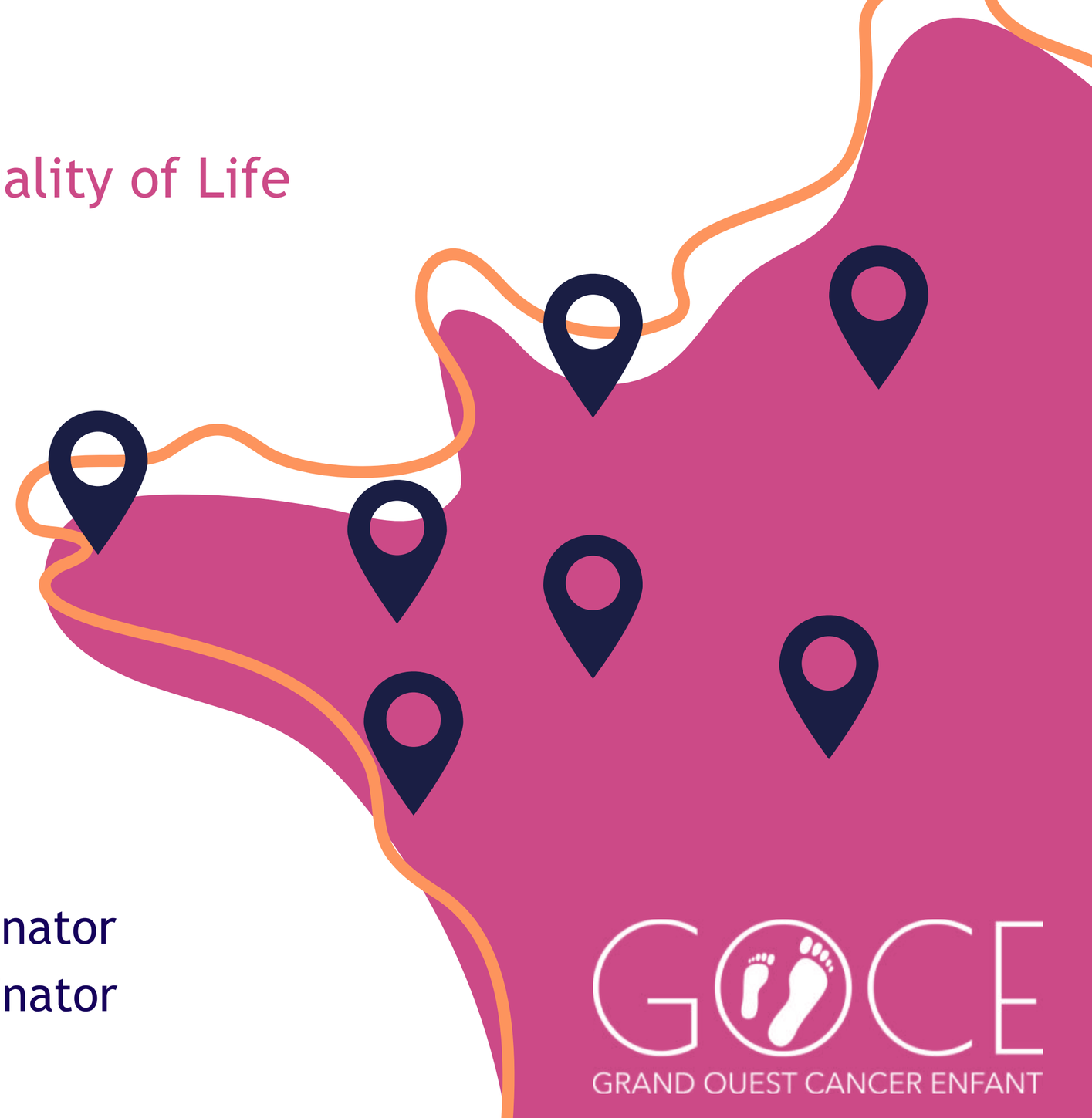
16th Monthly Meeting

Pediatric Cancer Survivorship & Quality of Life

07/10/2025



e·QuoL

Equality · Quality of life · Survivorship

Marion BEAUCHESNE - GCS HUGO Coordinator

Dr Charlotte DEMOOR - Scientific Coordinator

Benoit GERFAULT - Project Manager

GOCE

GRAND OUEST CANCER ENFANT

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101136549

2nd Amendment Update

Elements to include

- Resilience replacement
- QoL Cluster change
- AUH / AU Affiliated Entity
- ALP Status change
- T4.4 lead change
- Correct inconsistencies between WPs description and recapitulative tables at the end of the GA
- Add in-kind for ICO, CLB and CHUSE
- Adjust ICO's budget
- Add a publication line in CHUA's budget

Resilience Update

Handover continuation

- Licence Ownership Agreement for the contents: in revision
- Resilience updated their claimed costs according to the CE's feedback (PR1: 227 628,74€ + PR2: 70 447,06€ = 298 075,80€)
- 6 TERA of contents will be provided to the Coordination Team in a hard drive within the next 2 weeks → a work group will need to be constituted to revise them
- CHUA will launch a public procurement to identify the service provider who will take over the contents' finalisation and production

Epiconcept plan for MyCare

Presentation

Cineca update

SurPass

QoL Cluster Update

Cluster Change

WP progress

The floor is yours!

WP2:

- HUPON
- UNILU

WP3: UNIOSL

WP7: ISGlobal

Conclusion

Questions & next date

Your questions

October 7th, 2025

e-QuoL Project

WP2: State-of-the-art and Specification

e-QuoL Monthly Meeting
7 October 2025, Online

M2.1 Completion of the State-of-the-Art Review (MS1)

(1-3 months)

D2.1 State-of-the-art

(1-6 months)

needs

• children	HUPON
• CAYA	CLB
• family	UNILU

Needs of children with cancer, defining the specifications for potential interventions to consider future collaborative projects for younger patients

("childhood cancer" OR "pediatric cancer" OR "paediatric cancer" OR "child* with cancer" OR "pediatric oncology" OR "paediatric oncology" OR "childhood leukemia" OR "childhood leukaemia" OR "pediatric leukemia" OR "paediatric leukemia" OR "childhood malignan*" OR "pediatric malignan*" OR "paediatric malignan*" OR "childhood tumo*" OR "pediatric tumo*" OR "paediatric tumo*") AND ((patient* OR "Patient-reported") AND (outcomes OR need OR needs OR requirement OR requirements OR want OR wants OR preference OR preferences OR "information needs" OR "health needs" OR "health concerns" OR prefer* OR motivation* OR expectation* OR attitude* OR experience* OR necessit* OR support* OR "Health Services Needs and Demand"[Mesh] OR "Needs Assessment"[Mesh] OR "Patient Preference"[Mesh] OR "Attitude to Health"[Mesh] OR "Consumer Behavior"[Mesh] OR "Motivation"[Mesh] OR "Delivery of Health Care"[Mesh]))

Flow chart selection

60,980 N^0 of records before the duplicate removal

47,400 N^0 of records after the duplicate removal

820 N^0 of eligible studies based on title and abstract

98 N^0 of eligible full-texts

Needs of children with cancer

- (1) Physical Needs

  managing symptoms like pain, nausea, and fatigue

- (2) Emotional / Mental / Psychological Needs

  addressing emotional suffer

- (3) Developmental Needs

  addressing age-dependent developmental

- (4) Rehabilitation Needs

  supporting in physical activity restoration, cognitive difficulties

- (5) Information Needs

  delivering age-appropriate information and effective communication

- (6) Medical Needs

  tailored follow-up, health promotion, and transition programs

Send out drafts @ November 2025

Submit manuscript @ December 2025

Top general pediatrics (very selective)

- JAMA Pediatrics – Q1 (SJR 2024 = 5.085)
- The Lancet Child & Adolescent Health – Q1 (SJR 2024 = 4.289)

Pediatric oncology specialist

- Pediatric Blood & Cancer – Q1 (SJR 2024 = 0.994)

Survivorship / PRO / QoL / Supportive care

- Quality of Life Research – Q1 (SJR 2024 = 1.436)

Flagship QoL/PRO journal (ISOQOL)

- Journal of Cancer Survivorship – Q1 (SJR 2024 = 1.402)
- Supportive Care in Cancer – Q1 (SJR 2024 = 1.109)
- Journal of Adolescent Health – Q1 (SJR 2024 = 1.857)

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FACULTY OF HEALTH SCIENCES AND MEDICINE

HEALTH SCIENCES

e-QuoL
WP 3.4
A WEB-BASED INFORMATION TOOL FOR SUPPORT NETWORK MEMBERS OF CAYACS

ANNE MAAS
CRISTINA MÜLLER
GISELA MICHEL
KATHARINA ROSER
NINA KÄGI
VALERIIA BALAEVA

AIM: A MULTILINGUAL WEB-BASED INFORMATION TOOL FOR SUPPORT NETWORK MEMBERS OF CAYACS

- Integrated within PanCare website
- Generic evidence-based information related to CAYA cancer
- Country-specific information and adjustments

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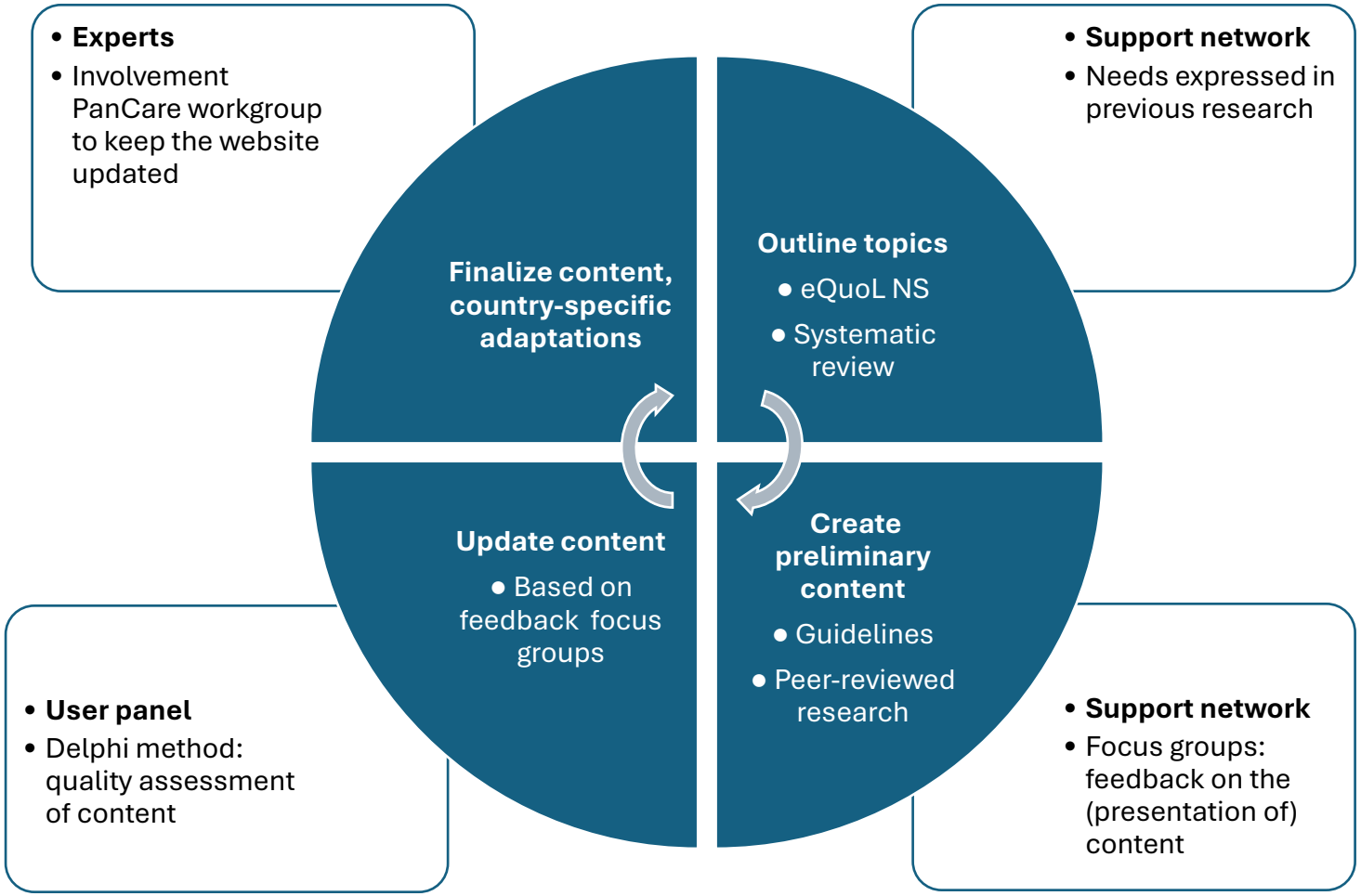
DEVELOPMENT OF THE WEB-BASED INFORMATION TOOL



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DOMAINS TO BE COVERED

Cancer-related health information

Cancer risk family members, supporting survivors with late effects, cancer recurrence vs. subsequent tumors

Psycho-emotional consequences

Emotional & mental health, coping, talking about cancer, parenting a survivor and their sibling(s)

Long-term follow-up care and surveillance

What is LTFU and why it matters, how to support the survivor with attending LTFU, and during the transition to adult health care

Insurance and financial consequences

General consequences of cancer on finances and insurances, the right to be forgotten, finding assistance

Education and employment

Potential challenges regarding education & employment for survivors and their network

Service and finding support

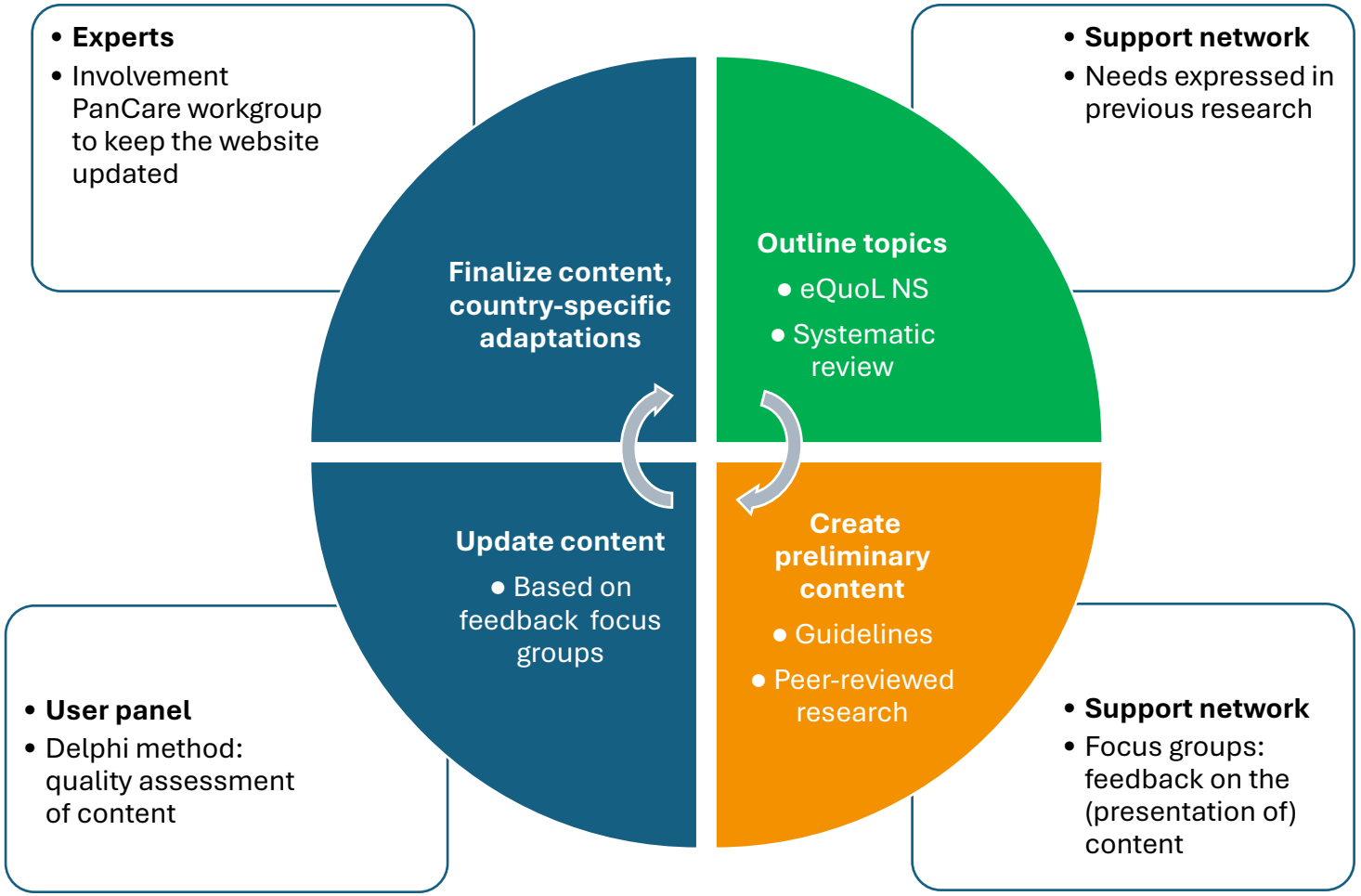
Peer & professional support: what peer support can and cannot offer, when to seek professional help

Sexuality

Impact of cancer treatment on sexual health and fertility, how to support the survivor, sexual counseling

Partners

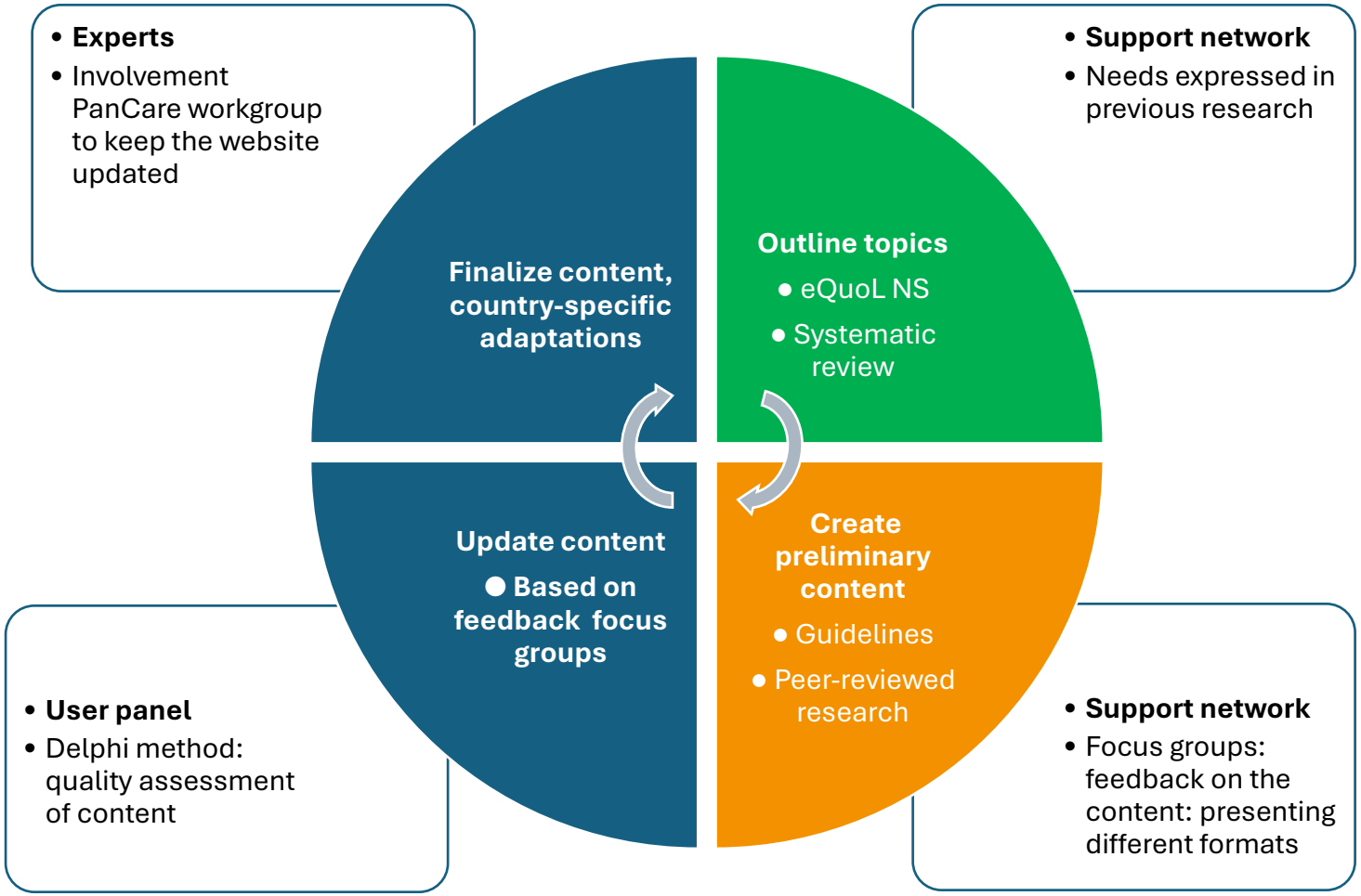
CREATING PRELIMINARY CONTENT



Prelimary generic content

- Easy-to-read, evidence-based content
- Systematic literature searches completed
- 13 drafts scheduled: 10 completed; 2 in progress
- Other formats for reviewing preferences: videos, factsheets

GATHERING FEEDBACK ON CONTENT: FOCUS GROUPS



- Ethical approval UNILU board
- Start recruitment: **02.09.2025**
- **Status:** four parents included
- **Recruitment support:** Help with including parents, partners, and siblings is welcome

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RECRUITMENT FOCUS GROUPS

- Target groups: parents, siblings, partners
- English language
- Recruitment started 02.09.2025 via European survivor and parent networks
- Shared flyer via email
- Please share with parents, support network members, or organizations
- Tips for relevant contact persons or recruitment are very much welcome

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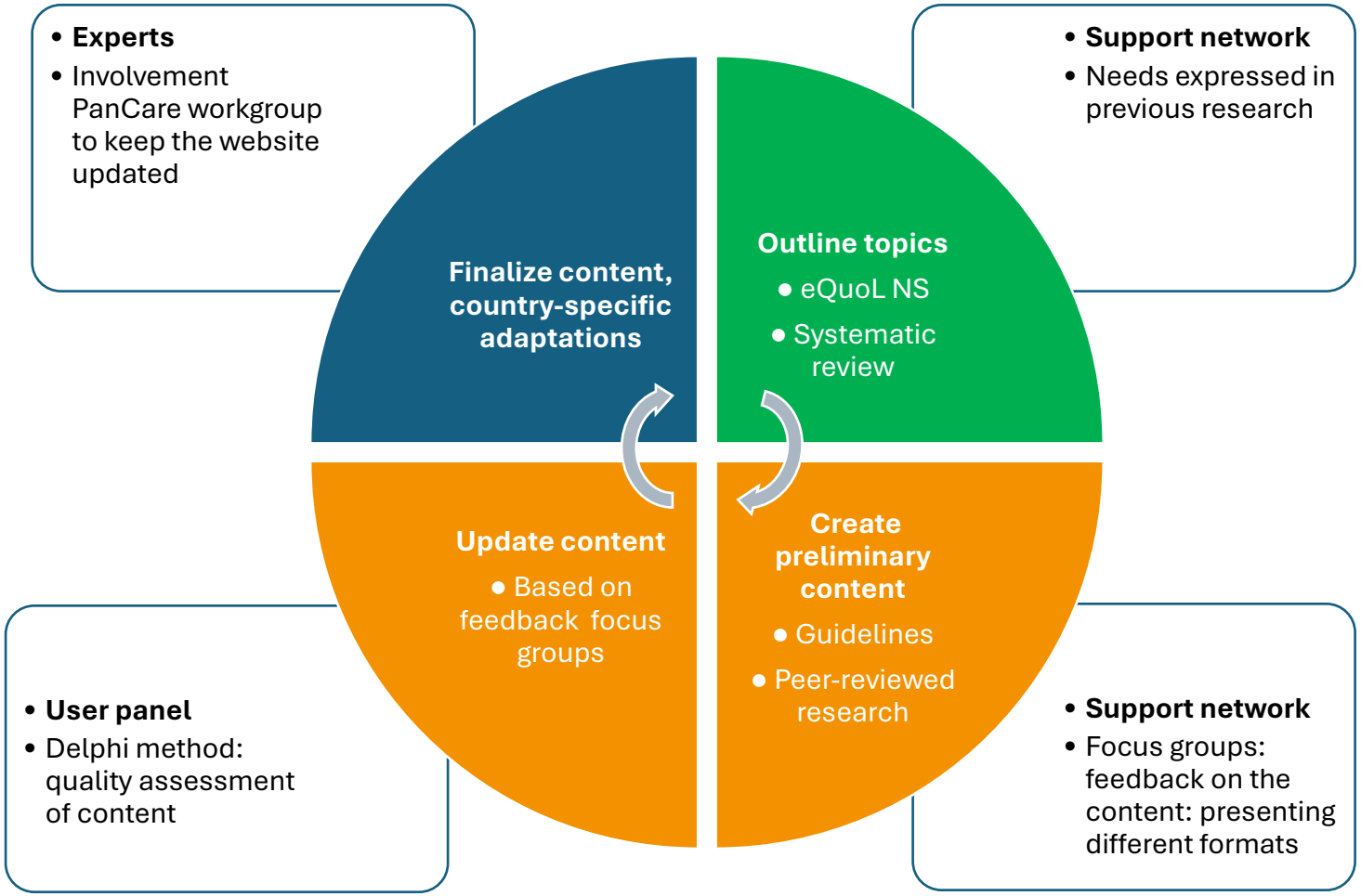
QUALITY ASSESSMENT CONTENT: DELPHI METHOD



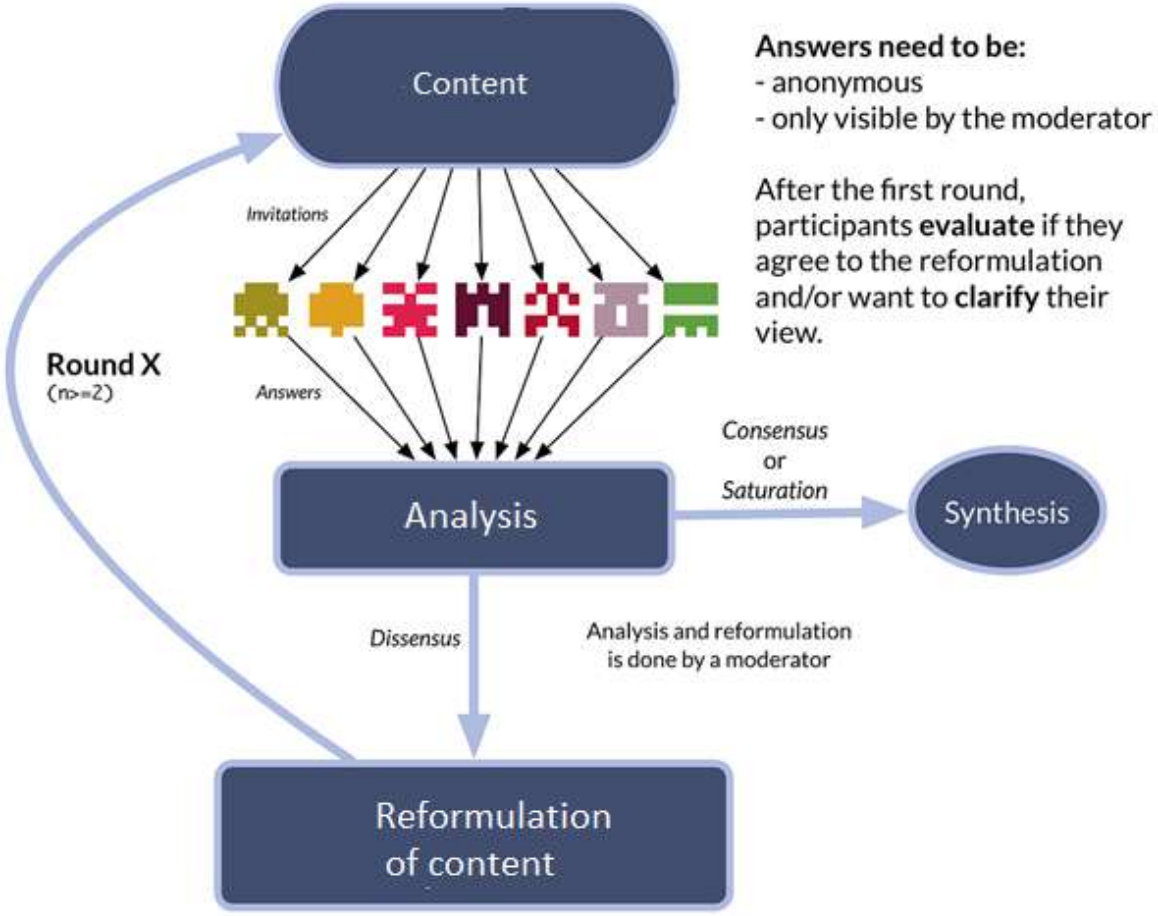
DELPHI METHOD

User panel

- Pediatric oncologists
- Psychologists or psychosocial specialists (PanCare psychosocial working group)
- Support network representatives (e.g., parent, partner, friend)

Process

- Reviewing and rating the content and its presentation
- Iterative process



ASSESSMENT TOOL – ADAPTING THE MAPPINFO CHECKLIST

KASPER ET AL., 2023

Domain, itemno.	Item	Assessment
Definitions		
1	The target group addressed by the health information is clearly defined.	0 / 1
2	The health information explains explicitly that an informed choice about a concrete problem should be facilitated.	0 / 0,5 / 1
Transparency		
3	The authors of the health information are named.	0 / 0,5 / 1
4	The funding source of the health information is disclosed.	0 / 1
5	A strategy for managing conflicts of interest is disclosed.	0 / 1
6	The health information indicates how up-to-date it is.	0 / 0,5 / 1
7	The sources of information are named.	0 / 0,5 / 1
8	The systematic search strategies underlying the generation of information are transparent.	0 / 1
Content		
9	The health problem is explained.	0 / 1
10	Options are named and explained.	0 / 0,5 / 1
11	The health information makes statements about stochastic uncertainty.	0 / 1
Content / Presentation		
12 /16	The natural course (in the case of diagnostic problems: the prevalence) of the disease is adequately presented.	0 / 1
13 / 17	The benefit is presented adequately.	0 / 1
14 / 18	The harm is presented adequately.	0 / 1
15 / 19	For diagnostic problems: Information on the quality of the test is presented appropriately.	0 / 1
Presentation		
20	The health information uses a neutral language throughout.	0 / 1
21	The health information does not use narratives that present relevant factual information.	0 / 1
22	Where applicable, graphics are designed in a suitable manner.	0 / 0,5 / 1
23	Information about benefits / harm are supplemented with complementary information (Gain Loss Framing).	0 / 0,5 / 1

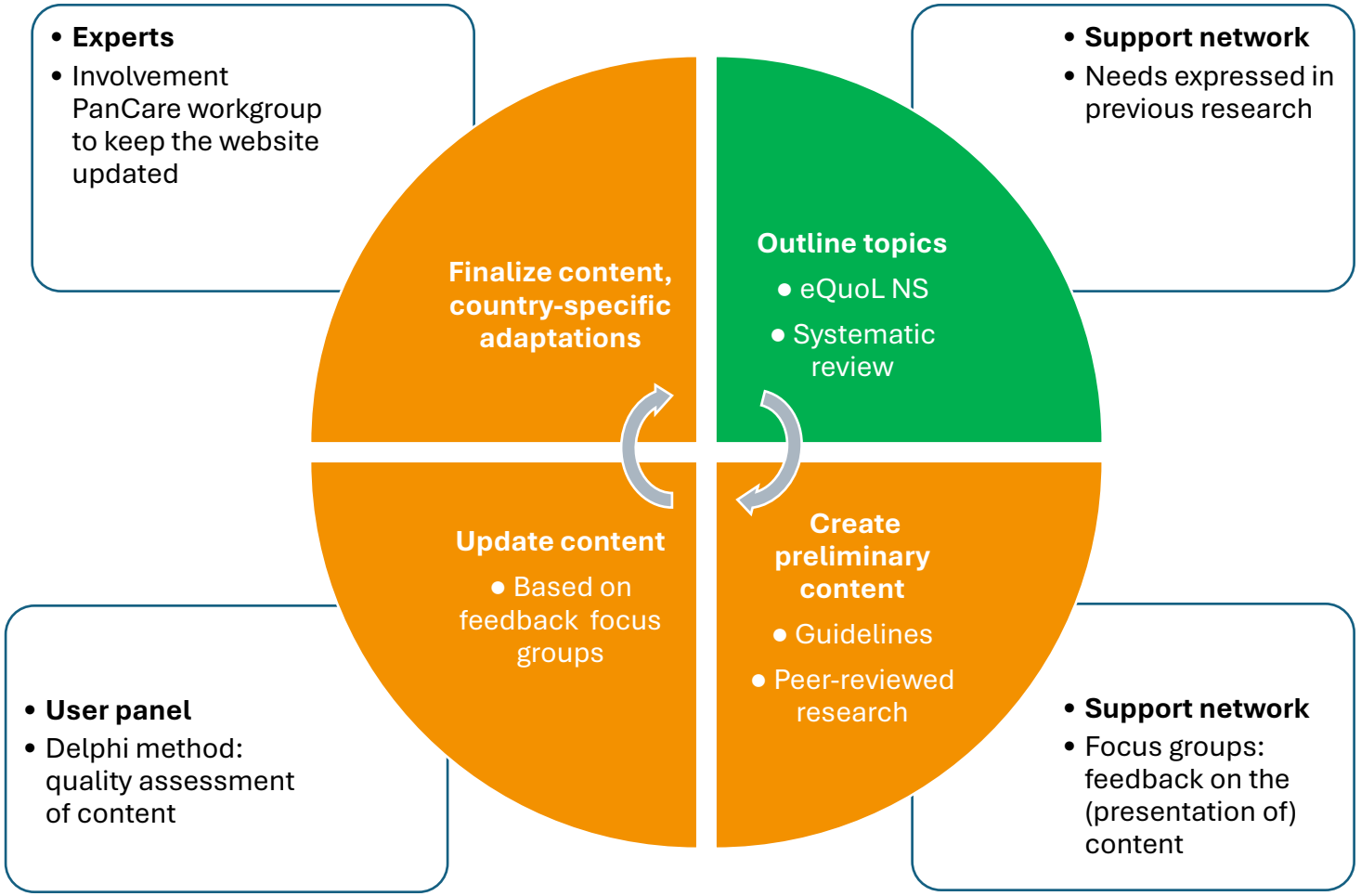
- **Focus difference**: MAPPinfo targets health information, our content is mainly psychosocial
- **Relevant items**: e.g., target group clearly defined
- **Not relevant items:** e.g., quality of the medical test
- **Reformulated items**: e.g., health problem clearly explained
- **Missing aspects**: e.g., completeness of information (text covers all important aspects)

DELPHI METHOD – ASSESSMENT TOOL

Assessed domain	Example item
Relevance for the target group	It is clear which target group the information is written for.
Completeness of information	The psychosocial or medical challenge is clearly explained.
Credibility	The text is credible and supported by evidence
Clarity and presentation	The text is understandable (plain, simple language).

- 17 items
- 4 response options: *Strongly disagree, disagree, agree, strongly agree*
- If participant does **not** choose *agree* or *strongly agree*, they are asked to give feedback on what to change

DEVELOPMENT OF THE WEB-BASED INFORMATION TOOL



Country-specific content

- Contact persons from each country have received a form via mail
- Request to complete the form by the end of September

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Theme		
Follow-up care	***Name website or organization***	***Link to website***
Late effects clinics / follow-up care for CAYACS		
National guidelines for long-term follow-up care		
Support organizations for patients, survivors, and their network		
Local networks for CAYACS and their support network (indicate for which group the network is)		
Meeting other CAYACS and support network members		
Professional cancer-related support		
Professional psychosocial support (individual support and group interventions)		
Professional support for health, including lifestyle, exercise, and fertility		
Daily life support		
Education assistance		
Employment assistance		
Practical support (informal care, accessibility, housing, transportation, legal aid)		
Financial & fiscal support after cancer		
Social security and financial assistance		
Insurance coverage (health, disability, life, travel)		
Other resources or cancer information websites		
Local websites about cancer or other resources		

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Country	Contact person
The Netherlands	Anne Maas
Finland	Päivi Lähteenmäki
Croatia	Jelena Roganovic
Bosnia and Herzegovina	Jelica Predojevic
Slovenia	Lorna Zaletel
Switzerland	Katharina Roser
England	Emma Potter
Germany	Eugenie Werbenko
Denmark (preliminary)	Louise Henriksen
Spain (preliminary)	Isabelle Thierrychef
Belgium (preliminary)	Maëlle de Ville de Goyet
Hungary	Miklós Garami
France	Charlotte Demoor
Norway	Hanne Lie
Italy	Monica Muraca
Romania	Katie Rizvi
Scotland	Alison Hall

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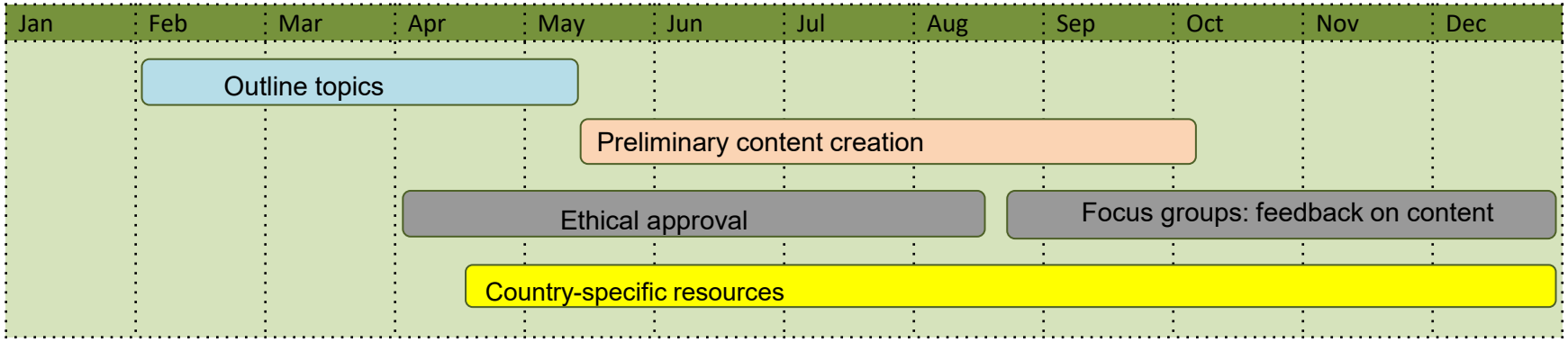
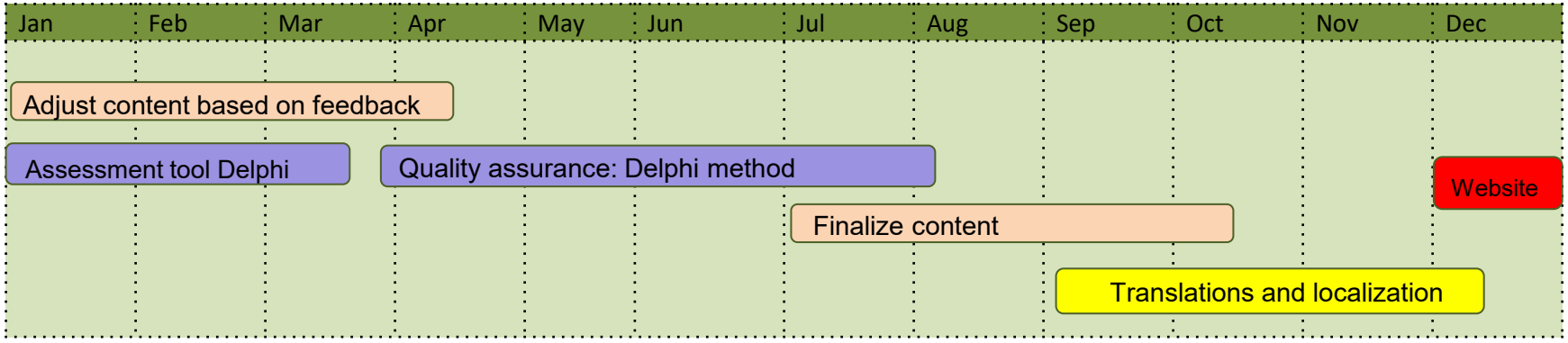
TIMELINE

2025



2026



UPDATE E-QUOL NS (WP 2.4)

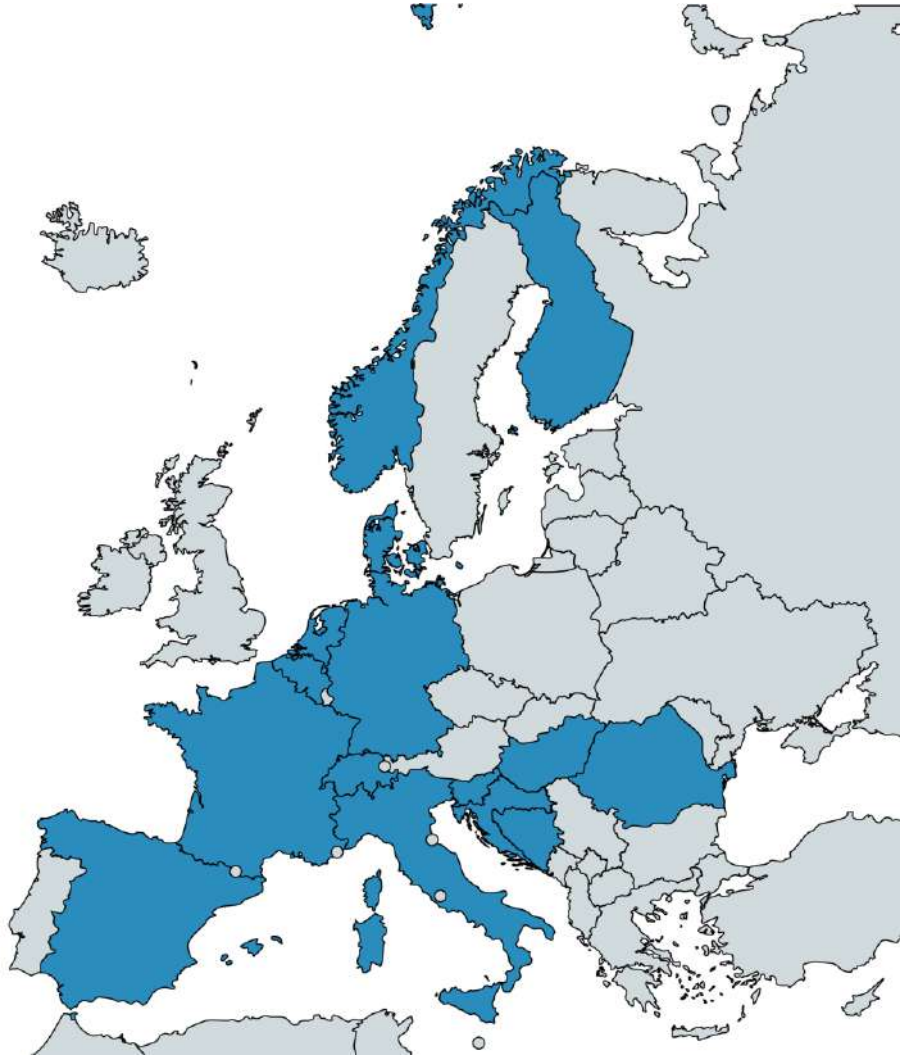
Using a quantitative survey, this project:

1) assesses the information and psychosocial support needs in CAYACS and their support network across Europe
2) analyzes the association with:
   a) cancer-related and socio-demographic characteristics
   b) knowledge, skills and confidence in managing their own wellbeing
   c) quality of life

SIOP 2025
INTERNATIONAL SOCIETY OF PAEDIATRIC ONCOLOGY
AMSTERDAM, THE NETHERLANDS | OCTOBER 20-23, 2025

Update:

- Two analysis protocols prepared (survivors and support network)
- Analysis completed, finalizing paper (survivors)
- Analysis in progress (support network)
- Results expected in the next meeting
- Signing up as co-author



THANK YOU!

Contact
equol-gmf@unilu.ch
Anne.Maas@unilu.ch

epiconcept

smart health

e-QuoL project - MyCare propositions

07/10/2025

Patient usage scenario

Patient usage scenario

1. Access to the app and autonomous account creation

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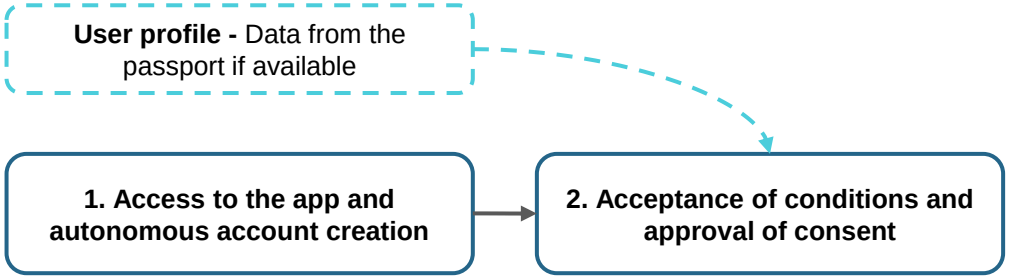
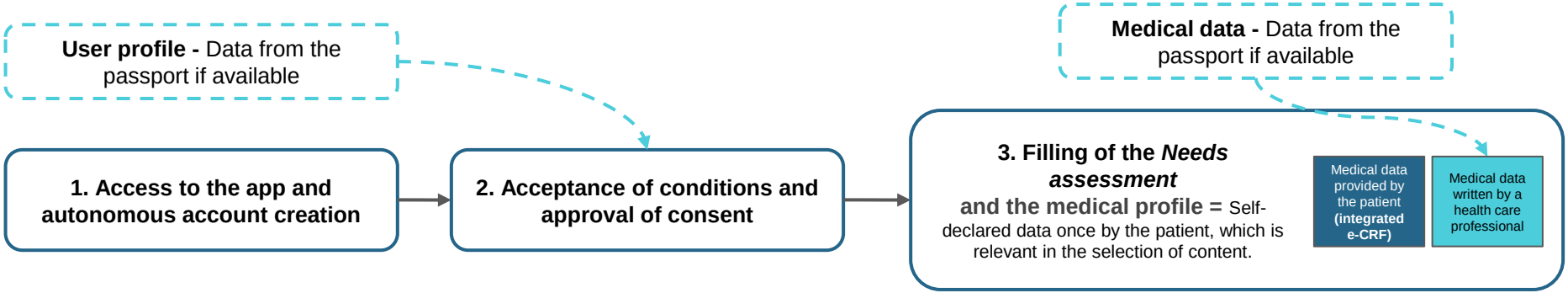
smart health

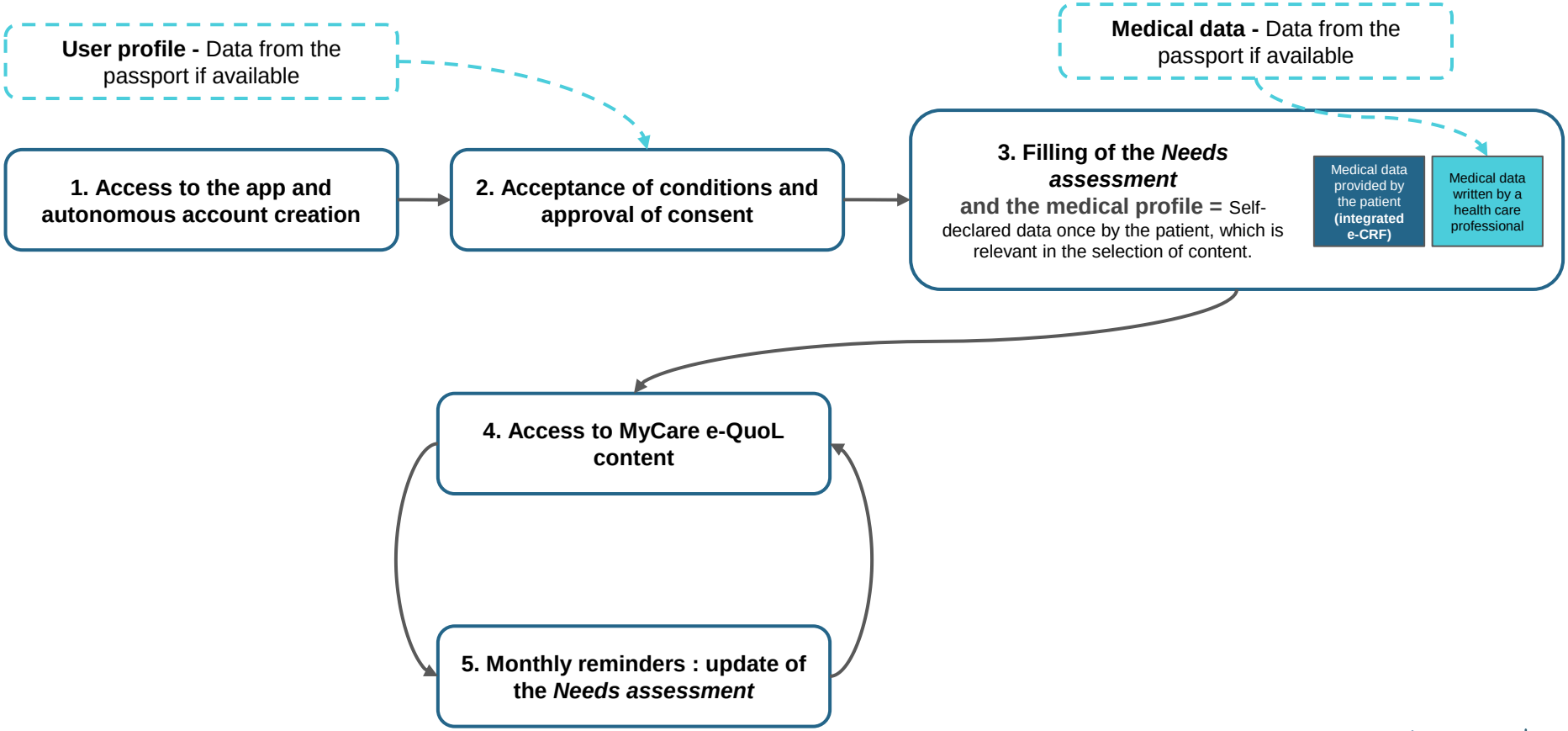
Patient usage scenario



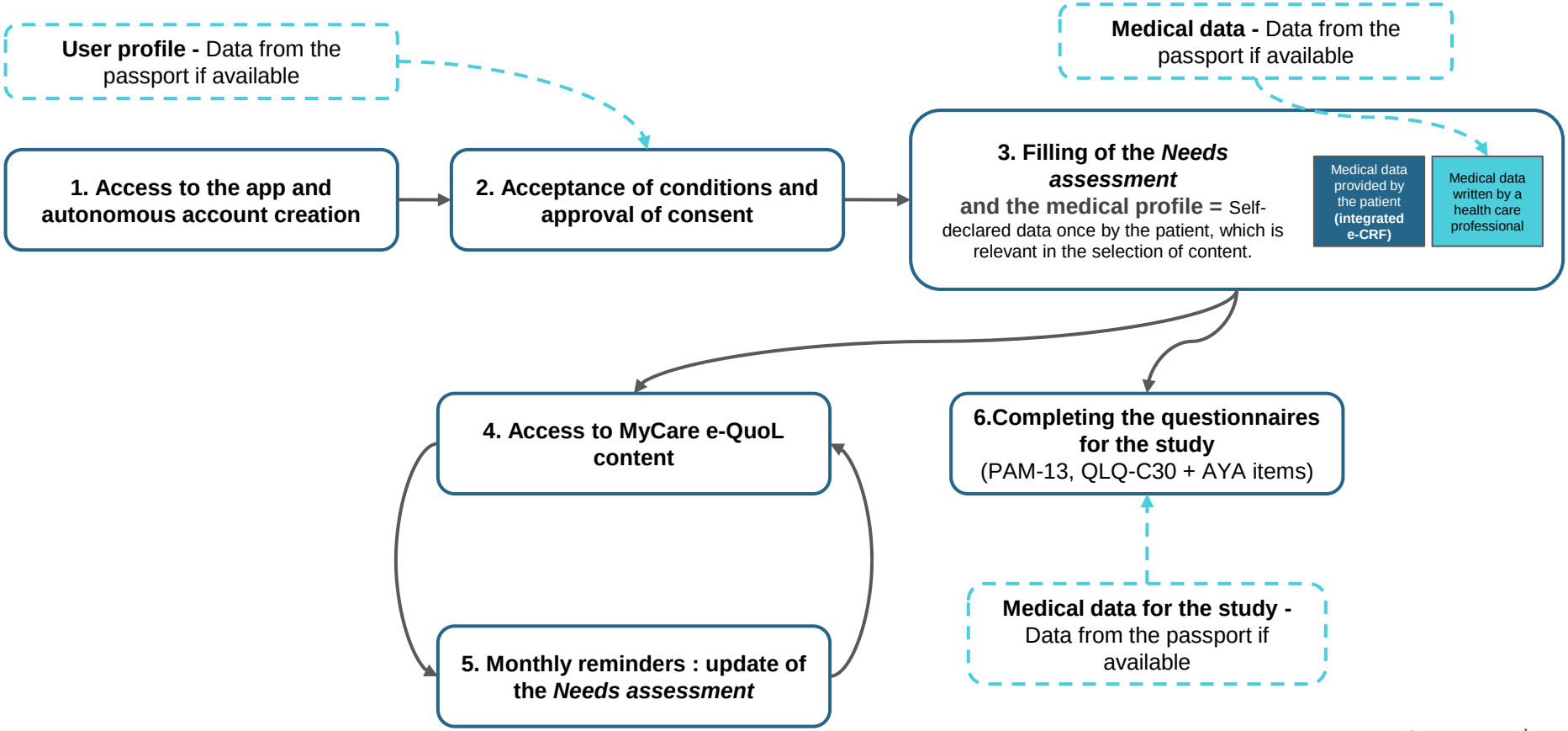
Patient usage scenario



Patient usage scenario



Patient usage scenario



Ergonomics

Ergonomics

- Reminder : Epiconcept develops web applications, so MyCare e-QuoL would be a web application adapted for mobile.
- Epiconcept applications are responsive and offer a mobile-adapted interface by default. This can be customized to adapt to the interfaces of each application.

Features

Features

Wireframe to represent the features - does not correspond to the target visual

- My profile
- My suggested content
- Bookmarked content
- My questionnaires
- Content library
- My tools

Content	Type	Description	Bookmark
How to track your fertility	Expert video	Lorem ipsum dolor sit amet	
Understand your emotional state	Expert video	Lorem ipsum dolor sit amet Lorem ipsum dolor sit amet	
Manage your visual health	Article	Lorem ipsum	
Organize your screening tests	Article	Lorem ipsum dolor sit amet Lorem ipsum dolor	
My life as an employee after an amputation	Interview	Lorem ipsum dolor sit amet	

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smart health

Features

- My profile
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How to track your fertility	Expert video	Lorem	
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Organize your screening tests	Article	Lorem ipsum dolor sit amet Lorem ipsum dolor	
My life as an employee after an amputation	Interview	Lorem ipsum dolor sit amet	

All content pushed to the patient depends on their answers to the needs assessment and their medical profile.

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smart health

Features

Content	Type	Description	Bookmark
How to track your fertility	Expert video	Lorem	
Understand your emotional state	Expert video	Lorem ipsum dolor sit amet Lorem	
Manage your visual health	Article	Lorem	
Organize your screening tests	Article	Lorem Lorem	
My life as an employee after an amputation	Interview	Lorem ipsum dolor sit amet	

All content pushed to the patient depends on their answers to the needs assessment and their medical profile.

The selection of content will be based on matching criteria, which are currently being defined.

We will notably rely on content tagging, which has been started and will be completed by Resilience.

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smart health

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WWW.EPICONCEPT.FR

CINECA SURVIVORSHIP PASSPORT PLATFORM UPDATE

Latest advancements in the deployment of the passport tool in eQuol

CINECA PROJECT OVERVIEW

Survivorship Passport Platform

The platform provides a detailed summary of cancer treatments and personalized care plans for survivors.

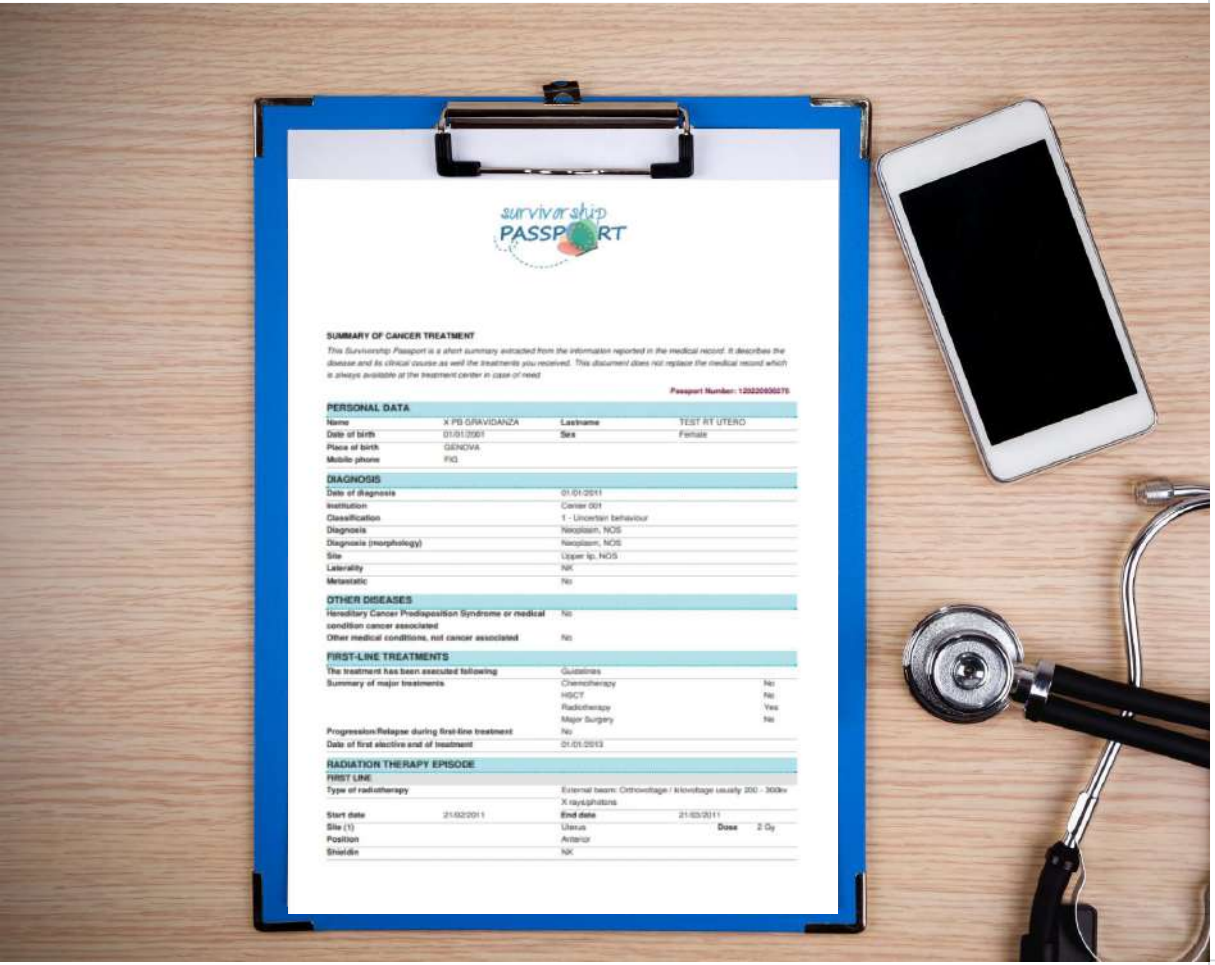
Intention to Treat Protocol

Care plans are generated automatically using guidelines (ad es. IGHG) and algorithms developed to ensure alignment with therapeutic goals and outcomes.

European Collaborative Effort

Five European countries collaborate to implement the platform (Croatia, Denmark, Germany, Hungary, Italy,).

CURRENT STATUS OF DEVELOPMENT



Platform Deployment

The survivorship passport platform testing environment is deployed and accessible to all five countries, enabling broad participation.

Structured Testing Guide

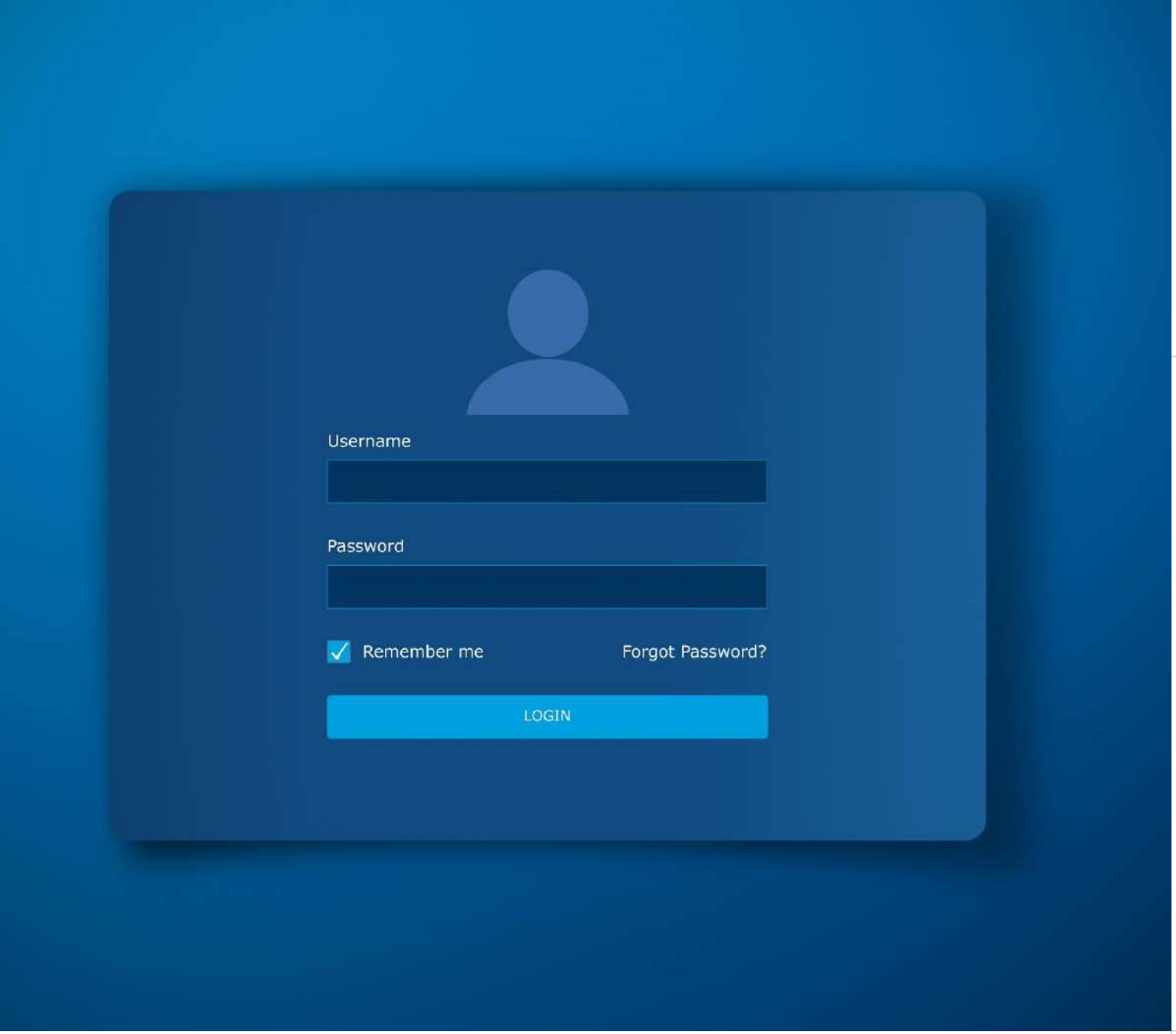
An Excel-based guide was shared to help partners systematically test platform functions and expected outcomes.

Bug Fixes and Final Testing

Bug fixes are nearly complete with final testing underway to ensure all issues are resolved.

Collaborative Feedback Loop

Active partner feedback drives iterative improvements, enhancing platform robustness and user experience.



TRANSLATION AND PERMISSIONS ISSUES

Translation Challenges

Missing field exports caused translation gaps, leading to inconsistencies across platform language versions

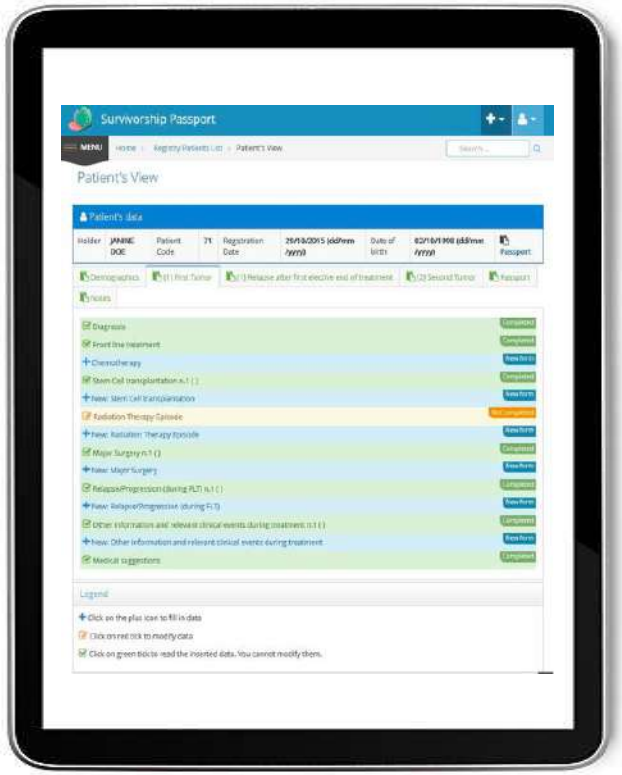
User Permissions Errors

Incorrect permission configurations during user profile creation limited access and functionality in Croatia.

Issue Resolution and Monitoring

With Hungary problems were resolved to ensure linguistic accuracy and secure system operations; ongoing monitoring continues.

PROGRESS IN PARTNER COUNTRIES



Croatia's Progress

Croatia quickly provided user details for profiles to create, resolved permission errors, and should now be able to operate the platform in clinics.

Hungary's Engagement

Hungarian clinic engaged actively with guidance calls during testing for effective platform use.

Italy's Testing Feedback

Italy received late access but is compiling initial feedback and prepares for final bug fixes.

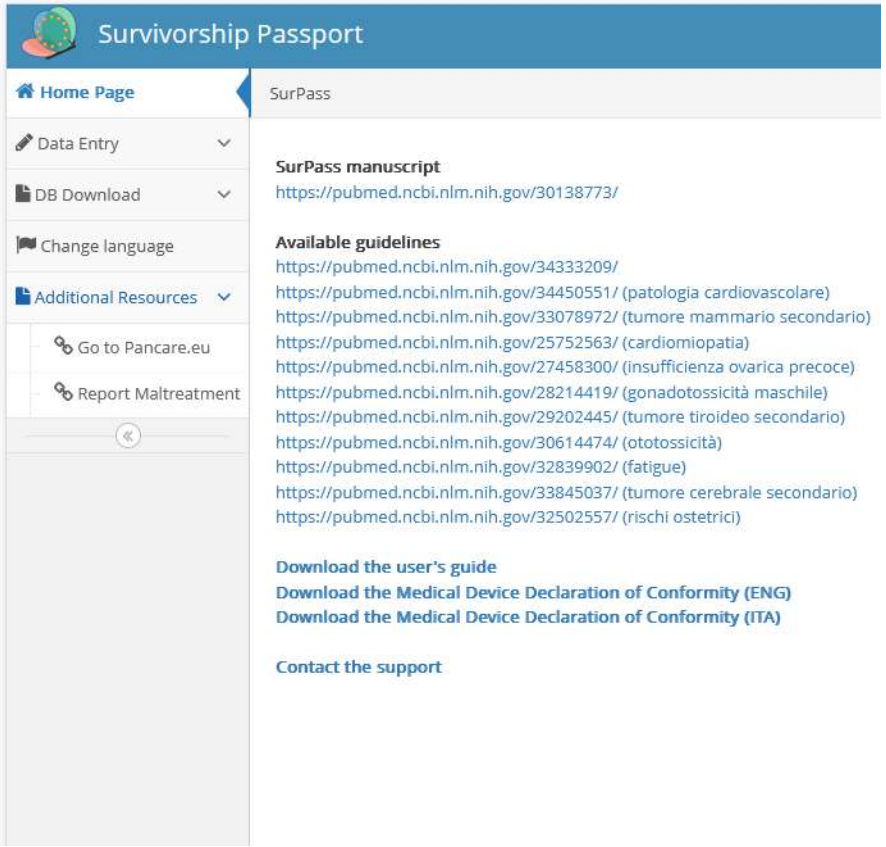
Initial feedback received from Germany

Germany provided initial feedback very quickly and is yet to provide list of profiles to create and further feedback for platform improvements.

Pending Feedback from Denmark

Denmark has access to the testing environment but is yet to provide feedback for further improvements including translations.

NEXT STEPS FOR CINECA



Final Testing and Translation

CINECA will support clinics in final testing and resolve translation issues for consistent platform interfaces.

User Profile Finalization

Partner countries will finalize user profiles list, CINECA is ready to receive the list and create the profiles in production

Transition to Production

Testing in the test environment, giving feedback and providing list of emails for profiles to be created facilitates transition to production environments.

CINECA
tr.ngidi@cineca.it

IGG
monicamuraca@gaslini.org

WP3 Updates: Content

October Monthly Meeting

Content Creation

Status		
Complete	37 articles	
	34 videos (video scripts not included)	
Not Complete (Awaiting Review)	1 article - needs review by PA expert	
	6 videos - fertility and sexual health to be reviewed post-production	
Still in Planning Stages	video	What do we tell other students?
	video	How not to compare yourself to others
	video	Building new relationships
	video	Explaining my experience to my own children
	video	Talking about survivorship with family and friends

Example Bulleted Summary

Using AI – UiO's ChatGPT and Hemmingway Editor – to create a three-bullet summary of each piece of written content (8th grade level or lower)

Article: What is Fear of Recurrence?

•Understanding the Fear: Many people who beat cancer worry it will come back or that they will get a new kind. This is normal and happens to many after treatment.

•What Causes the Fear: Some survivors worry more than others. Younger people and those who felt very bad from treatment often worry more.

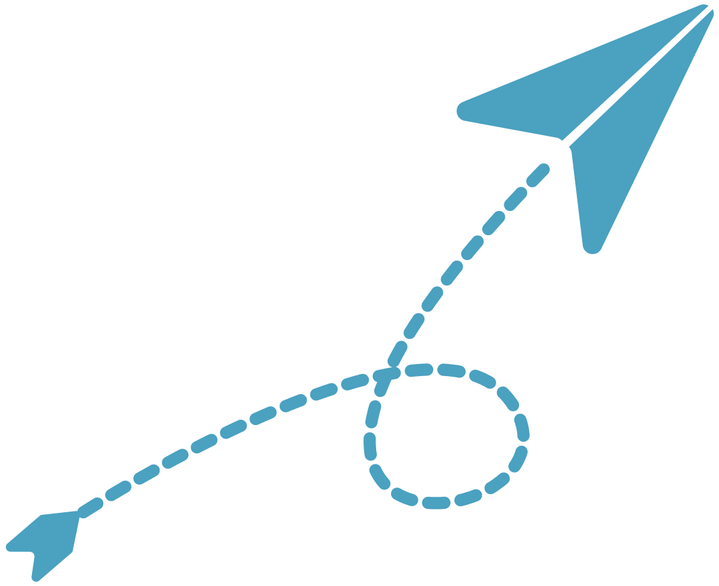
•When the Fear Grows: The fear gets stronger when treatment ends. Finishing treatment can feel good but not seeing the doctor as much can make survivors

Content Validation

- Sending new articles for translation is currently paused while navigating Resilience shift
- Kristen will send you a form to document changes outside of language and cultural adaptations, made during language translation checks

WP7. Communication, Dissemination and Exploitation

1. Upcoming Annual Newsletter
2. Excel Template for Communication Actions
3. Publications Reminder



1. Upcoming Annual Newsletter

Planned for early December

We will contact WP leaders by email shortly to collect input

Help us grow the GDPR-compliant mailing list – please share with your contacts!

SIGN UP form:

https://equolproject.eu/newsletter/

e·QuoL
Equality · Quality of Life · Survivorship

2. Excel Template for Communication Actions

📊 **Excel template to be shared**

- **Please fill it in with your latest communication actions.**
- **Timeframe: May 2025 – November 2025.**

3. Publications Reminder

🔔 **Please remember to:**

- **Update us on the status of your publications.**
- **Use the survey when submitting to the publication committee.**

e·QoL
Equality · Quality of Life · Survivorship

Thank you!

e·QoL
Equality · Quality of Life · Survivorship

ISGlobal

e·QuoL
Equality · Quality of Life · Survivorship

WP7 – QoL cluster

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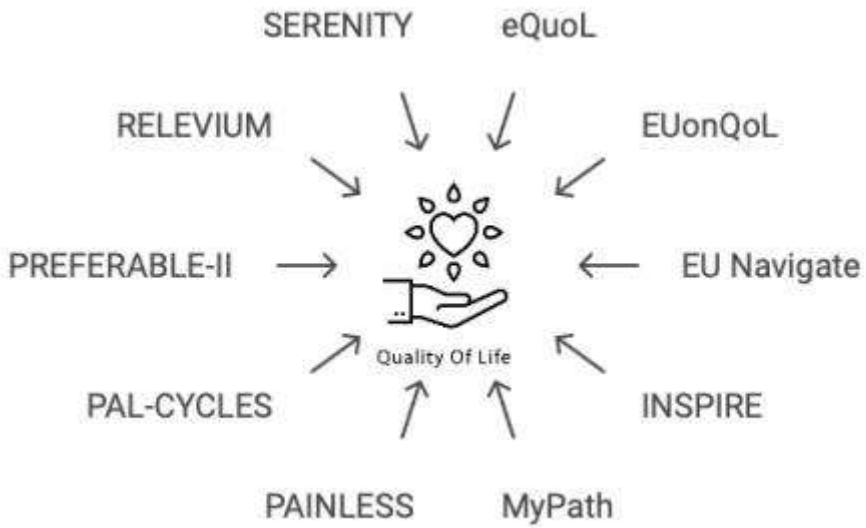
D7.5_Common workplan for scientific collaboration under the "QoL" cluster	mars-24
D7.6_Conclusions of common annual meeting of the "QoL" cluster V1	déc-24
D7.7_Conclusions of common annual meeting of the "QoL" cluster V2	déc-25
D7.8_Conclusions of common annual meeting of the "QoL" cluster V3	déc-26
D7.9_Conclusions of common annual meeting of the "QoL" cluster V4	oct-27
D7.10_Policy Brief formulating recommendations based on the research and innovation strand of the "QoL" annual cluster meeting V1	déc-24
D7.11_Policy Brief formulating recommendations based on the research and innovation strand of the "QoL" annual cluster meeting V2	déc-25
D7.12_Policy Brief formulating recommendations based on the research and innovation strand of the "QoL" annual cluster meeting V3	déc-26
D7.13_Policy Brief formulating recommendations based on the research and innovation strand of the "QoL" annual cluster meeting V4	déc-27
D7.14_Citizen engagement summary report	déc-27
D7.15_Addressing inequalities recommendations	déc-27
D7.16_Common cluster brochure	déc-24

QoL cluster – 01/2024-09/2025



QoL cluster – 01/2024-09/2025

- 1st meeting : 22/04/2024

→Common workplan for scientific collaboration under the QoL cluster

- **Existing tools to monitor the QoL situation** (which tool, what countries, user feedback, best practices, why this specific tool etc….) + Overview of the countries where we operate and in case there is similar needs in other countries

- To ease **Health economics evaluations** by providing experts consensus statements

- **“QoL”**: what taking into account when preparing QoL call for proposal. Potentially focus on barriers and difficulties when measuring QoL. The joint collaboration can provide recommendations about the tools used by project members when measuring QoL.

- **Cost effectiveness**: how to assess it? The different projects have for mandatory outcome to evaluate the effectiveness of interventions.

QoL cluster – 01/2024-09/2025

- Annual meeting : 28/11/2024 : Health economic analyses across Europe
  - Presentations of PREFERABLE-II project, PAINLESS project, RELEVIUM project

QoL cluster – 01/2024-09/2025

QoL cluster – 01/2024-09/2025

QoL AYA cluster – 09/2025 …

- 1st meeting : 25/09/2025

To be continued…