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

D6.1 - Ethical Challenges V1

WP6 - Ehtics and Social Challenges

e·QuoL

Equality · Quality of Life · Survivorship

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AUTHORS

Dr Charlotte DEMOOR-GOLDSCHMIDT
GCS HUGO
e-QuoL Scientific Coordinator
Charlotte.DemoorGoldschmidt@chu-angers.fr

Dr Pr Jelena ROGANOVIC
KDBZ
Senior Pediatric Oncologist
Jelena.Roganovic@kdb.hr

Marion BEAUCHESNE
GCS HUGO
e-QuoL Coordinator
marion.beauchesne@chu-angers.fr

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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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1. Ethical Reflexion Meetings

Several local meetings were held, succesfully bridging language barriers and enabling the presentation of well-developed reflections during plenary sessions. Two key plenary ethical reflection meetings have been conducted as part of the e-QuoL project to address complex ethical issues relevant to the project's objectives. Detailed insights from these discussions are outlined below:

1.1 First Plenary Meeting (May 17th, 2024)

This meeting served as the foundation for tackling ethical challenges associated with the inclusion of vulnerable populations in research. Discussions focused on the following topics:

- **Safeguarding Measures**: Strategies to prevent coercion, undue inducement, or the exacerbation of vulnerabilites among participants, especially children. Emphasis was put on ensuring that all content, particularly regarding oncosexuality, complies with national legal frameworks to protect minors;
- **Stigmatisation Risks**: It was noted that survivors often emphasize their resilience rather than their vulnerabilities. The group discussed mechanisms to avoid stigmatisation in video testimonials and materials, while maintaining the survivors' autonomy and agency;
- Oncosexuality, Ethical Risks, Risk of Abuse: Oncosexuality was identified as a sensitive topic. The group discussed the need for:
    - Trained professionals to guide conversations;
    - Culturally and legally sensitive content creation;
    - Anonymous participation options to reduce psychological distress;
    - Regarding abuse and research, a specific pathway is being developed and implemented at each centre.

1.2 Second Plenary Meeting (October 31st, 2024)

1.2.1 KEY TOPICS DISCUSSED

Several local meetings were held, succesfully bridging language barriers and enabling the presentation of well-developed reflections during plenary sessions. Two key plenary ethical reflection meetings have been conducted as part of the e-QuoL project to address complex ethical issues relevant to the project's objectives. Detailed insights from these discussions are outlined below:

1.2.1.1 CONCEPT OF AKRASIA

- **Definition and Challenges**: Akrasia, described as a lack of willpower, occurs when individual fail to act in accordance with their better judgement. It is a complex concept, oftenconfused with issues such as addiction or psychiatric problems. In such cases, akrasia is not the right concept;
- **Example of Manifestations**: Akrasia can manifest in various unhealthy lifestyle choices, such as not exercising regularly, maintaining poor diet, lack of sport activities or missing hospital appointments;
- **Philosophical and Medical Perspectives**: The discussion highlighted the philosophical nature of akrasia;
- **Role of Family and Autonomy**: The impact of family dynamics and the autonomy of adolescents, especially those who are survivors, were discussed in relation to akrasia, in particular how the limits imposed by parents can influence teenagers' behaviour;
- **Other**: Topics like the pleasure of the forbidden, "urgency to live" and the sensation of "all-powerful syndrome" were aslo discussed.

1.2.1.2 ETHICAL CONSIDERATIONS IN PATIENT CARE

- **Autonomy VS Benefit**: The balance between respecting patient autonomy and ensuring their well-being was debated, particularly in the context of young adults transitionning to adult care;
- **Shared Decision-Making**: Emphasis was placed on the importance of shared decision-making and patient empowerment, ensuring that patients are well-informed to make decisions about their health;

- **Education and Empowerment**: The need to educate and empower patients from the onset of diagnosis was discussed, with the idea of creating guidelines for age-specific education. The importance of involving parents and survivors in the decision-making process was emphasised.

1.2.1.3 LONG-TERM FOLLOW-UP (LTFU) AND SURVIVORSHIP CARE: RECOMMENDATIONS AND IMPLEMENTATION CHALLENGES

- **Equity and Access**: Concerns were raised about the equity of long-term follow-up care across different regions and socio-economic groups. We discussed if there was a need to adapt guidelines or to and then adapt at the implementation to local resources without compromising patient care. Even without any intentional adaptation, differences in the implementation of guidelines are noted, even among experts, highlighting the need for consistent education and training for healthcare professionals;
- **Psychological Support**: The importance of psychological support in survivorship care was hilighted, observing the lack of resources in some centers. This was also discussed in relation to guidelines. There is no way to predict the needs of psychological support when regarding the summary of treatments;
- **Radiotherapy and Innovative Treatments**: LTFU recommendations were derived from old cohorts. Challenges in adapting recommendations for patients treated with newer protocols were discussed.

1.2.1.4 ETHICAL ISSUES IN RESEARCH: WHAT TO DO IN CASE OF ABUSE AMONG MINORS DISCOVERED?

Handling Sensitive Information: The discussion on ethical issues in research regarding the discovery of abuse among minors highlighted several points:

- **Anonymity and Reporting**: There was concern about maintaining anonymity in research while addressing potential abuse. If a study reveals signs of abuse, It raises the question of whether researchers can or should break anonymity to report it;
- **Providing Support**: It was suggested that research should include a mechanism to offer support to participants. This could involve providing contact information for support services at the end of a questionnaire, allowing participants to seek help if needed.

Participant Autonomy: There was recognition that minors might indicate a need for help in a survey but may not take the initiative to contact support services on their own. Therefore, offering a way for participants to request follow-up contact could be beneficial. One practical solution discussed was to include a checkbox at the end of a survey for participants to indicate if they want to be contacted for further discussion, ensuring their anonymity is maintained while providing a pathway for support.

For example, the suggestion made was to offer participants the option to check a box at the end of a questionnaire, indicating if they would like to discuss their responses with someone. This could be followed by a separate link or form where they can provide their contact information, ensuring their anonymity is maintained in the research data. This approach allows researchers to reach out to participants who express a need for further discussion or support.

This should be shared with Résilience, Epiconcept and Cineca, responsible for the development of the digital passports and electronic-Personalised Supportive Care Tool (e-PSCT).

Deontological and Professional Responsibility: Researchers have a responsibility to link participants to appropriate healthcare professionals if issues are identified, even if these issues are not directly related to the research.

Overall, the conversation emphasized the importance of balancing ethical obligations to protect participants with the need to maintain research integrity and participant confidentiality.

1.2.2 RESEARCH ARTICLE ON AKRASIA

An article titled "Addressing Akrasia in Childhood, Adolescent and Young Adult Cancer Survivors: Implications for Long-Term Follow-Up and Preventive Health Intervention" has been finalized and is currently under formatting for submission. This work synthesizes key findings and recommendations from the reflexion groups.

The article explores the concept of akrasia, definied as intentional action against better judgement, and its implications for survivors of childhood and adolescent cancer. Survivors face psychological, social and emotional challenges, such as fear of recurrence and post-traumatic stress, which influence their health behaviours. The article emphasizes the need for tailored interventions, including:

- **Shared decision-making** to align care plans with survivor values;
- **Nudge-based strategies** to promote adherence to LTFU care;
- Addressing **psychological and logistical barriers**, such as "scanxiety" and access disparities, to improve adherence.

The article also discusses ethical concerns, including balancing autonomy with beneficience, and highlights the importance of multidisciplinary collaboration in creating effective survivorship care plans.

Authors List: Charlotte Demoor-Goldschmidt (GCS HUGO Hôpitaux Universitaires Grand Ouest, France), Kristopher Lamore (University of Lille, France), Zsuzsanna Jakab (Hungarian Pediatric Oncology Network, Hungary), Maëlle de Ville de Goyet (Cliniques Universitaires Saint-Luc, Belgium), Louis S. Constine (University of Rochester Wilmot Cancer Institute, USA), Desiree Grabow (University of Mainz, Germany), Louis Hinckel (University Hospital of Angers, France), Eric Thebault (Oscar Lambret Centre, France), Isabelle Thierry-Chef (Barcelona Institute for Global Health, Spain), Lorna Zadravec Zaletel (Ljubljana Institute of Oncology, Slovenia), Roderick Skinner (Great North Children's Hospital, United Kingdom), Jelena Roganovic (Children's Hospital Zagreb, Croatia), Marie-Celine Esnault (University Hospital of Angers, France), Aurore Armand (University Hospital of Angers, France).

1.2.3 FRENCH-SPEAKING MEETINGS

Three meetings have been held and while the two first were dedicated mainly to akrasia, the third went further.

The French-Speaking Ethical Reflexion Group delved deeply into ethical and psychological challenges faced by survivors, particularly related to akrasia and equitable access to care.

1. Concept of Akrasia;
2. Transition to Adult Care:
    - Highlighted significant challenges for young survivors transitioning from pediatric to adult healthcare systems;
    - Barriers included lack of preparation for independent decision-making and psychological discomfort in navigating new healthcare environments.
3. Equity in Access to Care:
    - Addressed regional and socio-economic disparities in access to long-term follow-up and specialised care;
    - Proposed actionable steps include:
        - Funding regional programs to reduce healthcare inequities;
        - Standardizing guidelines while allowing local adaptation based on available resources.

4. Psychological Burden of Surveillance:
    - Disucssed the concept of "scanxiety" (anxiety linked to routine follow-ups) and its impact on survivors' adherence to medical recommendations;
    - Solutions included providing psychosocial support, simplifying follow-up processes, and adopting telemedicine to reduce logistical stress.
5. Ethical Use of Digital Tools:
    - Evaluated the role of digital reminders and educational applications. Participants stressed the importance of ensuring that these tool enhance autonomy rather than impose paternalistic constraints.

2 Conclusion

These activities reflect a robust commitment to addressing complexe ethical challenges and enhancing survivorship care. By fostering multidisciplinary collaboration and integrating survivor voices, the e-QuoL project is well positioned to deliver innovative, ethically responsible interventions.

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