



## THE CONSTRUCTION OF A QUALITY OF LIFE WELLBEING INDEX FOR CANCER PATIENTS IN FOLLOW-UP: THE ONCORELIEF PROJECT

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# The project

ONCORELIEF aims to **improve post-treatment health status, wellbeing, and follow-up care of cancer patients** in a patient-centric way: independent of the specific treatment and pathway points, but specific to each patient's experience and needs, incorporating the patient's illness experience and the psychosocial context.

# The project

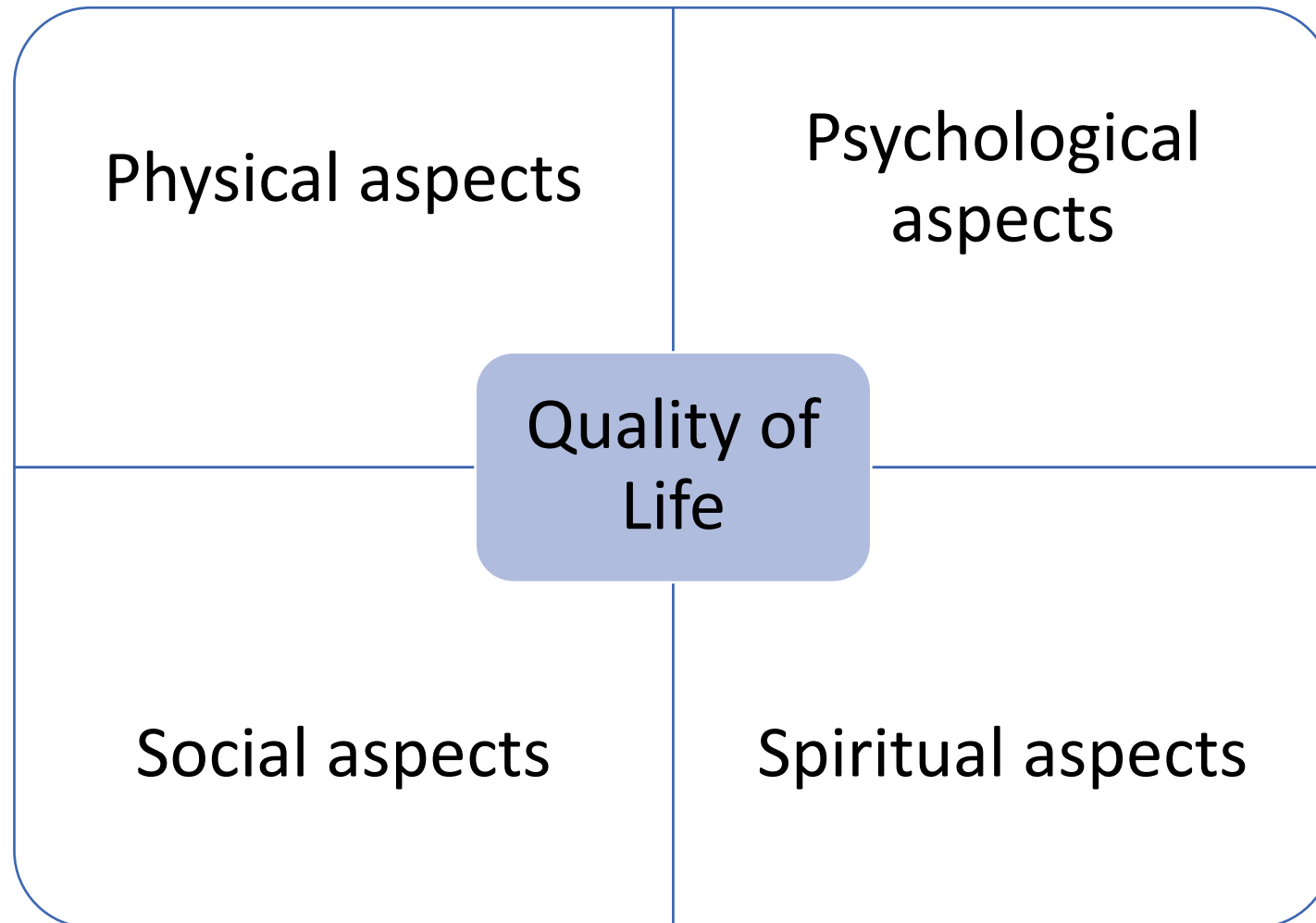
**ONCORELIEF** is based on:

1. A **downloadable application (Guardian Angel)** available for portable devices, connected both with the ONCORELIEF platform and the patients' sensing devices;
2. A **Back-end data platform** where data are securely collected, anonymized and stored;
3. An **AI Engine** built on top of the Back-end platform, which analyses data, extracts important features, produces meaningful AI models and updates them accordingly;
4. An **HCP Web app**, allowing the HCPs to monitor patient data as well as evaluate and decide on the proposed suggestions.

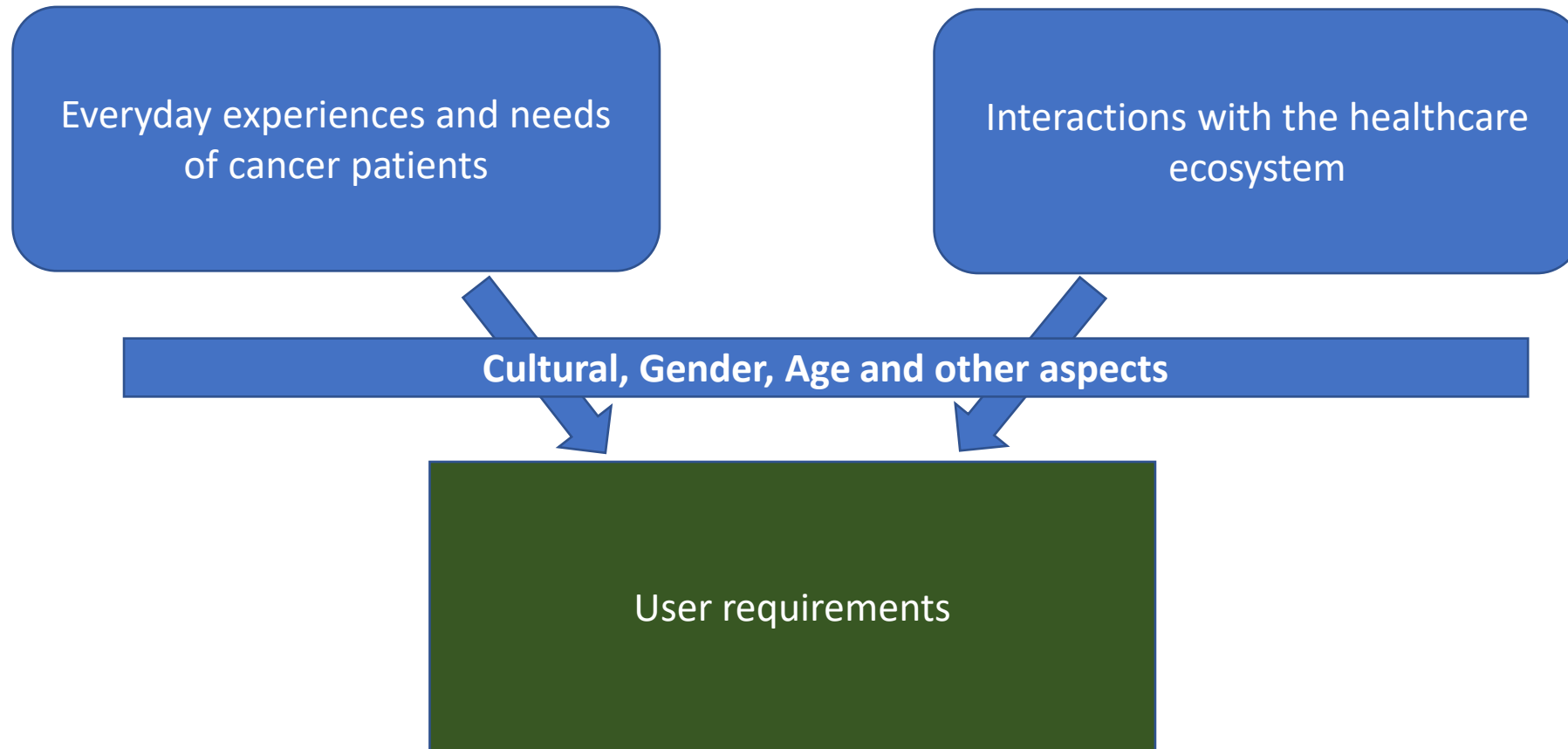
# Quality of Life Index

- ONCORELIEF visualizes current health and wellbeing of the patient with a personal **ONCORELIEF QoL Index**.
- It is based on:
  - the specific person (body);
  - cancer type and peculiarities (disease);
  - health literacy;
  - physical symptoms such as pain, etc. (symptoms);
  - how they feel and overall mental health such as anxiety, depression, positive and emotional distress or negative affect, etc. (feelings);
  - and how they live and work, including social capital, life satisfaction and socio-economic factors, exercise, nutrition and sleep (lifestyle).
- The Pilots will focus on **Acute Myeloid Leukaemia (AML)** and **Colorectal Cancer (CRC)**

# Quality of Life (ONCORELIEF index)



# Definition of User Requirements



# Patient environment factors

## 1. Initial brainstorming across cancer types:

- Literature review on adverse events;
- Patient input on the CareAcross platform;
- Side-effects for the most common treatments;
- Online discussion forums for cancer patients (e.g. Macmillan Cancer Support (UK), Cancer Research UK, Inspire.com, etc.)

## 2. Initial Brainstorming for Acute Myeloid Leukemia & Colorectal Cancer:

- Guidelines on treatments and medications for these cancer types;
- Side-effects of treatments;
- Online discussion forums and resources specifically for AML & CRC patients.

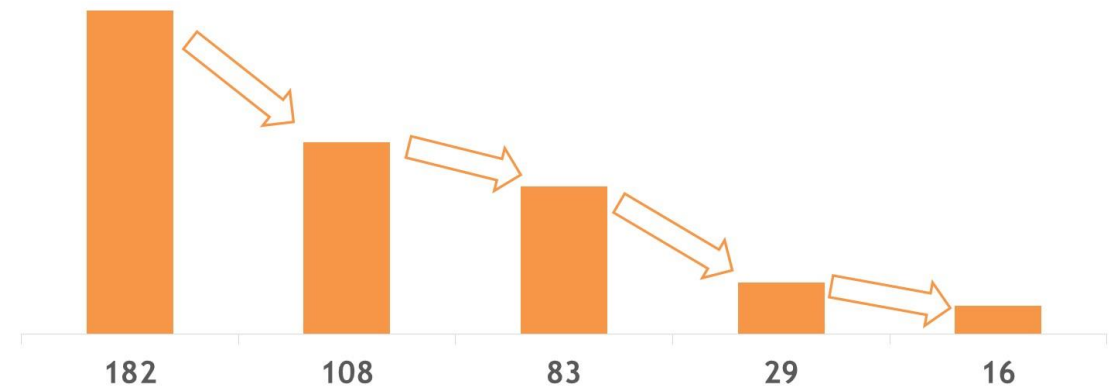
# Patient environment factors

3. Brainstorming outcome: 182 needs

4. Filtering of Brainstorming outcome based on:

- Repetition/similarities;
- Frequency;
- Easy to report or there is a wearable device that can report this need
- Measurable with intensity levels/grades;
- Etc.

5. Final identification of Patient Needs for ONCORELIEF





# Clinical and HCP environment factors

## 1. Literature review

## 2. Patient survey on 6 topics

- Relationship with Healthcare Professionals (12 items)
- Clinical Services (2 items)
- Data and Digital Services (4 items)
- “What would be important for you regarding a new digital product (a digital wearable)?” (7 items)
- Other Items/ Miscellaneous (8 items incl. psychosocial services)
- The Patient’s Digital Situation (6 items)

# Key determinants

**CRC Patients:** 6 Items with a mean value between “essential” and “very important”

Topic: My healthcare professionals...

- listen and explain well
- are well organized
- treat me with honesty and optimism
- instruct me how to help myself
- involve me in the decision-making process

Topic: Other items

- Information on who to contact if I am worried after I leave the clinic

**AML Patients:** 16 items with 3 items especially high on the importance scale

Topic: My healthcare professionals

- make me feel at ease
- give me time to fully describe my condition and say what I wanted to say
- instruct me on how to help myself

# Key determinants

The following two items were consistently rated as being **less important** by the patients:

- To know about /access to a self-help or support group.
- To know about/access to a social or psychological service.

The topic “My Own Digital Situation” gave the following results:

<b>My Own Digital Situation</b>	CR C	A ML
I often use (a) digital device/s.	63 %	75 %
Most of my friends/family use digital devices.	84 %	92 %
I can usually get help if I have technical problems.	92 %	92 %
I feel confident using most digital devices.	76 %	58 %
I keep up to date with new ideas, e.g. new health apps.	45 %	17 %
I already use a smart watch or an app supporting me in after-care	29 %	17 %

The survey also shows that a majority of patients use digital devices often, even if they are not very interested to get their own digital device (e.g. smart watch) to support them in after-care.

# Cultural, Gender, Age and other aspects

- Cultural Aspects
- Gender
- Age
- Socio-economic aspects
- Other aspects (health literacy, social support, etc.)
- Risk factors for introduction of biases through Big Data and Artificial Intelligence

# Identified needs

AML	
Category	Included Needs
Distress	<ul style="list-style-type: none"><li>• Depression</li><li>• Anxiety</li><li>• Other needs</li></ul>
Psycho-physiological	<ul style="list-style-type: none"><li>• Sleep</li><li>• Fatigue</li><li>• Lack of sexual interest</li><li>• Other needs</li></ul>
Physical symptoms	<ul style="list-style-type: none"><li>• Sore mouth</li><li>• Hair loss</li><li>• Weight loss</li><li>• Other needs</li></ul>

CRC	
Category	Included Needs
Distress	<ul style="list-style-type: none"><li>• Depression</li><li>• Anxiety</li><li>• Other needs</li></ul>
Psycho-physiological	<ul style="list-style-type: none"><li>• Fatigue</li><li>• Other needs</li></ul>
Physical symptoms	<ul style="list-style-type: none"><li>• Colitis</li><li>• Appetite Loss</li><li>• Peripheral neuropathy</li><li>• Weight</li><li>• Hand-Foot Syndrome</li><li>• Other needs</li></ul>

# Data Sources for Quality of Life Index



Measurements from wearable sensors (heart rate, respiration, temperature, oxygen saturation)



Data from questionnaires answered by the patients



Data from the medical record of the patient

# Selection of Patient Need Questionnaires

Cancer Type	Patient Need	Questionnaire
AML	Anxiety	HADS (Hospital Anxiety and Depression Scale)
AML	Depression	PHQ-9 (Patient Health Questionnaire-9)
AML	Fatigue	BFI (Brief Fatigue Inventory)
AML	Hair loss	<i>No validated questionnaire available</i>
AML	Lack of sexual interest	EORTC-SHQ-C22
AML	Sleep Problems	ISI (Insomnia severity index)
AML	Sore Mouth	EORTC-SHQ-OH15
AML	Weight loss	Part of EORTC-QLQ-C30
CRC	Anxiety	HADS
CRC	Depression	PHQ-9
CRC	Fatigue	BFI
CRC	Appetite Loss	Part of EORTC-QLQ-C30
CRC	Colitis	EORTC-QLQ-CR29
CRC	Hand-foot syndrome	Part of EORTC-QLQ-CIPN20*
CRC	Peripheral Neuropathy	EORTC-QLQ-CIPN20*
CRC	Weight changes	Part of EORTC-QLQ-C30

\*testing phase III – in development

In addition: Well-Being with Questionnaire WHO-5

# Quality of Life (ONCORELIEF index)

## Output

- Quality of Life index (0 – 1000)
  - 901 – 1000: Very Good
  - 801 – 900: Good
  - 601 – 800: Faulty
  - 401 – 600: Poor
  - < 400: Very poor
- The ONCORELIEF QoL Index moves up or down in real-time, depending on how body, symptoms, feelings and lifestyle change.
- When tracked over time, it will offer a good indicator of how the person's health and wellbeing is evolving.





# Thank you!