Nature	Dissemination level	Leading institution
R	**SEN**	**ALP**

D6.5 – Social Challenges V1

WP6 – Ethics and Social Challenges

e·QuoL

Equality · Quality of Life · Survivorship

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DELIVERABLE REFERENCE TITLE Version	**D6.5** Social Challenges Report V1 V01
LEADING BENEFICIARY	**ALP**
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DISSEMINATION LEVEL

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LIST OF PARTNERS

BEN – Beneficiaries / **AFF** – Affiliated partners / **ASS** – Associated partners

1.	BEN	GCS	HUGO Groupement de Coopération Sanitaire des Hôpitaux Universitaires Grand Ouest
1a.	AFF	CHUA	Centre Hospitalier Universitaire d'Angers
1b.	AFF	ICO	ICO Institut de Cancérologie de l'Ouest
2.	BEN	HUPON	Magyar Gyermekonkologiai Halozat – Magyar Gyermekonkologusok es Gyermekhematologusok Tarsasaga
3.	BEN	UNIOSL	Universitetet I Oslo
4.	BEN	CHUSE	Centre Hospitalier Universitaire Saint Étienne
5.	BEN	IGG	Istituto Giannina Gaslini
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20.	BEN	ALP	Asociatia Little People Romania
21.	BEN	CUSL	Cliniques Universitaires Saint-Luc ASBL
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23.	BEN	UMC-Mainz	Universitaestsmedizin der Johannes Guterberg-Universitaet Mainz
24.	BEN	PANCARE	PanCare
25.	ASS	UNILU	Universität Luzern
26.	ASS	IGR	Institut Gustave Roussy
27.	ASS	ERINTETTEK	Érintettek Egyesület
28.	ASS	AGUERRIS	Association Les Aguerris
29.	ASS	YCE	Fundatia Youth Cancer Europe
30.	ASS	RMH	The Royal Marsden National Health Service Trust

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Table of contents

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1. Introduction

In this task we plan to identify and address potential social challenges faced by the individuals who will use the tools developed in this project, such as accessibility, inclusiveness, and stigmatization. To accomplish this, we will utilize in-depth reflection across the duration of the e-QuoL project to pinpoint areas of social need, and actively address these identified social challenges. By engaging in this process, e-QuoL aims to promote social acceptance, inclusivity, and equitable distribution of benefits from the e-health tools.

User-centered collaboration will be fostered through a participatory approach where e-QuoL consortium members and volunteers from the user panel will be involved as active participants and primary decision makers in the reflection → action development process of the e-PSCT, as they are its potential users. This will ensure the tool addresses the most pertinent social challenges for users, therefore making the tool more valuable than other tools created without direct user input.

The first task has been to engage with stakeholders to establish the Social Challenges Reflection Group. In the first 12 months of the project, the group has met on two occasions and agreed on the group's objectives and work strategy.

1.1 Key Objectives

1. Identify potential social challenges.
2. Engage with stakeholders to develop strategies to address the identified social challenges

1.2 Deliverables

- Two virtual meetings a year (2 hours each) - more if required.

- Written report at 12, 24, 36 and 48 months. Identifying potential challenges and actions the task group and the consortium have taken or will take to address them.

2 The Social Challenges Reflexion Group

Two virtual meetings are planned per year with a duration of 2 hours each. Further meetings will be arranged as required. The group will aim to conduct a social impact assessment with in-depth reflection on the social context of the e-QuoL project from its conception to its dissemination.

2.1 Membership

The group is chaired by Diana Todea, Child Cancer psychologist, Association Little People Romania.

Emma Potter, Nurse Practitioner in Transition and Long Term Follow Up Child, Teen and Young adult Cancer, Royal Marsden Hospital Is the deputy chair.

Membership of the group is open to internal and external healthcare professionals, researchers, patient advocates, and those with expertise in the field. Each of the project work package leads and partner organizations were invited to nominate a representative.

This resulted in 15 participants attending the first meeting and 25 attending the second.

2.2 Objectives

The group identified and defined 6 objectives for the Social Challenges Reflexion Group, presented below:

- Identify potential social challenges;
- Engage with stakeholders to develop strategies to address social challenges;
- Advocate for the needs of those from underserved or minority populations;
- Foster a culture of social responsibility within the Project;
- Share Equality, Diversity and Inclusion (EDI) education and information resources with consortium members;

- Be a source of EDI expertise for consortium members.

2.3 Framework used for discussing Social Challenges

Resources produced by the European Commission co-funded project: EU-CAYAS-NET EU4H-2021-PJ-04:101056918 were utilized to underpin the work of the Social Challenges Reflexion Group. The EU-CAYAS-NET Equality, Diversity and Inclusion work stream identified four important areas to ensure fairness and inclusivity in cancer care and grouped their recommendations accordingly. The full white paper can be found here:

https://beatcancer.eu/resources/equality-diversity-and-inclusion/article/recommendations-for-equitable-cancer-care/

Recommendations for equitable, diverse and inclusive cancer care in Europe

- Race, ethnicity, culture, refugee or migrant status

To address disparities and ensure equitable access to cancer care for individuals from diverse racial, ethnic, and cultural backgrounds, including refugees and migrants.

- Gender identity and sexual orientation

To promote awareness and support for LGBTIQ+ individuals affected by cancer, ensuring they receive respectful and inclusive care regardless of their gender identity or sexual orientation.

- Age, physical and mental development and wellbeing

To recognize the unique needs of individuals at different stages of life, including children, adolescents, and young adults, and recognise mental health status and neurodiversity as important determinants of health outcomes.

- Education, career and socioeconomic status

To address social determinants of health and ensure that individuals from all socioeconomic backgrounds have access to quality cancer care, regardless of their education level, career status, or living conditions.

The working group reviewed and agreed on these areas as being appropriate for reviewing social challenges in the context of cancer care. It was also agreed they would be suitable in providing a framework for discussion of potential or existing social challenges within the e-QuoL project. The areas were prioritized for discussion and spread over 3 meetings to ensure adequate time for the discussion of each area.

Meeting 1: the topics of discussion for June 2024 were related toRace, Ethnicity, Culture, Refugee, or Migrant status.

Meeting 2: the topics of discussion for Nov 2024 were related to Age, Physical and Mental development, and Wellbeing.

Meeting 3: the topics of discussion forMarch 2025 would be related toGender identity and Sexual orientation and Education, Career and Socioeconomic status.

2.4 Description of the Social Challenges identified

2.4.1 FIRST MEETING JULY 15, 2024, 16:30 – 18:30 (EEST)

The following outlines the social challenges and barriers identified concerning race, ethnicity, culture, refugee, or migrant status, in the context of healthcare and cancer-related issues:

Barriers:

1. Individuals do not wish to be associated with cancer, and do not want the stigma associated with cancer in some countries and cultures. An individual wants to ‘move on’ and forget they had cancer.
2. Individuals do not wish to have data collected about them.
3. Comprehension difficulties.
4. Language barriers can significantly impact migrants or individuals seeking better healthcare in a country where they do not speak the primary language.
5. Cultural differences in seeking information. In some countries it may be considered not appropriate to seek further information or a second opinion.

Recommendations:

To address these challenges and barriers, the following recommendations were proposed by the participants:

1. Translation and Language Accessibility

- All-important output should be translated into as many languages as possible. Translation should not just be subtitles over spoken language. Having a multilingual glossary readily available for healthcare professionals (HCPs) is highly recommended;
- It would be desirable for users to be able to use their preferred language to access resources;
- Care should be taken when using translation done by AI, because this can miss context, produce inaccurate or unnatural language, and fail to capture cultural nuances. It needs a formal human verification process and validation;
- Mindful of using terms like 'cancer survivor', 'disability', 'handicapped'. For example, cancer survivor is not an acceptable phrase in France. Consider using alternative phrases like 'people living beyond cancer', former patient, person with experience';
- Healthcare materials must accommodate the challenges of individuals who are unable to read or write by incorporating more visual aids and straightforward explanations.

2. Cultural Sensitivity and Inclusivity
   - Information provided should be culturally sensitive. Everyone must have access to information, but we must carefully consider how to provide it so that users can control, access and maintain privacy, taking into account cultural differences (e.g.low literacy and digital literacy) in communities like the Roma;
   - Any visual resource including language, must be inclusive. Images and videos should reflect diverse ethnicities, a range of disabilities, same-sex relationships, and heterosexual relationships. Representation matters;
   - Partnerships with parent organizations: by collaborating with parent organizations, it is possible to gain valuable insights into the challenges and perspectives of caregivers, thereby enhancing support systems. Also, it is crucial to educate families in conjunction with patients, as they frequently lack essential information regarding healthcare.

3. Inclusive Representation
   - Inclusive of minority groups. Evidence/literature search needs to actively include evidence from minority groups;
   - Software compatible with a range of devices e.g. Android and iPhone;
   - Tool development: Developers/researchers need to include a diverse range of participants (healthcare professionals/patients/family members/members of the public). Valuable

resources for recruiting patient advocates are: Beat Cancer - Youth Cancer Survivors – Community;

- Targeted recruitment to achieve diversity of participation. Transparent about recruitment methods and why. Ensure feedback is provided to participants – results, how did their participation influenced / made a difference. Recognition of their involvement, contribution;
- Diverse Representation in Videos: It is imperative to incorporate actors from various countries into educational videos, ensuring that representation is inclusive of country specific challenges.

4. User Engagement and Feedback
   - Recommendation for dissemination: 'ambassador' to advise or be responsible for dissemination within their community. Spread awareness and create interest in the tool;
   - Healthcare Professionals' role: General practitioners and healthcare providers should actively encourage patients to use and engage with healthcare materials (e.g., Resilience applications);
   - Inclusive Access to Information: It is imperative to prevent the exclusion of individuals who lack a follow-up care plan. Flyers and physical materials should be distributed to individuals who may not have access to digital devices.

5. Country-Specific Challenges
   - Challenges specific to each country: When developing healthcare solutions, it is crucial to take into account the distinctive context and obstacles of each country;
   - Variability in Healthcare Systems: It is important to bear in mind that healthcare systems vary substantially across countries, and materials must be able to accommodate these differences;
   - Variability in Healthcare Systems: It is important to bear in mind that healthcare systems vary substantially across countries, and materials must be able to accommodate these differences.

The meeting concluded with final actions, which established the framework for the subsequent meeting. A report was prepared and available for any interested parties.

2.4.2 MEETING TWO: 4TH NOVEMBER, 2024, 4:30-6:30 PM (GMT+2), ONLINE

The following outlines the social challenges and barriers identified concerning Age, Physical and Mental Development, and Wellbeing in the context of healthcare and cancer-related issues.

Challenges identified:

1. To address sensitive topics like fertility, mental health, and emotional well-being in a clear, inclusive, and culturally sensitive manner, content design and accessibility are essential. It is highly important that this content is developed and presented by healthcare professionals (HCP) with specific expertise, as they bring the necessary understanding of cultural nuances and can ensure accurate, compassionate, and effective communication;
2. Ensuring accessibility features, such as translations, subtitles, and formats suitable for users with disabilities or low digital literacy, is crucial. It is important to engage healthcare professionals (HCP) with experience in accessibility of educational materials for an official revision of these products;
3. There's a lack of involvement, especially from marginalized groups like those with disabilities and shared vulnerabilities (e.g. individuals with disabilities, ethnic minorities or migrants);
4. Users are not receiving enough personalized and engaging content in formats like storytelling or gamification;
5. There are insufficient mechanisms for continuous feedback and adaptability, which hinders the refinement of tools to meet users' evolving needs;
6. The development and refinement of tools underrepresents young cancer survivors.

Recommendations:

1. Prioritize content design that is clear, inclusive, and culturally sensitive, especially when addressing sensitive topics;
2. Implement accessibility features, such as translations, subtitles, and user-friendly formats, to cater to diverse user groups, including those with disabilities or low digital literacy.

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3. Actively involve underrepresented communities, especially those with disabilities or multiple vulnerabilities, in testing and refining the tools;

4. Develop customized tools with personalized content using engaging formats such as storytelling and gamification;

5. Establish systems for continuous feedback and adaptability to ensure that resources evolve according to user needs;

6. Focus on the seamless integration of tools and resources to support a holistic approach to addressing challenges;

7. Increasing the participation of young cancer survivors in discussions and the development of tools to ensure inclusion and relevance to their specific needs is crucial.

2.4.3 SURVEY OF E-QUOL PROJECT TASK LEADERS

We conducted an extensive survey among e-QuoL project work package leaders to identify and tackle the social difficulties encountered by participants. The answers identified substantial obstacles and offered practical recommendations to promote inclusion and accessibility.

2.4.3.1 CATEGORIES OF RECOGNISED CHALLENGES AND SUGGESTED SOLUTIONS

1. **Race, Ethnicity, Culture, Refugee or Migrant Status**

Challenges: Systemic discrimination, linguistic obstacles, cultural disparities.

Proposed Solutions: Establish multilingual assistance and translation services, create culturally responsive materials, and enforce anti-discrimination regulations.

2. **Gender Identity and Sexual Orientation**

Challenges: Prejudice, insufficient representation, privacy issues.

Proposed Solutions: Enact inclusive policies, educate project teams on diversity and inclusion, employ gender-neutral language and imagery, and strengthen privacy controls.

3. **Age, Physical and Mental Development and Wellbeing**

Challenges: Age diversity, physical and cognitive impairments, mental health disorders.

Proposed Solutions: Develop inclusive tools featuring intuitive design and assistive technologies, promote privacy and user comfort, and guarantee ongoing input for enhancement.

4. **Education, Career / Employment and Socioeconomic Status**

Challenges: Barriers to accessibility, mental health difficulties, ergonomic concerns with digital tools.

Proposed Solutions: Create intuitive interfaces with accessibility enhancements, incorporate tailored mental health resources, and streamline engagement alternatives.

5. **Training and Support in Equitable, Diverse and Inclusive Cancer Care**

Challenges: Insufficient prior training in equity, diversity, and inclusion (EDI).

Proposed Solutions: Provide customized training sessions centered on EDI in cancer care to enhance participants' ability to meet the needs of marginalized communities.

6. **Support from the Social Challenge Group**

Challenges: Requirement for professional consultations and advice on content development.

Proposed Solutions: Offer customized tools, professional consultations, and comprehensive feedback systems for ongoing enhancement.

7. **Collaboration across Work Packages**

Challenges: Necessity for synchronization in plans and objectives.

Proposed Solutions: Emphasize ethical considerations and accessibility in the adaption of tools to guarantee inclusion.

The survey findings have revealed the social issues in the e-QuoL project, highlighting the necessity for specific measures to improve inclusivity and accessibility. By tackling systemic prejudice, digital literacy deficiencies, and insufficient representation, the initiative can foster a friendly atmosphere for individuals from varied backgrounds. The results emphasize the disparity in EDI training among consortium members, highlighting the necessity for continuous feedback and adaptation to address the changing requirements of stakeholders.

2.4.4 EQUITY, DIVERSITY AND INCLUSIVITY TRAINING

Following the results of the survey and discussion with the Social Challenges Group a decision was made to provide EDI training

Online training (approx. 90 minutes) will be set up as a pre-recorded webinar with materials from EU-CAYAS-NET's *Equity, Diversity, and Inclusion Principles in Cancer Train-the-Trainer Toolkit* and *Recommendations for Equitable, Diverse, and Inclusive Cancer Care in Europe* workbook. Additional materials from relevant academic publications and texts will also be included. The primary goal of this webinar will be to provide the audience with an overview of EDI principles and their application to cancer care and the greater e-QuoL project. The webinar will be accessible at any time through the e-

QuoL project's website and learning will be assessed via self-evaluation quiz. The e-QuoL team will benefit from this online training, and it will be accessible to any other interested partners.

The webinar will have three primary learning outcomes:

1. Discuss potential social challenges faced by CAYACSs;
2. Understand the mechanics of culturally-sensitive care in the context of LTFU;

Explain the importance of remaining culturally aware and having discussions of CAYACSs' potential and realized social challenges with colleagues.

2.4.5 DISSEMINATION

The following methods of dissemination have been used:

- Following each meeting of the social challenges group, a written copy of the minutes has been circulated to all group participants;
- A summary of the social challenges discussed and recommendations was presented to the project members at the November e-QuoL Consortium co-coordination meeting;
- Information on the work of the Task has been added to the project website, open to members of the public, link here: Fostering Ethical and Social Awareness in e-QuoL.

3 Achievements and Constraints

3.1 Achievements

1. Strong professional connections have been made with the project work package leaders and other members of the consortium, with several joining the Social Challenges Reflexion Group;
2. Two meetings of the Social Challenges Group have been held with good attendance;
3. Two of four focus areas have been discussed by the reflexion group and respective social challenges identified;
4. Social Challenges that have been Identified and recommendations for action have been shared at the November 2024 meeting of e-QuoL consortium members;
5. Survey of task leaders completed.

3.2 Constraints

1. At the first meeting it was recognized that English is not the first language for many participants. Some participants found It easier to express their thoughts in writing, using the chat function rather than verbally. In meeting two it was decided to formalize this approach with the use of 'Mural' a collaborative digital whiteboard to supplement the breakout room discussions;
2. Due to unexpected interest and enthusiasm for the group, 25 participants attended the second meeting. While this was most welcome it made managing the breakout rooms difficult. Thought will be given to how to secure active involvement and representation from interested project members while limiting group membership to 20 participants;
3. Only one childhood cancer survivor attended the first meetings of the Social Challenges Reflexion Group. The Group has agreed that increasing the voice of the childhood cancer survivors and family members needs to be a priority while being mindful of the need to maintain a maximum number of 20 participants in the Reflexion group. This goal has been included in the work plan for the first quarter of 2025.

4 Work Plan 2025

	Quarter 1 January / March 2025	Quarter 2 April / June 2025	Quarter 3 July / September 2025	Quarter 4 October / December 2025
Social challenges Group Membership review				
3rd Meeting	March 2025			
Presentation of findings – e-Quol monthly meeting		By May 2025		
EDI training package development				
4th Meeting				October 2025
Dissemination				
Production and submission for				

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deliverable 6.6				

Dec 2024 to March 2025 - Revise membership

Revise membership of social challenges. Increase the number of patient advocates. Consider reducing the consortium representation to two persons for each work package.

March 2025 - Meeting 3

Discuss final two areas of social challenges and identify social challenges most relevant to the e-QuoL project.

Reflect on the value of co-creation of health and social outcomes in the e-health digital ecosystem context. Identify and share areas of good practice within the project and identify areas where co-creation could or should be strengthened.

May 2025 - Dissemination

Present findings to E-Quol Consortium at monthly co-coordination meeting

Jan to June 2025 - Education & training

Create EDI training package

March 2025 - review of first draft by Social Challenges group

June 2025 EDI training package go live on project website

Oct 2025 - Dec 2027 - review use of education resources. Identify any further training requirements

Oct 2025 - Meeting 4

Review identified social challenges and the work to overcome them

Review draft Year 2 report

Dec 2025 - Dissemination

Present findings to E-Quol Consortium at monthly co-coordination meeting

March 2026 Meeting 5

Review identified social challenges and the work to overcome them

May 2026 - Dissemination

Present findings to e-Quol Consortium at monthly co-coordination meeting

Oct 2026 Meeting 6

Review identified social challenges and the work to overcome them

Review draft Year 3 report

Dec 2026 - Dissemination

Present findings to e-Quol Consortium at monthly co-coordination meeting

March 2027 Meeting 7

Review identified social challenges and the work to overcome them

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May 2026 - Dissemination
Present findings to e-Quol Consortium at monthly co-coordination meeting

Oct 2027 Meeting 8
Review and agree end of project report

5 Appendix

5.1 Meeting Minutes

5.1.1 JULY 2024 MEETING

The objectives of the working group:

1. **Identifying potential social challenges:** The group aims to examine and anticipate social challenges affecting disadvantaged or minority groups.
2. **Advocacy for the needs of disadvantaged groups:** They will ensure that the voices of those from underrepresented or minority populations are heard and that their needs are addressed.
3. **Distribution of EDI (Equity, Diversity and Inclusion) Education Resources:** Sharing educational materials and information related to inclusion, diversity and equity with consortium members.
4. **Provision of EDI expertise:** The group will act as a source of expertise for consortium members, providing advice and guidance on topics related to inclusion and equity.

Deliverables:

- Virtual meetings: Two virtual meetings per year, each lasting 2 hours, or more if necessary.
- Periodic Reports: The Group will submit reports at 12, 24, 36 and 48 months, identifying potential challenges and the actions the group and consortium have taken or will take to address them.

This type of work is important for promoting better social inclusion and ensuring that vulnerable or marginalized groups are properly represented and supported**.**

Minutes

Modality: Virtual (zoom platform)
Attendance: **Oana Rusu, Emma Potter, Nicha Le Dall, Diana Todea,** Anica Ilic**,** Jelena Roganovic, Zadravec Zaletel, Agnes Dumas, Valie Ganosi, Kristen Thompson, Ana Tototvina.

Gerfault Benoit, e-QuoL PM, technical support.

This was the first open meeting of the Social Challenges Group.
We will include discussions from this meeting in e-QuoL work packages and share them with project partners in the form of a recommendation whitepaper to ensure their meaningful integration into the development of cancer care tools and strategies.
The meeting commenced with a cordial welcome and introductions by Oana Rusu, which established the atmosphere.
Emma Potter delivered a presentation on the critical areas that must be considered when confronting social challenges [ATTACH the PRESENTATION]. This served as an opportunity for group discussion regarding the topics that should be prioritized. It was decided to focus on one area for discussions within the breakout rooms with further topics to be covered at future meetings.

1. Race, ethnicity, culture, refugee or migrant status:

Minority or vulnerable groups such as refugees and migrants often face barriers to accessing health services, either due to discrimination or language or cultural barriers. Ensuring equitable access to health services and removing these barriers is essential to creating an inclusive health system.

Participants were divided into two breakout rooms, with two facilitators in each room (Oana Rusu & Diana Todea in Room 1, and Emma Potter & Nicha Le Dall in Room 2). This facilitated a more intimate discussion of prospective social challenges that were relevant to the e-QuoL work packages.

At 17:00, the groups reconvened to discuss the main points and outcomes of their discussions at outlined below.

Social Challenges and Barriers

Both sections emphasize the need to address the inequities and discriminations in health systems and to provide fair and respectful care to all individuals. Racial, cultural and sexual diversity must be recognized and included in the development of health policies and services to create a more just and inclusive society.
The following outlines the social challenges and barriers identified concerning race, ethnicity, culture, refugee, or migrant status, particularly in the context of healthcare and cancer-related issues:

1. Individuals not wishing to be associated with cancer. Not wanting the stigma that is associated with cancer in some countries and cultures. An individual wanting to ‘move on’ and forget having had cancer.

2. Individuals not wishing to have data collected about them.

3. Comprehension difficulties.

4. Language barriers.

5. Cultural differences in seeking information. In some countries it may be considered not appropriate to seek further information or a second opinion.

Recommendations

To address these challenges and barriers, the following recommendations were proposed by the participants:

1. Translation and Language Accessibility

- All important output should be translated into as many languages as possible. Translation should not just be subtitles over spoken language.
- It would be desirable for users to choose preferred language to access resources.
- Care should be taken when using translation done by AI, because this can miss context, produce inaccurate or unnatural language, and fail to capture cultural nuances.
- Mindful of using terms like ‘cancer survivor’, ‘disability’, ‘handicapped’. For exemple cancer survivor is not an acceptable phrase in France. Consider using alternative phrases like ‘people living beyond cancer’, former patient, person with experience’.
- Healthcare materials must accommodate the challenges of individuals who are unable to read or write by incorporating more visual aids and straightforward explanations.

2. Cultural Sensitivity and Inclusivity

- Information provided should be culturally sensitive. Everyone must have access to information, but we must carefully consider how to provide it so that users can control access and maintain privacy, taking into account cultural differences in communities like the Roma.
- Any visual resource, including language, must be inclusive. Images and videos should reflect diverse ethnicities, a range of disabilities, same-sex relationships, and heterosexual relationships. Representation matters.
- Partnerships with parent organizations: By collaborating with parent organizations, it is possible to gain valuable insights into the challenges and perspectives of caregivers, thereby enhancing support systems. Also, it is crucial to educate families in conjunction with patients, as they frequently lack essential information regarding healthcare.

3. Inclusive Representation

- Inclusive of minority groups. Evidence/literature search needs to actively include evidence from minority groups.
- Software compatible with a range of devices e.g. Android and iPhone.
- Tool development: Developers/researchers need to include a diverse range of participants (healthcare professionals/patients/family members/members of the public). Valuable resources for recruiting patient advocates are: Beat Cancer - Youth Cancer Survivors - Community.
- Targeted recruitment to achieve diversity of participation. Transparent about recruitment methods and why. Ensure feedback is provided to participants – results, how did their participation influenced / made a difference. Recognition of their involvement, contribution.
- Diverse Representation in Videos: It is imperative to incorporate actors from various countries into educational videos, ensuring that representation is inclusive of country-specific challenges.
- Variability in Healthcare Systems: It is important to bear in mind that healthcare systems vary substantially across countries, and materials must be able to accommodate these differences.

4. User Engagement and Feedback

- Recommendation for dissemination: ‘ambassador’ to advise or be responsible for dissemination within their community. Spread awareness and create interest in the tool.
- Healthcare Professionals' role: General practitioners and healthcare providers should actively encourage patients to use and engage with healthcare materials (e.g., Resilience applications).
- Inclusive Access to Information: It is imperative to prevent the exclusion of individuals who lack a follow-up care plan. Flyers and physical materials should be distributed to individuals who may not have access to digital devices.

5. Country-Specific Challenges

- Challenges specific to each country: When developing healthcare solutions, it is crucial to take into account the distinctive context and obstacles of each country.

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- Variability in Healthcare Systems: It is important to bear in mind that healthcare systems vary substantially across countries, and materials must be able to accommodate these differences.

The meeting concluded with final actions, which established the framework for the subsequent meeting.
Date of Next Meeting: Monday, 4th November 2024 @ 15.00 (CET)

5.1.2 NOVEMBER 2024 MEETING

Agenda

- 15:30—Welcome and Introductions
- 15:40 Presentation: Progress of the E- QuoL Project and Next Steps
- 15:50: The Social Challenges Group reviewed the previous meeting minutes and presented them.
- 16:00: The results of the survey were presented to the task leaders.
- 16:30: Exploring Social Challenges within E-QuoL Work Packages—Breakout rooms facilitated by Emma Potter and Diana Todea.
- 17:10: Return to the Main Room; share key points and discuss action items.
- 17:20—Collaborative Work on the Mural Tool: Identify challenges and solutions using Mural.

We started the meeting with Charlotte Demoor, who presented the E-QuoL project and their main objectives. Following this, Emma Potter summarized our progress in the social challenges group and presented the minutes from the previous meeting.

Results of the Survey of Task Leaders

To better understand the social challenges faced by participants and to develop targeted solutions, the leads of the work packages within the e-QuoL project completed a survey. Their responses highlighted key barriers and provided actionable insights for addressing these challenges. The following sections outline the identified issues and proposed solutions based on their feedback.

1. Race, ethnicity, culture, refugee, or migrant status

The responses emphasized systemic discrimination, language barriers, and cultural differences as significant challenges. To address these, the project must implement multilingual support and translation services to improve accessibility. To ensure relevance and engagement with diverse communities, we should develop culturally adaptive materials. All activities should enforce anti-discrimination policies to foster an equitable environment for all participants.

2. Gender identity and sexual orientation.

The survey identified challenges such as bias, lack of representation and privacy concerns. We should implement inclusive policies that protect LGBTQ+ participants and train the project team on diversity and inclusion to address these issues. Project materials must include gender-neutral language and imagery to ensure broader representation. We should also put in place enhanced privacy controls to protect participants' identities and ensure confidentiality.

3. Age, physical and mental development, and wellbeing

Participants emphasize the importance of creating inclusive, accessible, and supportive tools to meet their diverse needs. Challenges such as age diversity, physical and cognitive disabilities, and mental health issues require a thoughtful, user-centered approach. By integrating features such as intuitive design, assistive technologies, simplified modes, and mental health resources, insurance projects provide greater accessibility and use. Flexibility and continued development through feedback and more user experience, while meeting accessibility standards and ergonomic design, promote inclusion. Prioritizing privacy and user comfort also addresses concerns about stigma and personal security.

4. Education, career/employment, and socioeconomic status

The participants highlighted accessibility barriers, mental health challenges and ergonomic issues with digital tools. In response, user-friendly interfaces must include built-in accessibility features such as screen readers, closed captioning, and ergonomic design. We should integrate simplified engagement options and personalized mental health resources to support participants of all ages and abilities.

5. Training and support in equitable, diverse, and inclusive cancer care.

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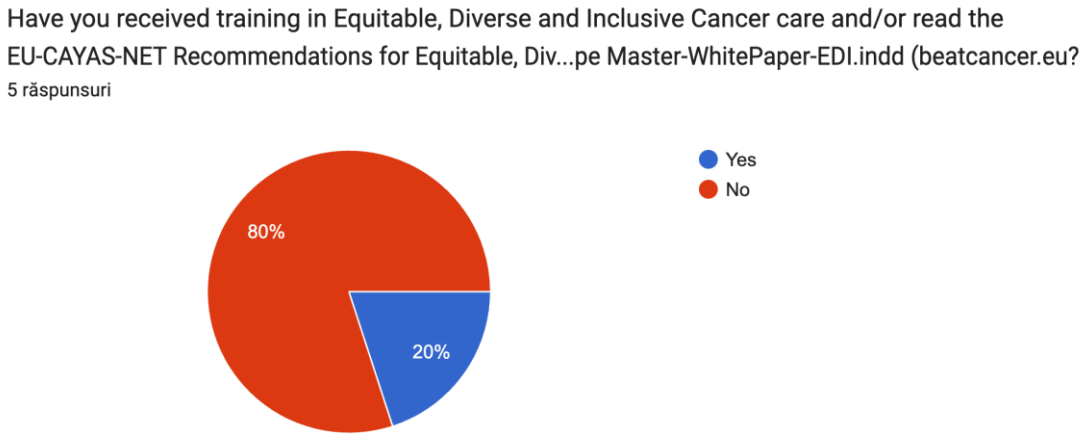
The survey revealed a notable gap, with 80% of respondents (Fig. 1) indicating they had not received prior training. This presents an opportunity to offer tailored training sessions focusing on equity, diversity, and inclusion (EDI) in cancer care. Such training would help project participants understand and address the needs of underserved or minority populations effectively.



6. Assistance from the Social Challenges Group

Several respondents expressed a need for assistance from the Social Challenges Group to address specific challenges (Fig. 2.) . They requested expert consultations, guidance on culturally competent content design, and support in improving accessibility. They also suggested tailored resources and robust feedback mechanisms to ensure continuous improvement and alignment with participant needs.

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7. Collaboration Across Work Packages

The responses from work package leaders further highlighted the importance of collaboration across work packages) to align strategies and goals. We must prioritize ethical reflections and accessibility considerations in the adaptation of tools to ensure inclusivity for all users.

Conclusion

The insights gathered from the work package leads' survey have provided a further understanding of the social challenges within the e-QuoL project. The proposed actions focus on improving inclusivity, accessibility, and engagement by addressing barriers such as systemic discrimination, digital literacy gaps, and lack of representation. By implementing these solutions and fostering collaboration across work packages, the e-QuoL project can create a more equitable and supportive environment for participants from diverse backgrounds. Another conclusion from the survey is the inequity in the provision of EDI training among consortium members, with some professionals working in the field of childhood cancer having received training while others had not. These findings underscore the importance of ongoing feedback and adaptation to ensure that the project meets the evolving needs of its stakeholders.

Breakout Room Discussions

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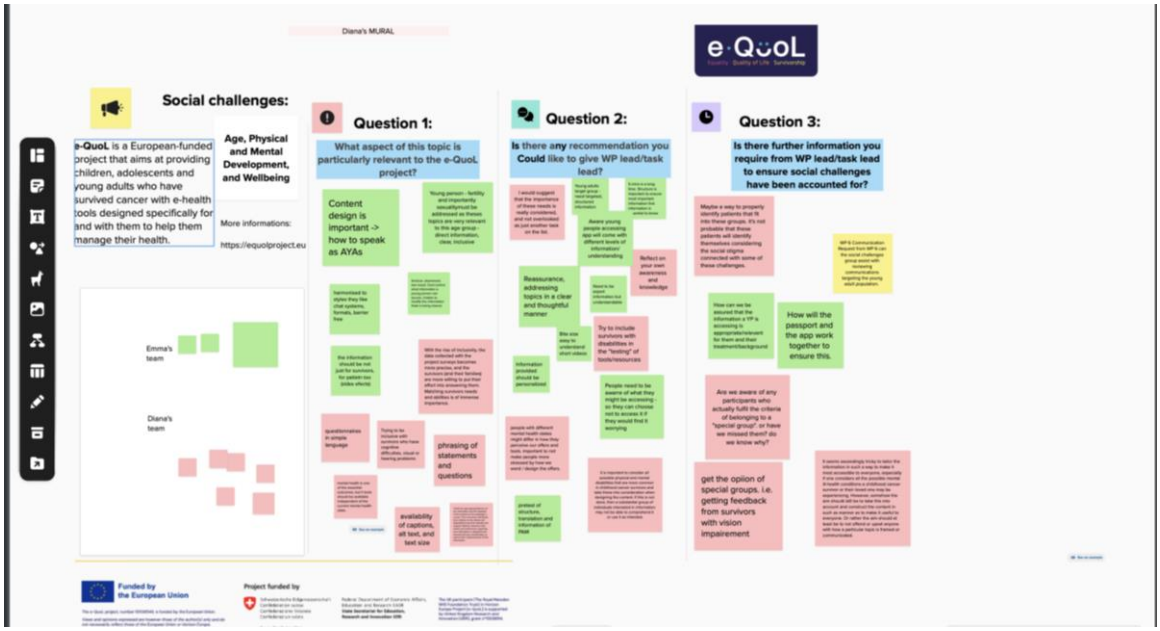
We divided the participants into breakout rooms to discuss challenges within the **Age, Physical and Mental Development, and Wellbeing category.**

Breakout Room 1: Facilitated by Emma Potter, supported by Ana Totovina.

Breakout Room 2: Facilitated by Diana Todea, supported by Hilda Hajdu.

Mural Contributions



Question 1: What aspect of this topic is particularly relevant to the e-QuoL project?

Team 1:

1. Content design is crucial when communicating with AYAs (Adolescents and Young Adults).
2. The information should not only benefit survivors, but also patients, as it impacts everyone.
3. Phrasing of statements and questions.

Team 2:

1. Young people: fertility and sexual health are addressed as very relevant; direct information needs to be clear and inclusive.
2. It conforms to styles such as cyber systems, formats, and is barrier-free.
3. Captions, alt text, and text size are all available.
4. We fully integrate tools designed with inclusivity (translations, user-friendly wording, barrier-free tools).

Question 2: Do you have any recommendations for a WP lead or task lead?

Team 1:

1. You provide reassurance by addressing topics in a clear and thoughtful manner.
2. Information provided should be personalized.
3. Phrasing of statements and questions.
4. Present examples of personalized information and patient management (PIM).

Team 2:

1. Include survivors with disabilities in the testing' of tools and resources.
2. Ensure people know what they can access so they can opt out if uncomfortable.
3. Understand survivors' perspectives on sensitive topics.
4. Broaden tools beyond basic accessibility needs.
5. Use easy-to-understand words and visuals.

Question 3: Do you need any additional information from the WP lead or task lead to confirm that social challenges have been considered?

Team 1:

1. Are we aware of any participants who meet the criteria for belonging to a "special group"? Have we missed any?
2. Gather feedback from survivors with vision impairment.

Team 2:

1. The WP 8 Communication Report can link WP 6 to these social challenges through specific testing.
2. Ensure the passport and the app work together to address challenges.
3. Identify patients fitting these groups—individuals may not self-classify due to stigma.
4. Participants who meet the inclusion criteria (survivors or others with specific challenges) are aware of this.

Key points from the group discussion:

- Accessibility barriers for users with disabilities.
- The importance of culturally inclusive outreach.
- Project tools must incorporate mental health resources.
- **Content Design and Accessibility:** Resources should address sensitive topics like fertility, mental health, and emotional well-being in a direct, clear, and inclusive manner. We must prioritize accessibility by incorporating features such as captions, alt text, translations, and formats that cater to users with disabilities or low digital literacy.

- **Inclusive participation**: Survivors from diverse backgrounds, particularly those with disabilities or from underrepresented communities, must be actively involved in testing and refining tools. Addressing intersectionality (e.g., survivors with overlapping vulnerabilities) ensures the tools cater to all needs.
- **Personalized and empowering resources**: Tools should foster empowerment by providing tailored content, relatable stories, and interactive formats like gamification or

storytelling. Survivors should feel supported and engaged through easy-to-use, barrier-free materials.

- **Feedback and adaptability**: Robust feedback mechanisms are essential for refining tools based on real user experiences. Ongoing evaluation ensures tools remain relevant, effective, and aligned with survivors' evolving needs.
- **Integration of tools**: All tools and resources (e.g., apps and passports) must work seamlessly to address challenges holistically. Clear communication about available features and how to use them is crucial for accessibility and user satisfaction.
- We also decided to include more younger cancer survivors in our next meeting.

Conclusions

The most critical aspects of the e-QuoL project revolve around creating tools that are inclusive, accessible, and user-centered. By actively involving diverse survivors, prioritizing feedback, and designing empowering resources, the project can address the physical, emotional, and social challenges faced by survivors.

Actions:

- Review group membership. Actively recruit childhood cancer survivors and family members to join the Reflexion group.
- Create a subgroup of the Reflexion group to develop Equity, Diversity, and Inclusivity Training resources
- Next meeting March 3, 2025. The meeting will address gender identity, sexual orientation, education, job, and socioeconomic situation.

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5.2 Meetings Attendance

Participants Social Challenge Reflexion Meeting	Institution Country	Meeting 1 _ 15072024	Meeting 2_04112024	
Nicha Le Dall	AP-HP	X		
Kathleen Ostheim	UNILU	X	X	
Emma Potter	RMH	X	X	
Kristen Elizabeth Thompson Thornton	UNIOSL	X	X	WP3
Diana Todea	ALP	X	X	
Anica Ilic	UNILU	X		
Lorna Zadravec Zaletel	onko-1	X		
Ana Totovina	ALP	X	X	
Jelena Roganovic	KDBZ	X		WP6
Agnes Dumas		X	X	
Valie Ganosi		X	X	
Zsuzsanna Jakab	HUPON	X	X	WP2
Marion Beauchesne	GCS HUGO	X	X	
Oana Rusu	ALP	X		
Benoit Gerfault	CHU Angers	X	X	

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Hilda Hajdu	YCE		X	
Georgia Demarteau	CUSL		X	
Gisela Michel	UNILU		X	WP2
Katharina Roser	UNILU		X	WP2
Isabelle Thierry-Chef	ISGlobal		X	WP7
Didier Bouton	AP-HP		X	
Miklos Garami	HUPON		X	WP2
Anne-Sophie Robineau			X	
Desiree Grabow	UMC-Mainz		X	WP5
Charlotte Demoor-Goldschmidt	CHU-A		X	CT - WP1
Aleksandra Klindic			X	
Anna-Elina Rahikainen	TUCH		X	
Magali GIRODET	CLB		X	
Milos Malesevic			X	
Paivi Lahteenmaki	TUCH		X	
		15	25	

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