</i>

2. End-user groups 3 & 4 (health professionals and managers)

2.1. Summary of local recruitment procedures

Please provide an account of recruitment procedures at your site, including duration of recruitment.

Suggested word-count: 300-400 words.

2.2. Summary of accrual and participant characteristics

Please provide an account of accrual rates, response rates, reasons for refusal, total number of participants, numbers of participants taking the survey v. being interviewed.

Please provide an account of participant background characteristics. Please make use of Tables 8 and 9 below.

Suggested word-count: 300-400 words (excluding Tables).

If no health managers were recruited, please delete accordingly.

Table 8. Health professional characteristics		
Variables	Responses	n (%)
Gender	Female Male	
Health professional role	<i>Add a list here as appropriate based on local data.</i>	
Time working in cancer (years)	1-5 6-10 11-15 16-20 21+ less than one	
Time working in current role (years)	1-5 6-10 11-15 16-20 21+ less than one	
Area of specialty	<i>Add a list here as appropriate based on local data.</i>	

Table 9. Health manager characteristics		
Variables	Responses	n (%)
Gender	Female Male	

Table 9. Health manager characteristics		
Variables	Responses	n (%)
Health professional role	<i>Add a list here as appropriate based on local data.</i>	
Time working in cancer (years)	1-5 6-10 11-15 16-20 21+ less than one	
Time working in current role (years)	1-5 6-10 11-15 16-20 21+ less than one	
Area of specialty	<i>Add a list here as appropriate based on local data.</i>	

2.3. Summaries of end-user perspectives of post-treatment care

2.3.1. Health professional perspectives

Please provide a detailed account of findings, combining data from the corresponding thematic categories.

Please present thematic categories, corresponding codes and representative quotes per thematic category, using Table 10 below.

Suggested word-count: 500-1000 words (excluding Table 10).

Table 10. Health professionals' perspectives on patients' post-treatment care	
Thematic category 1 - Involvement in patient care	
<i>Insert corresponding code here. Please use one row per code.</i>	<i>Insert representative corresponding quotes in quotation marks here. Each quote must be followed by the participant's local ID (e.g. UK12, SP12, GR12, SW12). Please limit representative quotes to 2-3 per code.</i>
Thematic category 2 - Perspectives on patient's post-treatment health needs	

Table 10. Health professionals' perspectives on patients' post-treatment care	
<p><i>Insert corresponding code here.</i></p> <p><i>Please use one row per code.</i></p>	<p><i>Insert representative corresponding quotes in quotation marks here.</i></p> <p><i>Each quote must be followed by the participant's local ID (e.g. UK12, SP12, GR12, SW12).</i></p> <p><i>Please limit representative quotes to 2-3 per code.</i></p>
Thematic category 6 - Views on patients' experiences due to COVID	
<p><i>Insert corresponding code here.</i></p> <p><i>Please use one row per code.</i></p>	<p><i>Insert representative corresponding quotes in quotation marks here.</i></p> <p><i>Each quote must be followed by the participant's local ID (e.g. UK12, SP12, GR12, SW12).</i></p> <p><i>Please limit representative quotes to 2-3 per code.</i></p>
Thematic category 4 - Views on support or information required by patients and families	
<p><i>Insert corresponding code here.</i></p> <p><i>Please use one row per code.</i></p>	<p><i>Insert representative corresponding quotes in quotation marks here.</i></p> <p><i>Each quote must be followed by the participant's local ID (e.g. UK12, SP12, GR12, SW12).</i></p> <p><i>Please limit representative quotes to 2-3 per code.</i></p>
Thematic category 3 - Professional priorities	
<p><i>Insert corresponding code here.</i></p> <p><i>Please use one row per code.</i></p>	<p><i>Insert representative corresponding quotes in quotation marks here.</i></p> <p><i>Each quote must be followed by the participant's local ID (e.g. UK12, SP12, GR12, SW12).</i></p> <p><i>Please limit representative quotes to 2-3 per code.</i></p>
Thematic category 5 - Views on health services at post-treatment	
<p><i>Insert corresponding code here.</i></p> <p><i>Please use one row per code.</i></p>	<p><i>Insert representative corresponding quotes in quotation marks here.</i></p> <p><i>Each quote must be followed by the participant's local ID (e.g. UK12, SP12, GR12, SW12).</i></p> <p><i>Please limit representative quotes to 2-3 per code.</i></p>
Thematic category 7 - Views on important PROMs or PREMs	

Table 10. Health professionals' perspectives on patients' post-treatment care	
<p><i>Insert corresponding code here.</i></p> <p><i>Please use one row per code.</i></p>	<p><i>Insert representative corresponding quotes in quotation marks here.</i></p> <p><i>Each quote must be followed by the participant's local ID (e.g. UK12, SP12, GR12, SW12).</i></p> <p><i>Please limit representative quotes to 2-3 per code.</i></p>

2.3.2. Health manager perspectives

Please provide a detailed account of findings, combining data from the corresponding thematic categories.

Please present thematic categories, corresponding codes and representative quotes per thematic category, using Table 11 below.

Suggested word-count: 500-1000 words (excluding Table 11).

If no health managers were recruited, please delete this section.

Table 11. Health managers' perspectives on patients' post-treatment care	
Thematic category 1 - Involvement in patient care	
<p><i>Insert corresponding code here.</i></p> <p><i>Please use one row per code.</i></p>	<p><i>Insert representative corresponding quotes in quotation marks here.</i></p> <p><i>Each quote must be followed by the participant's local ID (e.g. UK12, SP12, GR12, SW12).</i></p> <p><i>Please limit representative quotes to 2-3 per code.</i></p>
Thematic category 2 - Perspectives on patient's post-treatment health needs	
<p><i>Insert corresponding code here.</i></p> <p><i>Please use one row per code.</i></p>	<p><i>Insert representative corresponding quotes in quotation marks here.</i></p> <p><i>Each quote must be followed by the participant's local ID (e.g. UK12, SP12, GR12, SW12).</i></p> <p><i>Please limit representative quotes to 2-3 per code.</i></p>
Thematic category 6 - Views on patients' experiences due to COVID	

Table 11. Health managers' perspectives on patients' post-treatment care	
<p><i>Insert corresponding code here.</i></p> <p><i>Please use one row per code.</i></p>	<p><i>Insert representative corresponding quotes in quotation marks here.</i></p> <p><i>Each quote must be followed by the participant's local ID (e.g. UK12, SP12, GR12, SW12).</i></p> <p><i>Please limit representative quotes to 2-3 per code.</i></p>
Thematic category 4 - Views on support or information required by patients and families	
<p><i>Insert corresponding code here.</i></p> <p><i>Please use one row per code.</i></p>	<p><i>Insert representative corresponding quotes in quotation marks here.</i></p> <p><i>Each quote must be followed by the participant's local ID (e.g. UK12, SP12, GR12, SW12).</i></p> <p><i>Please limit representative quotes to 2-3 per code.</i></p>
Thematic category 3 - Professional priorities	
<p><i>Insert corresponding code here.</i></p> <p><i>Please use one row per code.</i></p>	<p><i>Insert representative corresponding quotes in quotation marks here.</i></p> <p><i>Each quote must be followed by the participant's local ID (e.g. UK12, SP12, GR12, SW12).</i></p> <p><i>Please limit representative quotes to 2-3 per code.</i></p>
Thematic category 5 - Views on health services at post-treatment	
<p><i>Insert corresponding code here.</i></p> <p><i>Please use one row per code.</i></p>	<p><i>Insert representative corresponding quotes in quotation marks here.</i></p> <p><i>Each quote must be followed by the participant's local ID (e.g. UK12, SP12, GR12, SW12).</i></p> <p><i>Please limit representative quotes to 2-3 per code.</i></p>
Thematic category 7 - Views on important PROMs or PREMs	
<p><i>Insert corresponding code here.</i></p> <p><i>Please use one row per code.</i></p>	<p><i>Insert representative corresponding quotes in quotation marks here.</i></p> <p><i>Each quote must be followed by the participant's local ID (e.g. UK12, SP12, GR12, SW12).</i></p> <p><i>Please limit representative quotes to 2-3 per code.</i></p>

2.4. Summaries of end-user desired functionality of the developing platform

2.4.1. Health professional perspectives

Please provide a detailed account of findings, combining data from the corresponding thematic categories.

Please present thematic categories, corresponding codes and representative quotes per thematic category, using Table 12 below.

Suggested word-count: 300-500 words (excluding Table 12).

Table 12. Health professionals' desired functionality of the system	
Thematic Category 8 - Perceptions on system benefits and drawbacks	
<i>Insert corresponding code here. Please use one row per code.</i>	<i>Insert representative corresponding quotes in quotation marks here. Each quote must be followed by the participant's local ID (e.g. UK12, SP12, GR12, SW12). Please limit representative quotes to 2-3 per code.</i>
Thematic Category 9 – Required information and monitoring	
<i>Insert corresponding code here. Please use one row per code.</i>	<i>Insert representative corresponding quotes in quotation marks here. Each quote must be followed by the participant's local ID (e.g. UK12, SP12, GR12, SW12). Please limit representative quotes to 2-3 per code.</i>
Thematic Category 10 - Frequency of information	
<i>Insert corresponding code here. Please use one row per code.</i>	<i>Insert representative corresponding quotes in quotation marks here. Each quote must be followed by the participant's local ID (e.g. UK12, SP12, GR12, SW12). Please limit representative quotes to 2-3 per code.</i>
Thematic Category 11 – Presentation of information	
<i>Insert corresponding code here. Please use one row per code.</i>	<i>Insert representative corresponding quotes in quotation marks here. Each quote must be followed by the participant's local ID (e.g. UK12, SP12, GR12, SW12). Please limit representative quotes to 2-3 per code.</i>

Table 12. Health professionals' desired functionality of the system	
Thematic category 12 - Requirements for system implementation	
<i>Insert corresponding code here. Please use one row per code.</i>	<i>Insert representative corresponding quotes in quotation marks here. Each quote must be followed by the participant's local ID (e.g. UK12, SP12, GR12, SW12). Please limit representative quotes to 2-3 per code.</i>

2.4.2. Health manager perspectives

Please provide a detailed account of findings, combining data from the corresponding thematic categories.

Please present thematic categories, corresponding codes and representative quotes per thematic category, using Table 13 below.

Suggested word-count: 300-500 words (excluding Table 13).

If no health managers were recruited, please delete this section.

Table 12. Health managers' desired functionality of the system	
Thematic Category 8 - Perceptions on system benefits and drawbacks	
<i>Insert corresponding code here. Please use one row per code.</i>	<i>Insert representative corresponding quotes in quotation marks here. Each quote must be followed by the participant's local ID (e.g. UK12, SP12, GR12, SW12). Please limit representative quotes to 2-3 per code.</i>
Thematic Category 9 – Required information and monitoring	
<i>Insert corresponding code here. Please use one row per code</i>	<i>Insert representative corresponding quotes in quotation marks here. Each quote must be followed by the participant's local ID (e.g. UK12, SP12, GR12, SW12). Please limit representative quotes to 2-3 per code.</i>
Thematic Category 10 - Frequency of information	

Table 12. Health managers' desired functionality of the system	
<i>Insert corresponding code here. Please use one row per code.</i>	<i>Insert representative corresponding quotes in quotation marks here. Each quote must be followed by the participant's local ID (e.g. UK12, SP12, GR12, SW12). Please limit representative quotes to 2-3 per code.</i>
Thematic Category 11 – Presentation of information	
<i>Insert corresponding code here. Please use one row per code.</i>	<i>Insert representative corresponding quotes in quotation marks here. Each quote must be followed by the participant's local ID (e.g. UK12, SP12, GR12, SW12). Please limit representative quotes to 2-3 per code.</i>
Thematic category 12 - Requirements for system implementation	
<i>Insert corresponding code here. Please use one row per code.</i>	<i>Insert representative corresponding quotes in quotation marks here. Each quote must be followed by the participant's local ID (e.g. UK12, SP12, GR12, SW12). Please limit representative quotes to 2-3 per code.</i>

3. Conclusions

3.1. Overview of end-user perspectives of post-treatment care

Please summarise perspectives from all end-user groups to create a brief conclusions section, by providing a list (bullet points) of the most common / most important perspectives emerging from your data.

Suggested word-count: 300 words.

3.2. Overview of end-user desired functionality of the developing platform

Please summarise suggestions from all end-user groups to create a brief conclusions section, by providing a list (bullet points) of the most common / most important suggestions emerging from your data.

Suggested word-count: 300 words.

8.5 EU SURVEY SCREENSHOTS

Eligibility and Consent

LifeChamp... | Dashboard | Surveys | Exports | Address Book | Settings | New Survey

Overview | Editor | **Test** | Results | Participants | Privileges | Translations | Properties | Activity

2 Eligibility and Consent

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Please read the information in the Participant Information Sheet and Privacy Notice (above).

Following this, read the statements below, and if you agree, tick all boxes. Please note: All boxes must be ticked in order to move on to the survey.

I confirm that I have read and understood the Participant Information Sheet Version 2, Dated 08/05/2020.

I confirm that I am aged 50 years or above and a patient with cancer living in the UK
OR
I am an adult (aged 18 years or above) family member or informal carer of a patient with cancer who is 50 years old or older living in the UK.

I confirm that I have read and understood the Privacy Notice Version 2, Dated 04/05/2020.

I have had the opportunity to think about the information and ask questions, and understand the answers I have been given.

I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason and without being affected in any way.

I agree to the way my data will be collected and processed, and that research data will be stored for a minimum of 10 years in University archiving facilities in accordance with relevant Data Protection policies and regulations.

I understand that all personal and research data and identifiable information I provide will be kept confidential and will be seen only by researchers at the University of Glasgow.

I understand that only fully anonymised summaries of my research data will be shared within the research group and transferred outside the UK.

Please tell us about yourself

LifeChamp... | Dashboard | Surveys | Exports | Address Book | Settings | New Survey

Overview | Editor | **Test** | Results | Participants | Privileges | Translations | Properties | Activity

3 Please tell us about yourself

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3.1 What country do you live in?
 Greece
 Spain
 Sweden
 United Kingdom
 Other (please detail in box below)

3.3 Your gender?
 Male
 Female
 Other
 Prefer not to say

3.4 Your role?
 I am a cancer patient
 I am a family member, friend or carer to a cancer patient

3.5 Your age? (years)
Only values between 50 and 130 are allowed

3.8 What type of cancer have you been diagnosed with?
 Breast
 Prostate
 Skin (incl. melanoma)

3.13 How many months has it been since you finished your initial treatment for cancer?
(This is usually chemotherapy / surgery / radiotherapy, please put your answer below)

3.16 Have you been diagnosed with any other health condition by a doctor or health care professional?
(For example, Diabetes, heart disease, COPD, high blood pressure, asthma, osteoporosis)
 Yes

Please tell us about your views and experiences

EU5urvey

LifeChamp... Dashboard Surveys Exports Address Book Settings New Survey

Hello Rebecca MARSHALL MCKENNA (Logout) Help Language

Overview Editor **Test** Results Participants Privileges Translations Properties Activity

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4 Please can you tell us about your views and experiences.

4.1 What are your priorities in life now that you move beyond cancer and cancer treatment?
(Think about what life is like since you finished your treatment, have you been able to return to your previous activities or whether life now is a 'new normal?')

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?**
(Think about any side effects of treatment, work, mobility issues, support, medication)

4.6 **Only answer if you are aged 65 years or more, what are your concerns or needs since finishing cancer treatment?**
(Think about things such as side effects of treatment, work, mobility issues, support, medication)

4.8 In general, due to the **coronavirus** and after having treatment for cancer, what are your experiences, needs or concerns?

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?
(Think about the type of support or advice that you needed)

4.13 What kind of support do you feel your family or partner might need right now?

4.15 In an ideal world, what type of **health services** would have been useful to you at the end of cancer treatment?

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