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Care Leaver Statistics (CLS): Ethical challenges, rights-based perspectives and data protection in longitudinal research with marginalized and vulnerable groups

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ABSTRACT

Care Leaver Statistics (CLS study) is the first Germany-wide panel study across all providers to focus on the transitions undergone by youth and emerging adults leaving out-of-home care. It examines their perspectives for societal participation during their life course transitions. At the beginning of the longitudinal study, the participants are 16 up to and including 19-years-old. The survey reaches around 1.500 care leavers, accompany them in seven survey waves and collect data on multidimensional perspectives for societal participation. In addition to sociodemographic data, data will be recorded on relevant dimensions such as institutional constellations prior to leaving care, opportunities for complaints and participation, sense of coherence, social networks, housing, health, school qualifications and education, employment, financial situation and leisure time.

Research involving young people with experiences of out-of-home care (e.g. foster or residential care), such as the CLS study, requires careful conceptual preparation and a comprehensive ethical framework. Diversity-sensitive implications should be systematically considered and reflected upon throughout the research process. Creating a diversity concept adapted to the study is an option for a guiding framework, illustrating possibilities and limitations of applying ethical principles in quantitative research with marginalized and vulnerable groups e.g. care-experienced youth. Implementing elements of participatory research that support community building and can be a resource for empowerment are other options that should be considered on ethical grounds.

1. Introduction

Research ethics is about social responsibility, methodological awareness and should go beyond legal regulations. Every ethical framework should focus on raising awareness of ethical principles in research (Miethe, 2023; 2013; Miethe and Gahlleitner, 2010). This means that thinking about the ethical dimension of research work should be an integral element of training researchers, students and professionals (Rakebrand, 2019; von Unger, 2016). It is not enough to address ethical challenges once, during an introductory event or the ethics committee review as part of the scientific work. Some areas of research, including medical research, intersect very directly with ethical issues, while in other areas awareness of ethical challenges only emerge during the research process (RatSWD, 2023; RatSWD, 2017; Lenk, 2014; Mitscherlich & Mielke, 1949). It is only possible to raise awareness to a limited extent about research ethics, privacy issues and data protection by reading the fundamental literature, developing conceptual considerations and following the legal requirements (Fuchs et al. 2010; DFG, 2025; ESRC, 2005). Corresponding events, in which professional and research ethic issues, data protection topics, rights-based perspectives, and relevant prevention and intervention measures taking into account current evidence-based knowledge are discussed or used for training researchers, must be included. This has not always been the case, especially in social research, except where individual researchers have consciously made it their focus (Rakebrand, 2020, 2019). The necessities always have to be re-evaluated and negotiated during research processes with a view to the respective research content, research subjects, research methods and research questions (Schaar, 2022; Wagner, 2017; von Unger & Narimani, 2012). In such cases, where data is made available for future research, for example in Scientific or especially in Public Use Files, ethical considerations remain crucial for guiding the responsible use and reporting of the data.

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In addition the ethics committee review is an important act before the research project starts. Every research ethic framework should focus on protecting the rights of the research subjects and encompass data gathering, data processing and data access. In this paper, we present the current panel study in the field of care-leaving in Germany (CLS), focusing on the challenging topic of research ethics, right-based perspectives and data protection during the whole research process with a group of care leavers. Lowe & Griffiths (2025) argue for a clear distinction between PTSD, compassion fatigue, moral injury, and burnout, as each requires specific interventions in professional fields. While their analysis is grounded in high-stress work environments, its relevance extends to research settings involving marginalized and vulnerable populations. Our article builds on this perspective by exploring moral injury within research processes that pose ethical and socio-emotional challenges not only for participants but also for researchers. We aim to raise awareness of these often-overlooked dynamics and advocate for more reflective and responsible research practices.

2. Discussing vulnerability and marginalization in the context of care-leaving

According to Judith Butler, all people are vulnerable and are affected from surrounding people and things. To be vulnerable does not only mean to be affected by negative things, but also form positive things e.g. love. Basically, everything and everybody around a person is influencing this person and having an impact on their individual. Thus, environments (social, structural, historical …) have a great influence on the development of individuals. According to Butler, vulnerability is not limited to a certain phase of life, but all people are vulnerable throughout their lives – furthermore from an epigenetic point of view, especially with regard to transgenerational transmission. However, if people belong to a certain group or have had certain experiences, they may be more or less vulnerable. The existential experiential background of belonging to societal groups, which unfolds in an intersectional manner, influences vulnerabilities across the life course. Although vulnerability is often attributed to groups of people, it is experienced individually and has an individual impact (Pistrol, 2016).

In every research process there is a need to address vulnerability as a part of ethical challenges that leads to special focus on data protection. When research is conducted with target groups that are more likely to be marginalized such as children, youth, emerging adults, adults and elderly people in emergency situations (e.g. subject to violence, sexualized violence, racism, and discrimination) or in dependent relationships and circumstances (e.g. people with different kinds of disabilities and marginalized groups who cannot exercise their right to freedom of expression) it is particularly important for researchers to take vulnerability and marginalization into account. During research processes, reflection on this topic is necessary in certain research fields (e.g. medicine, sociology, linguistics, theology, sports science, or nursing science). Every research process needs to address the issue of whether there are inclusive or exclusive and violent research practices that need to be addressed. In particular social science research encounters aspects of vulnerability and marginalization in terms of deviation from the norm, for example research on (1) gender differences, (2) colonialism, (3) stigmatization or (4) the representation of people of color in society and in cultural fields (Sting et al., 2025; Kelly et al., 2025; Federici, 2021; 2018).

Care leavers are not inherently more fragile or vulnerable than other members of society; however, the structural conditions under which they must navigate their life course, as well as their education, career, and entrepreneurial pathways often render them more vulnerable and more exposed to systemic risks, structural injustices, discursive discrimination and institutional betrayal (Muir et al. 2019; Oterholm, 2018; Köngeter et al., 2012; Stein & Munro, 2008). In care-leaving research, ethical questions are never abstract or secondary; rather, they are inherently tied to the investigation of institutional violence, power asymmetries, and dependency relations highlighting how young people experience systemic, discursive and structural institutional betrayal and societal exclusion (Brännström et al., 2017; Dinisman et al., 2013; Courtney et al., 2011). This makes care-leaving research not only an ethical undertaking, but also an implicit contribution to organizational development and policymaking.

Furthermore, young people transitioning from care are particularly vulnerable in research contexts due to their histories of instability, collective and individual trauma, and marginalization (Groinig, 2025; Boullier & Blair, 2018; Ferguson and Wolkow, 2012). They often experience limited control over their life courses while in care, frequent placement changes, and disrupted relationships, which can lead to mistrust toward institutions, including researchers (Abeling, 2023; Farragher et al., 2023). Many care leavers feel dehumanized, being reduced to case files or statistics rather than being recognized as individuals (Abeling, 2023; Purtell, 2023). This contributes to feelings of invisibility and disempowerment, which are exacerbated when research practices overlook the importance of trauma-informed and participatory approaches (Purtell, 2023; Reason & Bradbury 2008). Without intersectional diversity-sensitive (e.g. gender-reflexive), trauma-informed, dignity-based and empowering research methods, care leavers may decline participation, resulting in underrepresentation of those most affected and limiting the reliability and relevance of research findings for this population (Gonzalez Alvarez et al., 2022; Lopez Lopez et al., 2022; Hagleitner et al., 2022). This might have critical implications for policy and practice aimed at supporting care leavers (Keller et al., 2023; Purtell, 2023). Empowering and inclusive research practices that prioritize care and collaboration are essential for adequately represent this marginalized and vulnerable group and producing meaningful knowledge (Farragher et al., 2023; Cataldo et al., 2020).

While vulnerability is deeply shaped by individual life course experiences and biographies, it is also exacerbated by institutional and systemic processes – such as marginalization, stigmatizing discourses, normative expectations surrounding 'independence,' and insufficient aftercare support during life course transitions (Cameron et al. 2018; Walther, 2015; Stauber & Walther, 2013). Studies have shown that care leavers face various intersecting forms of discrimination, cultural misrecognition, lack of resources, and political underrepresentation – all of which mutually reinforce their marginalization (Kelly et al., 2025). Despite a growing body of literature, care-leaving research has historically suffered from a “poverty of theory” (Stein, 2006; updated Van Breda & Reuben 2025), which has hindered efforts to capture the relational and structural dimensions of vulnerability in sufficient depth. The concept of institutionalized vulnerability highlights how young people are often further burdened by systems that individualize responsibility and reproduce dependency-related victim-blaming, rather than addressing systemic dysfunctions (Disney & Walker 2023). Similarly, qualitative studies show that care leavers frequently encounter economic exclusion, cultural invisibility, and social stigmatization – all of which profoundly shape their transition to adulthood and mental well-being (Frimpong-Manso et al 2025). Given the complex and intersectional nature of vulnerability, research involving such groups must be ethically designed that vulnerability is not reinforced by research practices. This includes being trauma-informed and rights-based, and – where appropriate – adopting participatory approaches. While not all research can or must directly address structural vulnerabilities, it should at minimum avoid reinforcing them. When done responsibly, research can contribute to increasing the visibility of participants lived experiences and potentially stimulate structural or political change (Chikwava et al., 2025). In doing so, research can play an active role in making oppressive structural norms visible, exposing systemic inequalities, and fostering spaces of recognition, agency, and co-creation for care-experienced young people. At the same time, it must be acknowledged that individual and biographical vulnerabilities – often rooted in deeply personal, family-systemic, transgenerational, and painful experiences –

cannot be ’healed’ or resolved through research. Creating space for voice and recognition is important, but personal meaning-making, healing, coping, and transformation remain deeply individual processes, shaped by each person’s own pace, context, choices, and structural access to societal participation. Therefore, it is essential that research contexts provide access to appropriate referral guidance – not only regarding transitions, counselling and infrastructural support, but also including trauma-informed therapeutic services.

3. Addressing institutional betrayal and institutionalized vulnerability through participatory approaches

One way to factor in institutional betrayal (Gardner, 2022) and institutionalized vulnerability respecting ethical principles is to incorporate participatory elements into the whole research process. The participation of subjects and their representatives is one way to challenge and validate the researchers’ point of view and to confront directly the scientific field with the subjects’ collective and individual perspectives. Therefor the focus of participatory elements needs to include different perspectives of different people who are affected by vulnerability in different ways. It depends on the research topic what kind of participatory element would fit the best.

By involving participants throughout a study – such as in the design, data collection, and interpretation phases – the research not only fosters a sense of ownership and empowerment among participants but also gains richer and more nuanced data. In direct contact, like in interview situations, researchers need to be particularly sensitive with vulnerable and marginalized groups, as there is always a risk of possible re-traumatization, exertion of power, embarrassment and cause uncertainty. For research projects involving work with vulnerable and marginalized groups, it is important to be in contact with advisory institutions that the researchers and participants can consult if necessary. It is also important to consider how the researchers or institutions deal with research subjects who seek contact after a project and want to share their personal stories or perspectives. It is not ethical for researchers or institutions to reject these people because the project funding has expired. In this point institutions and funding givers need to reconsider their practices, being innovative and develop new ways to prevent such a situation. This collaborative approach helps to mitigate power imbalances that frequently exist between researchers and marginalized communities, thereby enhancing ethical standards and building trust. Moreover, embedding participation elements in the research process supports the development of interventions and policies that are directly informed by those affected, increasing their applicability and sustainability over time. Ultimately, this method enables the study to produce more valid, actionable findings that contribute to the long-term well-being and resilience of vulnerable populations, while simultaneously advancing methodological innovation by bridging quantitative rigor with participatory engagement (Reason & Bradbury 2008).

Building on the incorporation of participatory elements, it is essential to critically reflect on the quality and depth of participation itself. Laura Lundy (2007) highlights in her conceptualization of Article 12 of the UN Convention on the Rights of the Child that ‘voice’ alone is insufficient; effective participation requires not only that children and young people express their views but also that these views are actively listened to by a legitimate audience and given due weight in decision-making processes. This model – consisting of Voice, Audience, and Influence – provides a crucial framework for research involving vulnerable youth, emphasizing that meaningful participation goes beyond tokenism and must translate into tangible impacts on the research and related policies. Similarly, Diaz (2020) calls for a systemic shift in social work and related fields – and therefore also social work science – to ensure children and families are engaged more meaningfully in decisions affecting them, arguing that current practices often fall short in implementing genuine participation. Furthermore, Jackson et al. (2022) critically examine collective participation in the foster care system, revealing that while such engagement can offer personal benefits that mitigate some hardships of care, it frequently fails to yield substantial influence on policy or lived experience due to systemic limitations and resource constraints. These reflections underline the ethical imperative and methodological challenge to design participatory research elements that not only empowers participants but also challenges institutional structures of vulnerability and betrayal by promoting sustained dialogue and influence. Integrating these perspectives and discussions into studies and research practices enhances both the ethical robustness and practical relevance of research with care-experienced youth and emerging adults, fostering interventions and policies grounded in the genuine priorities and voices of those affected.

4. Ethical rules, guidelines and laws in Germany and Europe

The discussion on research ethics procedures and legal standards regarding data protection has become more important in the social and educational sciences in German-speaking countries in recent decades. In Germany, ethical requirements for research vary strongly across research fields. Requirements are strict and legally binding in medical or biomedical research (e.g. AMG, 2022; EU 536/2014, 2014; MPDG, 2021) and more loose in the social sciences. In the latter context, ethical questions are instead addressed within the framework of self-regulation by professional associations of sociologists or psychologists (Kiegelmann, 2020). More general standards are set out in the guidelines on good scientific practice established by the German Research Foundation since 1997 (DFG, 2025). These guidelines encompass all fields of scientific research and focus strongly on questions of ethical behavior among researchers. The DFG recommended that universities and other research institutions establish their own guidelines based on the DFG guidelines. In 1998, it was decided that research institutions receiving funding from the DFG had to establish rules securing good scientific practice (Oellers & Wegner 2009). While ethic committees at the research institutions advise professional associations on ethical questions, it is in no way involved with approving research projects from an ethical point of view (RatSWD, 2017; Wagner, 2017; Oellers & Wegner, 2009).

A particularly important law for compliance with ethical standards is that on federal data protection, which is based on the European General Data Protection Regulation (GDPR). This law addresses issues of consent, data gathering, storage and processing for all kinds of research. It sets out some general standards for data-related issues in scientific research, such as the duty to anonymize information. The GDPR does not apply to data that has been anonymized. In the course of effective anonymization, all personal references must be permanently removed. The requirements are stricter when particularly sensitive data is processed. The processing of personal data can be justified by the consent of the data subject (Art. 6, Para.1a GDPR) or a legitimate interest of the researchers (Art. 6, Para.1a GDPR). “*The guarantee of freedom inherent in the concept of academic freedom is affected by a restriction on the free use of data by researchers whenever researchers are unable to collect the data required for their research in full or are restricted in the collection process*” *(*Becker 2022, p. 110*)*. There is a tension between these two fundamental rights. In the most favorable case, a balance can be found between data protection and freedom of research so that both fundamental rights can be exercised (Metschke & Wellbrok 2002, p. 9ff). Ensuring data protection is a key ethical responsibility in research, especially to avoid increasing the vulnerability of participants. It should be seen not just as a legal requirement, but as an ethical safeguard in its own right.

During the planning and development of research projects, the first question to be asked is about scientific quality and the researchers’ integrity, which is usually assessed primarily based on their academic qualifications. However, scientists at universities and non-university research institutions are embedded in structural balances of power and interdependence that are subject to economic and political conditions. Basically, the question arises as to who is interested in research (e.

g. qualification work, contract research, evaluation research, third-party funded projects, public funding lines) and what consequences the research can have for the subjects or participants. In contrast to the strict data protection laws there is nothing strict that focuses on ethical approval in the social and educational sciences. It is important to ensure that data protection rights and the privacy of all parties are adequately considered. However, data protection is assessed through a legal review or a statement from the data protection officer not through an ethics vote. This distinction is crucial, as data protection serves legal compliance, whereas ethics committees address broader ethical concerns such as participant vulnerability. Nonetheless, obtaining ethics approval is often a prerequisite for both funding and the implementation of research projects. The extent to which existing research funding frameworks are adequate to foster ethical practices – without the implementation of legal requirements – needs to be examined and debated considering the practical experiences of specific research projects.

5. Conceptual considerations on ethics, right-based perspectives and data protection in the context of Care Leaver Statistics (CLS)

Care Leaver Statistics (CLS) is the first cross-organizational Germany-wide panel study on the transitions undergone by young people leaving out-of-home care (e.g. foster care and residential care). It examines societal participation[1] across the life courses of in the beginning 16-year-old up to and including 19-year-old adolescents and emerging adults. Until now there is an underrepresentation of care leavers in general surveys in Germany and therefore a lack of empirical data about transition (Erzberger et al., 2019). So, the CLS study aims to establish, for the first time, a cross-organizational Germany-wide data infrastructure on leaving care. For this purpose, the research network of the CLS study developed a multidimensional survey instrument that will be adapted in the study progresses. The standardized survey is carried out by infas, the Institute for Applied Social Sciences, in a personal environment chosen by the adolescents. In the first wave of the survey, all the young people were interviewed in person (CAPI) or by telephone (CATI). Additional web-based interviews (CAWI) are used in further survey waves. The survey is carried out annually, with the first wave in 2023. In the end of 2025, there will be a publication about basic findings across all societal participation dimensions.

The survey instrument captures multidimensional data on opportunities for and barriers to societal participation, studying the young people's subjective and objective situations during life course transitions, institutional affiliations and individual aspirations (Ehlke et al., 2022; Bartelheimer, 2020; 2004; Fend et al. 2009). These have been operationalized as the pre-care-leaving constellation, co-determination, rights, complaints, agency, living place, qualifications, work, finances, social ties, health, social demographics, leisure and satisfaction with life. During the development of the survey questionnaire participatory elements were used. For example, focus groups were organized to check whether all relevant topics for care leavers were covered in the questionnaire. The participants also provided useful tips on formulating questions and possible answers. The comprehensibility and length of the questionnaire were tested in pretests.

Ongoing communication with study participants during and between the times of data collection is maintained via the basic panel maintenance model and supplemented by an optional supporting program, which is grounded in participatory methods. In addition to established panel maintenance practices (such as incentives, regular contact, accessible information and public relations), the voluntary offers seek to foster peer communities-building and support connection to care-leaving networks. One such offer, the #CLS_networkspace, is a regular (in the beginning weekly, later monthly) digital meeting format for exchange, learning and networking, launched in August 2022. In this way, the CLS team not only considers the usual measures of panel care but also fulfills the ethical requirements that research with a vulnerable group entail.

The design of the panel study, the additional offers, staff training, and preparatory phases all required intensive engagement with both research and professional ethics. From the start, the CLS team undertook a reflexive process to address diversity, social exclusion, barriers to societal participation, and questions of ethical responsibility. This resulted in the development of a diversity concept, a code of conduct, and the incorporation of participatory elements. Together, these form the ethical framework for the CLS study and are continuously reflected upon and adapted throughout the research process.

5.1. Reflexive elements of the diversity concept and the code of conduct

From the outset, the CLS research association engaged in a reflexive debate (von Unger 2021; 2016) on how to address diversity, social exclusion, barriers to research participation, and research ethics in a quantitative longitudinal study. This ongoing reflection is grounded in a diversity concept, a code of conduct, and participatory elements, which together form the ethical framework guiding the study throughout its duration.

To support transparency and critical reflection, a dedicated working group was established early in the research process to document the state of affairs, resulting in a publicly accessible text on the CLS study website (current version: autumn 2022).[2] This document outlines key topics and serves as a basis for continued ethical discourse.

The CLS diversity concept encompasses four fundamental elements: (1) recognition and openness towards diversity and difference, (2) awareness of discrimination with a commitment to inclusion, (3) reflection on power relations, oppression, and inequality, and (4) transparency regarding boundaries and decisions.

These principles are operationalized and elaborated in the code of conduct, which addresses specific areas including: (1) reflective use of language, (2) development of research instruments, (3) participant involvement, (4) sensitivity to experiences of violence, (5) interviewer training, and (6) secondary data analysis.

The CLS team continuously applies, reflects on, and develops these ethical elements throughout the research process, adapting them as necessary to meet the demands of specific contexts and stages of the project.

This section therefore focuses on two core dimensions of this framework: (1) the reflexive elements and the deliberate handling of diversity and vulnerability and derived from this (2) the integration of participatory approaches into the research process. This structure reflects the study's progression and highlights ethical reflection as an ongoing practice, from the initial study design to participant interaction.

In this context, research ethics, right-based perspectives and data protection challenges can be considered across three levels: (1) at the planning and initiation of the study, (2) during the research process, and (3) in the dissemination of findings, secondary analyses. These three levels will be discussed in the following sections.

5.2. Research ethics, right-based perspectives and data protection when planning and beginning a research project

During the planning of the CLS study, a data protection manual was

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[1] In German-speaking contexts, we use the term 'Partizipation' to discuss participatory approaches in research, practice development, and organizational development. The term "societal participation" is a distinct concept that corresponds to the German word 'Teilhabe' and thus relates specifically to the research field, theory development, and the central focus of the CLS study. When we write about 'societal participation', the term 'social engagement' may help distinguish this from other uses of 'participation'.

[2] https://cls-studie.de/ueber-die-studie/publikationen-1.

drawn up based on the General Data Protection Regulation (GDPR). The manual comprehensively shows and documents the processing of study participants' personal contact details and address data. The data protection manual for the CLS study begins by documenting and discussing the fundamental approaches and content of the data protection declaration and informed consent to the CLS study, including information, data subjects' rights, options to refuse or withdraw from participation, and the deletion of personal data. A legal opinion by the German Institute for Youth Welfare and Family Law (DIJuF e.V.) assessed whether the study participants, all aged 16 or over, had given their informed consent in terms of their ability to understand the risks and consequences of participating in the CLS study.

The CLS study is carried out by infas. Therefore, cross-site activities involving the processing of personal data, and the institutions' technical and organizational measures, are checked and documented. The risk forecast and the data protection impact assessment are also documented in the data protection manual. The data protection officers of the associated institutions and the BMBFSFJ (Federal Ministry of Education, Family Affairs, Senior Citizens, Women and Youth) assessed the questionnaire, the data protection manual and the resulting information material for potential participants in the CLS study (including information material, an information brochure and an informational website[3]), and whether participants had given their informed consent (Schaar, 2017). In addition, ethical approval was obtained from the Ethics Committee of Department of Education and Social Sciences at the University of Hildesheim (von Unger & Simon, 2016). All assessments – from the DIJuF e.V., the BMBFSFJ, the Ethic Committee – were positive evaluated.

The CLS study collects two forms of particularly sensitive data: (1) health data, gender and sexual identity and (2) some third-party data. Against this background, a comprehensive discussion had to be held as to how this data would be collected, processed and anonymized (Rösch, 2021; Kämper, 2016). The example of health shows the complexity of balancing the interests of knowledge and data protection – especially for vulnerable groups. The CLS questionnaire e.g. does not include questions about what disorders the participants had been diagnosed with or what medications they were taking, as other youth studies do. However, the questionnaire used in the study focuses on more general things that might affect their participation over their life course (e.g. if they have a disease and whether it affects their everyday life). The priority of the CLS study is to investigate how care leavers cope with transitions across their life course. Therefore, it is more important how they cope with diseases in everyday life than what exact disease they have.

5.3. *Research ethics, right-based perspectives and data protection during the research process*

The survey is conducted by interviewers from infas. This interviewers are prepared for the interview situations within a training course. In interview situations, interviewers need to be particularly sensitive to vulnerable and marginalized groups, as there is always a risk of possible re-traumatization. Therefore, after each survey, each interviewer gives a postcard to participants with a link that leads to addresses where they can get assistance or advice if they wish. In addition, study participants receive information about whom to contact if they have any complaints regarding the interview or study procedures, either via established channels or through a dedicated email address. This clarifies the support available a) if the participants did not feel comfortable in the interview situation or in the context of the study, so that the CLS team can adapt things for future waves and b) if the questionnaire triggered something, so that participants get direct access to assistance in different areas.

5.3.1. *Participatory elements during the research process: Additional offers in context of panel maintenance*

To support meaningful involvement of the research subjects in the research process a comprehensive concept was developed as an additional part of panel maintenance. This concept includes both digital and in-person participatory elements that actively involve CLS study participants. The most regular format is the digital platform #CLS_networkspace, which serves as a confidential environment for information exchange, peer interaction, educational processes, and networking. It is designed to create added value for all participants besides the aim of a longitudinal study to avoid panel dropout. The space facilitates dialogue between researchers and participants and is methodologically designed as a low-threshold space for peer-to-peer counselling, information exchange, networking, and referral to support services. For researchers, it offers opportunities to reflect on and validate their assumptions, perspectives, and roles within the research process, which helps to regularly reflect on research practices and its ethical grading. For the CLS participants, #CLS_networkspace provides:

(1) updates on the CLS study's implementation and progress,
(2) access to mechanisms for raising concerns or complaints about the CLS study,
(3) a wide range of open discussion topics,
(4) the chance to talk to participants, experts and peers about different topics around the care leaving process,
(5) cultural and social engagement opportunities, including informal and peer-led learning formats, and opportunities to connect with peers experiencing similar life transitions,
(6) a shared space for solidarity, support, and resilience-building.

These community spaces are strictly private and protected. Social media platforms such as Facebook or Instagram are intentionally not involved to avoid unwanted public exposure and to minimize risks related to data privacy and the loss of control over personal information. During the digital meetings, communication rules are regularly discussed with the participants to ensure a respectful and safe exchange. Participation takes place using first names only, and activating video is optional. These precautions are taken to ensure a safe environment and to protect participants' privacy and autonomy, addressing the vulnerabilities that arise in public or semi-public digital spaces (Rosenthal, 1995).

At the same time, it must be acknowledged that involvement in participatory formats can lead to implicit disclosure of care experience. All additional offers within panel maintenance are therefore strictly voluntary and take place in protected, low-threshold spaces, allowing participants to decide freely how and to what extent they wish to engage. Therefore, additional instruments were designed to offer support within certain limits and to provide referral counselling, if needed. A variety of support services available to study participants are listed and accessible via the study's webpage.

Given the intimate nature of the protected settings in which participatory elements occur (von Unger & Narimani, 2012), ethical, right-based and data protection considerations must be continuously revisited. Research practice should therefore include professional self-care strategies and reflexive self-awareness – such as individual and team supervision, peer consultation, and ongoing professional development.

Moreover, the research team is continuously discussing the extent to which the additional offers – particularly regarding their advisory function – are ethically and methodologically justifiable and at the same time consider it our ethical responsibility to provide supportive formats. To control potential effects, specific measures were included in the questionnaire, as they may intervene in the everyday lives of the target group.

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[3] https://www.cls-studie.de.

5.4. Research ethics, right-based perspectives and data protection relating to the results

From an ethical point of view, it is essential to consider how people would like to be addressed, especially in data analyses and when presenting results. Elements of participatory research should therefore be inserted. In evaluation workshops before publishing the findings, it is necessary to align the interpretations of researchers and participants or research subjects. There should be a discussion about what the results mean and how to position them in the subjective and objective context. In this way, the researchers' and participants' perspectives can be irritated, which can provide an important impetus for reflecting on ethical challenges in research processes. Research findings must be framed in a way that avoids reinforcing stigma or discrimination against the target group.

CLS data will be provided for the scientific community in a Scientific Use File. For researchers who are going to do secondary analysis, it is customary and necessary to sign a data use agreement under the data protection law. However, this usually does not contain any binding regulations on the ethical principles according to which the data are to be handled. Therefore, new ethical challenges arise. Against this background, the research ethics principle is about ensuring that social groups and individuals are not harmed by research processes, findings and public science activities. This includes an appropriate strategy for publication and the use of data in science, journalism and media. It is even more complex if more groups of people have an interest in the data, e.g. policymakers, stakeholders and funding institutions. This is why the type of communication and it's process used are essential during public science activities. Communication should not be exaggerated in terms of interpretations or recommendations. Simplification leads to distortion and undermines the credibility of science. Therefore, the complexity and intersectionality of the results should be reflected and taken into consideration. The results need to be placed within established empirical theories and the state of the art, whether or not they confirm them. Aspects that are not apparent from the data, and any limitations of the methods, should be stated openly, not concealed. In this way, scientific discourse is advanced, new insights can be gained and trust in science does not suffer (Wagner 2019).

6. Conclusion

The reflections on research ethics, rights-based perspectives and data protection presented in this paper highlight that ethical considerations and data protection law must be treated as an integral part of every phase of the research process and must not be dealt with only formally. Research in the field of care leaving inherently involves addressing institutional power asymmetries, dependency relations, and experiences of structural violence. As such, care-leaving research always implicitly engages organizational development and policymaking.

In this light, research that meets ethical standards cannot be reduced to the act of obtaining formal ethics approval – even though such approval is increasingly required by funding institutions (e.g. DFG, FWF, BMBF, BMBFSFJ) and academic journals and is widely regarded as a marker of research quality. Rather, ongoing engagement with ethical tensions within research teams is essential, particularly in relation to issues of participation of subjects in the research process, data access for the scientific community, informed consent of the participants, and the handling of sensitive data. The discussion in this paper of avoiding certain questions in surveys should therefore not be read as a normative demand, but as an indication of the need to weigh the fundamental right to academic freedom against the ethical responsibility to protect when conducting research with marginalized and vulnerable populations.

The CLS research association addresses these challenges by working with a diversity concept, a code of conduct, and an expanded model of involving participants in the research process. Participatory elements – both digital and analogue – not only support sustained engagement in the panel but also create space for the continuous reflection of ethical questions and data protection concerns throughout the research process.

Overall, the CLS study demonstrates that in the context of care-leaving research, ethics, right-based perspectives and data protection must not only be legally regulated, but actively shaped and continually negotiated in practice – with the aim of enabling socially embedded, reflective, and ethically responsible research. This is important not only for the research participants but also for the researchers themselves—especially when they have to cope with challenges such as PTSD, compassion fatigue, moral injury, and burnout in the course of their work.

CRediT authorship contribution statement

Maria Groinig: Conceptualization, Methodology, Writing – original draft, Writing – review & editing. **Martina Pokoj:** Conceptualization, Methodology, Writing – original draft, Writing – review & editing.

Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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Data availability

No data was used for the research described in the article.

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