

Standards for Healthcare Ethics Consultation

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Healthcare Ethics Consultation is an established approach to improving the quality of care for people receiving treatment, care, and support in various healthcare facilities and services. It sees itself as support service for all those involved in healthcare in ethically difficult or challenging situations. Healthcare Ethics Consultation deals primarily with issues relating to the care of individuals. This can be supplemented by an organizational ethics consulting approach that addresses organizational influences on and responsibilities for compliance with ethical standards of care. Ethics structures such as ethics committees, case consultations, ethics forums or ethics consultants are being implemented in more and more healthcare facilities and services. Ethics Consultation is also increasingly seen as an important quality criterion for the certification of healthcare facilities and services.

Against this background, the "Healthcare Ethics Consultation" working group at the Academy of Ethics in Medicine (AEM)¹ has revised the following standards for Healthcare Ethics Consultation. They are intended as an inventory of existing forms and structures and describe the minimum requirements and quality criteria for Healthcare Ethics Consultation. They thus provide orientation for existing and newly emerging counseling services.

The first version of the standards was adopted by the AEM Board of Directors on February 24, 2010 and an updated version was adopted on December 21, 2022.

1 Goals and Domains

The fundamental concern of Healthcare Ethics Consultation is to support all those involved in healthcare (e.g., the staff and management of the facility, the people receiving care there and their relatives and representatives) in dealing with ethical issues and challenges in an appropriate and balanced manner and to contribute to transparent and ethically justified action.

Concrete objectives of Healthcare Ethics Consultation are:

- raising awareness of ethical issues,

¹ The Academy of Ethics in Medicine is the German-speaking professional association for medical ethics.

- promoting competence in dealing with ethical issues, uncertainties, and conflicts,
- the management and resolution of ethically challenging situations,
- the consideration of generally recognized ethical standards and criteria, and
- improving the quality of care.

These objectives are implemented within the following domains:

- providing individual ethical case discussions (ethics case-consultation),
- developing internal guidelines and recommendations (ethics policies)
- organizing internal and public events on healthcare ethics topics (ethics training)
- systematically promoting ethical competency on site and ethical reflection in the regular processes of everyday professional and healthcare practice (ethics transfer), and
- advising the management on organizational ethics issues (organizational ethics).

2 Ethics consultation in clinical and extra-clinical settings

Healthcare Ethics Consultation can be divided into two areas: clinical and extra-clinical ethics consultation.

Clinical ethics consultation encompasses a group of consulting services in inpatient care in hospitals and rehabilitation clinics. This can be organized in different ways, e.g., by bodies such as clinical ethics committees, by ethics working groups, or by ethics consultants who are independent of committees. Clinical ethics committees are usually multi-professional bodies made up of qualified employees of the site/the institution as well as external experts (e.g., from fields of ethics, jurisprudence, pastoral care, or patient representation). They have a statute or rules of procedure, and their members are appointed by the management of the site or organization for a specific period of time. The activities of ethics working groups and independent ethics consultants are often less formally organized.

Extra-clinical ethics consultation is situated outside the clinical sector, including in the general practitioners' sector, in (semi-)inpatient care facilities and outpatient services, in hospices, and in integration assistance. Exemplary structures include extra-clinical ethics committees or networks for extra-clinical ethics consultations. Similar to clinical ethics committees, these are multi-professional in composition. They can be internal to an organization (e.g., within a nursing home) or external to an organization (e.g., as an independent association). As facilities and services in the extra-clinical sector are often too small for an own independent advisory body, there are also – more frequently than in the clinical sector – cross-facility advisory bodies (e.g., at a regional or a system level). In addition, some medical associations offer an ethics consultation service for doctors in private practice.

Extra-clinical ethics consultation differs from clinical ethics consultation in terms of logistical and organizational conditions as well as content-related or legal requirements. The organizational forms of extra-clinical ethics consultation can be very heterogeneous, which results from the required or desired different areas of activity or responsibility. Extra-clinical ethics consultation situated outside an organization, e.g., an association serving an entire district, must inevitably be organized differently than, for example, an internal ethics consultation service for a nursing home. External ethics consultation is often not an integral part of an existing system. This results in further logistical, administrative, and social challenges. For example, not all of the people to be involved are regularly available in one

place, the distances to be covered can be considerable, open forms of consultation (e.g., telephone or video consultation) are often required, and access may be restricted to individual professional or care teams. The ethics consultants are then often external to the system, which requires additional clarification of legitimacy, of the binding nature of the counseling result, of confidentiality, and of data protection.

In terms of issues, extra-clinical consultation often has a different thematic focus, in which issues of privacy and care processes play a role, e.g., in long-term care with permanently restricted capacity to consent, issues of nutrition and fluid administration.

3 Organization, structure and implementation of ethics consultation

a) Relationship to management and institution

Ethics consultation aims to create a culture of transparent, participatory, and professional engagement with ethical issues. In this sense, in addition to providing support in specific ethical conflicts, ethics consultation also strives for continuous reflection and further development of the organizational framework for ethical decision-making and action. This can only succeed if ethics consultation is wanted by the management of an institution and its employees. Clarifying the mandate and roles therefore plays an important role in the context of ethics consultation.

For internal services in the clinical and extra-clinical setting, a central prerequisite for successful ethics consultation is dual support from both the management and the employees (top-down and bottom-up principle). The statute or rules of procedure of an ethics consultation service should reflect this (e.g., with regard to the nomination and appointment of consultants). In this context, working-hours regulations, resources, and budget should be clarified. Internal guidelines developed by the ethics consultation service must be confirmed and implemented by the management in order to come into force. The organization's management and employees are regularly informed about the activities of the clinical ethics consultation.

External ethics consultation services (e.g., by associations) are also dependent on a good information strategy for their desired area of activity, for example through newspapers, lectures, or information material, depend on the support and recognition from the persons/institutions to be advised, and must clarify their relationship with management and employees in advance of an ethics consultation. In particular, it must be taken into account that this form of ethics consultation is external to the system and may also be perceived as such. This must be considered in the consultation processes. The clarification of the assignment also includes the question of estimated costs (e.g., travel costs, expense allowances). In the case of external advisory structures, the administrative and logistical procedures must be determined in principle at best, and sometimes on a case-by-case basis.

Ethics consultation is not bound by hierarchical instructions when it comes to its issues and the its approach within the scope of their mandate. Clinical and extra-clinical ethics consultation services internal to an organization are part of the care offered by the respective institution and therefore act in an organizational context. They take the organization's structure into account and help to shape it through their specific services. Even external consultation services are not completely independent of

the organization's structure, must take this into account, and, if necessary, obtain information in advance or involve people who are familiar with the respective structural characteristics. Ethics consultation works towards integrating ethics into the processes and decision-making structures in the institution and therefore requires a close coordination process with the organization served. At the same time, it remains a critical counterpart to the organization (due to its mandate and rules of procedure). It is a particular challenge for ethics consultation to strike an appropriate balance between institutional integration and autonomy.

b) Clarifying mission and roles

A prerequisite for successful ethics consultation is that it is commissioned by the management of an institution or service on the one hand and by those who seek ethics consultation on the other. Due clarification of the mandate is a multi-layered process that generally involves extensive conversations. Clarifying the mission includes, among other things, an agreement on the issue to be dealt with, on the persons to be involved in the consultation or to be informed about it, and on the time frame, as well as a role reflection with regard to the task at hand, one's own competencies, and the limits of meaningful options for action. This applies in particular to the clarification of the mandate for organizational ethics issues. If there is any ambiguity in the process of clarifying the mandate, an ethics consultation should be postponed, as acting on an (unclarified or partially clarified) mandate can, in a worst case scenario, substantially impair the ethics work as a whole.

c) Structural, financial and personnel requirements

Statutes or rules of procedure are required for all forms of ethics consultation bodies. These regulate, among other things, the name of the body, its independence in terms of issues and judgment, the objectives and tasks, its composition, the mode of appointment, the chair, the working methods, issues of data protection and confidentiality, as well as reporting and documentation obligations.

However, there are differences in terms of composition: ethics committees are generally multi-professional and consist of around 5 to 20 members, depending on the size of the institution or service. The specific composition depends on the respective organizational framework and the associated tasks and can vary significantly depending on the context. If integrated into an institution, the members should come from different areas and hierarchical levels. Members with medical, nursing and ethics training are required. Membership by people with a legal, pastoral/religious, psychosocial, and administrative professional background is also desirable. A patient or resident perspective is also desirable, which can be taken on by patient or nursing home advocates, members of self-help groups, hospital support, or committed citizens, among others.

In the case of an internal ethics consultation service (e.g., a clinical ethics committee), members are appointed by the management of the institution for a specific period (e.g., 3 years). As continuity, trust, and practical experience are important for the success of ethics consultation, it should be possible to reappoint them. The activities of the ethics consultation should be recognized as working time for the members, provided they are employees of the institution. Care must be taken to ensure that staffing in the members' genuine area of work makes this possible. Appropriate financial resources must be made available for training and further education, public relations work, internal and public events,

business trips, etc., in accordance with the size and work mandate of the institution. External ethics consultation, on the other hand, is formed by an association of qualified persons, for example, in the form of a not-for-profit association. As these are not tied to an organization or institution, other ways of funding must be found, e.g. by a foundation, by fees for ethics case consultations, by membership fees and donations to (not-for-profit) associations, or by funding from professional organizations.

Structures such as an office for management or coordination should be created in all organizational forms of clinical and extra-clinical ethics consultation. This requires appropriate human resources, e.g., in the form of a managing director or coordinator. The office for management or coordination supports the executive board of an ethics committee particularly in following tasks :

- Coordinating and preparing ethics case consultations
- Organizing events and developing guidelines
- Managing budgets, public relations, preparation of an annual report, evaluation
- Coordinating committees and working groups

Furthermore, the office for management and coordination ensures that the ethics consultation service can be reached.

d) Qualifications

The members of an ethics consultation service should have communication and discursive skills, time availability as well as appropriate further training, and a willingness to undergo continuous training. The qualification should be in accordance with the AEM curriculum² : Persons involved in ethics case consultations should at least be qualified in accordance with the competencies listed in the curriculum under K1. Persons who take on coordinating tasks should at least be qualified in accordance with the competencies listed in the curriculum under K2.³ The responsible body or the healthcare organization's management must ensure that further and advanced training opportunities for internal members can be realized as part of their work duties. The qualification requirements apply analogously to ethics consultants external to the organization.

Ethics consultants and ethics coordinators (K1/K2) should be able to recognize and name the fundamental significance of organizational influences on an individual ethical problem (e.g., if a patient remains in an inpatient context longer than indicated due to a lack of adequate follow-up care or is discharged to their home without ensuring care) in order to support good solutions at the individual level. For the design of complex organizational ethical reflection processes, an extended competence profile is required, which includes methods of organizational consulting and development. Ethics consultants take into account the limits of their own competencies and, if necessary, refer to specialized organizational ethics consulting services.

² Curriculum Ethikberatung im Gesundheitswesen (2022) https://www.aem-online.de/fileadmin/user_upload/Ethikberatung/Curriculum_Ethikberatung_im_Gesundheitswesen_2019-06-24_geaendert_am_21.12.22_.pdf

³ The AEM curriculum distinguishes three levels of competence: level 1 represents the basic qualification that every ethics consultant should fulfil; level 2 is for people who head an ethics committee or are responsible for ethics consultation in an institution, and level 3 is for people who train others in ethics consultation. Based on these three levels of competence, the AEM has been offering voluntary certification ethics consultation since 2014.

e) Data protection and duty of confidentiality

Ethics consultation must comply with data protection and the requirements of medical confidentiality. This can be done in different ways:

In the area of clinical ethics consultation, there should be a documented decision on the part of the organization's management that ethics consultation is part of patient care. In order to make this decision transparent to patients, reference should be made to the possibility of ethics consultation in the admission contract in the general terms and conditions as well as in corresponding information materials (e.g., flyers, website). Each member of the consultation service should sign a specific confidentiality agreement upon appointment. A reference to confidentiality in the statute or rules of procedure is not sufficient. Being part of patient care also implies documentation and storing obligations, as they apply to other areas of patient care. It also requires that the members are appointed by the organization's management.⁴

In the case of extra-clinical ethics consultation, data protection and the requirements of confidentiality can be met in an analogous manner if it takes place within the organization that has taken over the medical care of the patients. In case of ethics consultations outside the organization, the persons concerned should be asked before each consultation for their written consent to processing their data (e.g., in the results protocol) and waiving of confidentiality, unless the ethics consultation is anonymous.

The obligation to maintain confidentiality also applies to information that ethics consultants learn about the institution or its employees in the course of clinical or extra-clinical ethics consultation.

4 Implementing and organizing the mission

The five domains are interrelated and complement each other. Ideally, ethics consultation covers all five domains equally. This increases the effectiveness of ethics consultation, whose primary aim is to improve the quality of care with regard to ethical aspects.

a) Providing individual ethical case discussions (ethics case-consultation):

Ethics case consultations offer support in ethically unclear decision-making or treatment situations. They can be requested by anyone involved or affected (e.g., employees of the facility, people receiving care in the facility, their relatives and representatives, general practitioners). In principle, a distinction must be made between individual consultations (e.g., in cases of individual conflicts of conscience) and joint ethical case discussions (e.g., in cases of ethical uncertainties and conflicts). In the case of ethical case discussions, it must be clarified who is to take part in the discussion and who is to be informed about it. In the interests of multi-perspectivity, the participation of all persons (groups) involved or affected should be sought, whereby the specific composition always depends on the question to be answered. If possible, the person whose care is at issue should be included. In addition, it should be stipulated in which cases this person's consent to the ethical case consultation is to be obtained.

⁴ Duttge G, Lipp V, Nauck F, Simon A (2021) Empfehlungen zur Schweigepflicht und zum Datenschutz in der klinischen Ethikberatung. MedR 4: 345

The ethics case consultation takes place in a protected, non-disruptive environment. The legal provisions on data protection and confidentiality must be observed.

The consultations are moderated by qualified ethics consultants; it makes sense to use a pre-established structure (guideline) for the discussion. As ethics case consultation is a process, follow-up consultations are possible. When designing the process, time for the implementation as well as for the preparation and follow-up of the ethics case consultation must be taken into account.

Ethics case consultation combines moderation and consultation skills with ethical expertise. The task of the ethics consultants is, on the one hand, to make all the details necessary for the assessment of the case visible and to give all those present space to participate, and on the other hand to work out the ethical questions and assess the options for further action according to ethical criteria. The theoretical aspects and the actual circumstances must be weighed up in a manner so that those responsible can determine the next steps and translate them into action. A consensus should be sought; this is achieved when all those involved in the ethical case consultation can support the proposed solution and take joint responsibility for it.

The result of an ethics case consultation is documented.

b) Developing guidelines and recommendations (ethics policies)

Ethics guidelines are recommendations for action that are derived from recurring situations (e.g., dealing with advance directives, placing a PEG tube, resuscitation, changing goals of care) and serve as a guide for individual decisions. They are developed thematically according to existing needs.⁵

Ethics guidelines are developed up by members of the ethics committee on a specific issue with the involvement of experts from within or outside the institution. They must comply with legal regulations and scientific standards and must therefore be updated regularly.

Ethics guidelines, which are understood as normative guidelines (policy), must be approved by the management of the institution or the responsible body.

c) Organizing of events on healthcare ethics topics (ethics training)

Ethics training courses serve to raise awareness of ethical issues, transfer ethical knowledge, and strengthen competencies in dealing with ethical problems and challenges. Target groups include the employees of an organization, the people receiving care in the facility and their relatives, as well as interested members of the public. Ethics training courses can also be offered and carried out cross-sector wise. The spectrum of ethics training courses can range from topic-related team meetings to public events (e.g., ethics day, patient forum).

d) Promoting a professional approach to ethical challenges in the standard processes of everyday care (ethics transfer)

⁵ Empfehlungen zur Erstellung von Ethik-Leitlinien in Einrichtungen des Gesundheitswesens. Ethik Med 27 (2015):241-248

Ethics transfer refers to concepts, methods, and processes that aim to integrate ethics consultation services into an institution as a whole. This should have a positive influence on how ethical challenges are dealt with in day-to-day care. To this end, it is important that the services of clinical and extra-clinical ethics consultation reaches employees. This can be implemented using different strategies that vary in scope and complexity depending on the qualifications of the ethics consultants and the resources available for ethics work. A comparatively feasible example is providing a regular presence on site, in which individual ethics committee members act as permanent contact persons (liaisons) for individual wards and areas. More complex implementation concepts are the facility-wide implementation of local ethics officers or ethics working groups or the regular monitoring of parameters for successful ethics work (e.g., standards for documenting patient wishes) as part of quality management. The area of ethics transfer is thus an expression of the cross-cutting nature of ethics in healthcare facilities, as is also the case for the topics of quality and safety.

e) Advising the management on organizational ethics issues (organizational ethics)

In addition to recognizing and naming organizational influences on an individual ethical problem (e.g., in ethics case consultation) and striving for ethics transfer, advising the management on organizational ethics issues (e.g., in the context of allocation or prioritization decisions) can also be a task of ethics consultation. Organizational ethics deals with the influence of organizational structures, processes, and dynamics (mid level) on the ability of individuals to make decisions and act according to their own responsibility (micro level). Ethics consultation focusing on individual cases (individual ethics) and organizational ethical reflection in healthcare facilities (organizational ethics) are complementary fields of activity. There is a close connection between the two, as organizational influences also have an impact on the consideration of the individual case. Ethics consultants should be aware of these connections and take them into account wherever possible. However, this can only be done to the extent that the responsible ethics consultants have the necessary competencies.

5 Documentation and evaluation

The various activities of ethics consultation are documented in an appropriate manner and continuously evaluated for the purpose of quality assurance⁶. Clinical and extra-clinical ethics consultation bodies prepare regular (e.g., annual) activity reports, which are made available to management, staff and, where appropriate, the public in a way that promotes professional exchange about the activities (e.g., via the committee's webpage).

Results of an ethics case-consultation that have a concrete impact on the further treatment or care of the person concerned must be documented in writing in the medical records. A copy of the documentation is kept by the ethics consultation body in accordance with data protection regulations for the assurance of those involved in the discussion and for evaluation purposes.

⁶ Empfehlungen zur Evaluation von Ethikberatung in Einrichtungen des Gesundheitswesens. Ethik Med 25 (2013): 149-156

The documentation of an ethics case consultation should largely be limited to a report on the results, with a focus on the ethical justification for the chosen course of action or procedure in relation to the underlying issue.⁷

In order to ensure the quality of ethics consultations, it is advisable to discuss the results of an ethics case consultation, e.g., at the next meeting of the ethics committee.

6 Appendix: Definition of key terms used in ethics consultation

Healthcare Ethics Consultation: Institutionalized consultation service for ethical questions, problems and conflicts that arise in the care of people in healthcare organizations and services.

Healthcare ethics consultant: A person qualified in ethics consultation who provides ethics consultation in healthcare organizations and services. This person can be a member of an ethics committee or a comparable advisory body or she may offer her service independent of such a body.

Clinical ethics consultation: ethics consultation in inpatient care in hospitals and rehabilitation clinics.

Extra-clinical ethics consultation: Ethics consultation outside of clinical settings, including general practitioners, (semi-)inpatient care facilities, and outpatient services, hospices, and integration assistance.

Internal ethics consultation: Ethics consultation provided by a structure linked to the institution (e.g., an ethics committee appointed by the institution's management or an ethicist employed by the institution).

Ethics consultation from outside the organization: Ethics consultation from a structure not tied to the institution (e.g., an association for extra-clinical ethics consulting).

Ethics committee: Multi-professional body for ethics consultation, usually made up of qualified employees of the organization/the provider and external experts (e.g., from the fields of ethics, jurisprudence, pastoral care, or patient representation).

Ethics case-consultation: a domain of ethics consultation. Structured deliberation on a specific treatment or care situation. This can take the form of individual consultations (e.g., in cases of individual conflicts of conscience) or joint ethical case discussions (e.g., in cases of ethical uncertainties and conflicts between the various parties involved).

- *Prospective ethical case-consultation:* consultation on a current treatment or care situation. The outcome of the consultation usually has an impact on the future care of the person concerned.
- *Retrospective ethics case-consultation:* consultation on a past treatment or care situation that is perceived as ethically difficult or problematic by those involved, or where no consultation could take place due to a decision under time pressure. The result of the consultation serves to improve understanding of the situation and to clarify matters between those involved. It often has no effect on the future care of the person concerned, but does have an impact on similar situations in the future.

⁷ Empfehlungen für die Dokumentation von Ethik-Fallberatungen. Ethik Med 23 (2011):155–159

- *Preventive ethics case-consultation*: Outreach form of consultation in which ethics consultants regularly participate or are integrated into ward rounds, handovers, ward meetings, etc., in order to clarify ethical questions that arise spontaneously or to point out normatively relevant questions and aspects and to think ahead in the case of questions that can be anticipated.

Ethics guideline: a domain of ethics consultation. Written recommendations for action as an orientation and decision-making aid for recurring ethical issues in healthcare facilities and services.

Ethics training: a domain of ethics consultation. Information and training courses on ethical topics, e.g., for employees of the organization, patients and residents, as well as interested members of the public.

Ethics transfer: Ethics transfer combines the services of clinical and extra-clinical ethics consultation with the structures of the institution and services in order to ensure that ethical challenges are dealt with professionally within routine processes.

Organizational ethics: deals with the influence of organizational structures, processes, and dynamics (mid level) on the ability of individuals to make decisions and act according to their own responsibility (micro level).

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Compliance with ethical guidelines

Conflicts of interest: Gerald Neitzke and Annette Riedel are members of the Executive Committee of the AEM and of the Advisory Board of the journal Ethics in Medicine. Alfred Simon is a director of the AEM and a member of the editorial board of the journal Ethics in Medicine.

Ethical standards: The authors did not conduct any studies on humans or animals for this article. With regard to the studies cited, the ethical guidelines mentioned there are applied.