DATAETHICS

CHANGING LANDSCAPES IN THE HEALTH AND LIFE SCIENCES : ETHICAL CHALLENGES OF BIG DATA

DATAETHICS Intellectual Output 4

DATAETHICS Handbook

Co-funded by the Erasmus+ Programme of the European Union

INTELLECTUAL OUTPUT 4

e-HANDBOOK

Georg Wietzorrek and Sandra Santos Sierra[1],
Sieglinde Weyringer[2], Jean-Luc Patry[2], Xavier Gasull[3],
Arko Gorter[4], Zoe Säflund[5], Agnieszka Buelens[6],
Christoph Schwarzer[1], Gabriele Werner-Felmayer[1,]

with DATAETHICS Consortium

[1]Innsbruck Medical University, Austria; [2]Paris Lodron University Salzburg, Austria, [3]University of Barcelona, Spain; [4]Leiden University Medical Centre, the Netherlands; [5]Karolinska Institutet, Stockholm, Sweden; [6]Georg-August-University Göttingen, Germany;

- With DATAETHICS Consortium

The IO4 output is a comprehensive handbook on the adaptation and implementation of the VaKE teaching/learning method in the DATAETHICS Summer and Winter Schools. The handbook summarizes the theory underlying VaKE, the description of the DATAETHICS VaKE principles applied in the praxis together with examples and possible challenges (troubleshooting) experienced by the participants, trainers and students during the DATAETHICS project.

The objective underlying the e-Handbook production was to provide a guide for teachers and students enabling them with a tool that facilitates the design and implementation of different teaching/learning practices and methods in various settings. Hence, we believe that the organization of other teaching/learning events with different backgrounds (from artificial intelligence to genetics or healthcare) may profit from the experiences acquired during the application of VaKE in the DATAETHICS Schools and compiled in this handbook.

EUROLIFE DATAETHICS

https://www.dataethics-eurolife.eu/

Index

Introduction

We are currently living in an era of data science that integrates and interprets large data sets, so-called Big Data. To explore potential benefits for humans in modern medicine and health care, researchers need to share and use data as is envisioned by the Open Science concept. To govern such data sharing, appropriate ethical and legal frameworks are needed to protect human rights, e.g. privacy, equality and fair healthcare. Therefore, higher education institutions (HEI) need to develop education opportunities for researchers and physicians on ethical aspects of this field, as they are important actors in the further development of research-based medicine and health care for the benefit of all members of a democratic society.

The pace of data collection and data generation in biomedical sciences (e.g., the advent of genomics technologies, high throughput imaging, and patient cohort collections) as well as tools such as systems supported by artificial intelligence (AI) for making sense of these data, is extremely fast. It has far exceeded the pace in educating students and researchers on these topics, particularly their ethical, social and legal issues (ELSI).

In the Eurolife DATAETHICS project carried out between September 2020 and August 2023, we addressed the substantial need for updated study material and novel educational approaches. We have developed new practical tools and content that combine the latest expertise in data-driven medicine and biomedical research with its ethical dimensions and implications. In order to give students/learners/professors/teachers/trainers who focus on biomedical and health services research a simple yet reflective approach to dealing with ethical perspectives of emerging technologies, we used **Va**lues *and* **K**nowledge **E**ducation (**V*a*KE**, see chapter 1). This method allows an open way to explore ethical dimensions and reflect moral concepts to educate students and researchers from various biomedical fields and cultural backgrounds as represented by the nine Eurolife partner institutions and their culturally diverse students and faculty. A practice-oriented approach and real-life examples are the essential elements of V*a*KE, which gives learners the opportunity to work with case studies in a nuanced way.

As research becomes increasingly globalized and online and hybrid meetings gain prominence, DATAETHICS reconsidered the original concept of V*a*KE, which was primarily designed for in-person training. The Covid pandemic and the geographical distribution of the DATAETHICS consortium across Europe necessitated the adaptiation of V*a*KE from its exclusive reliance on in-person formats to a hybrid style. The purpose of this handbook is to provide comprehensive support to all consortiums aiming to implement such a structure in their training programs.

This handbook summarizes our experience in using V*a*KE principles, which we gathered throughout five DATAETHICS Winter/Summer Schools. Settings in which we have gained this experience include distance learning using blended learning approaches and digital tools for academic collaboration and knowledge enhancement, as well as classroom training. The handbook provides best practice recommendations of how to adapt V*a*KE. It addresses all trainers (academic and industry) who are involved in educating students – or, more generally, learners – from diverse research, cultural and educational backgrounds. The handbook is intended for all who are seeking a simple, versatile and yet structured and powerful way of ethics education, here applied to the numerous ethical implications of data-intensive medicine and healthcare. In this setting, supervisors become disseminators of ethics education by encouraging students' input in a learning-friendly environment, hence supporting autonomous learning. The handbook aims to also support teachers in their professional development by enabling them to develop their instructional design and encouraging them to teach in a flexible way. This enables students to acquire knowledge in the context of a particular dilemma (a situation in which the protagonist has to decide on the outcome, and whatever he or she decides, an ethical imperative is broken).

The handbook first introduces the V*a*KE method in chapter 1. Chapter 2 deals with the creation of a case study, the construction of a dilemma and how teachers and students can work with this case scenario. Chapter 3 deals with the requirements for online as well as face-to-face teaching with V*a*KE. We also present guidance for monitoring progress and quality control (chapter 4) and provide information on how to organize hybrid events (chapter 5). Chapter 6 finally is dedicated to troubleshooting.

We have strived to present an informative guide to the implementation of V*a*KE through the intentionally concise and pragmatic structure of the DATAETHICS handbook. We hope that this resource equips you with the necessary knowledge to effectively incorporate this method into your teaching practice, fostering enriching and inspiring learning environments for both you and your students.

Foreword -Why V*a*KE

Any action has an ethical component, since it has an influence, which – in principle – requires ethical justification. Actions of medical professionals are particularly concerned with ethical considerations, as they deal with human health and sometimes with life and death. It is imperative, thus, that medical and life science education addresses issues of ethics.

On one hand, it is essential that medical professionals base their decisions on the best available scientific results; these results are descriptive, i.e., they say what *is* or can be the case and what consequences a certain action in a given situation may have – but they do not say what *ought* to be done, and why. On the other hand, in situations of conflicting values (which happen very often), the medical professionals need to set priorities based on ethical considerations. The two components are related: The ethical decisions will be based on both the descriptive theories that the professional knows (knowledge) and on the normative, ethically justified priorities (values), both addressing the same situation.

In professional education, typically, the two components are taught separately: descriptive and technological knowledge ("what to do and how to do" it) in theory and methods teaching units and values competence ("why to do it") in ethical units. V*a*KE is a teaching/learning method that permits to combine both components, knowledge and values, on a constructivist basis. This approach has been shown to be successful. While we do not pretend that it is the only approach that satisfies the requirements to combine knowledge and values, we observed during our Summer and Winter Schools, that it is an appropriate concept for reference, and therefore we recommend using V*a*KE in the education of biomedical professionals.

Ethical issues arise in all domains of medical professions. In the DATAETHICS project, one domain has been chosen as a prototype to deal with the education of values and knowledge: biomedical big data. The principles demonstrated in this domain can be applied in other domains as well. Even further: Ethical issues in the biomedical big data domain are always dependent and have an impact on ethical issues in other domains. The priority on the biomedical big data domain, hence, does not mean it is more important or relevant than others, but rather it is used as an example to show the main characteristics of V*a*KE.

1. What is V*a*KE

1.1. Theoretical base

V*a*KE – **V**alues ***a****nd* **K**nowledge **E**ducation – is a didactic approach, which combines values education and knowledge acquisition in terms of skill development, to allow both aspects to come into play when making everyday decisions. Its basic standpoint is "Decisions based on values but without including knowledge are blind, decisions based on knowledge but without including values are irresponsible!" Any action entails both values and knowledge. Practical issues cannot be dealt with based on values alone, as the given circumstances need to be considered: Justified interests of different stakeholders exist and are obstacles to "pure" implementation of values. On the other hand, knowledge means empowerment, which needs control through values. Overarching values like Human Rights (United Nations, 1948, and subsequent) may be used as reference points, which include, among others, the protection of minorities (stakeholders defending different values). Not everything that *can* be done is also ethically *justified* to be done. The underlying theoretical framework is shown in Figure 1.

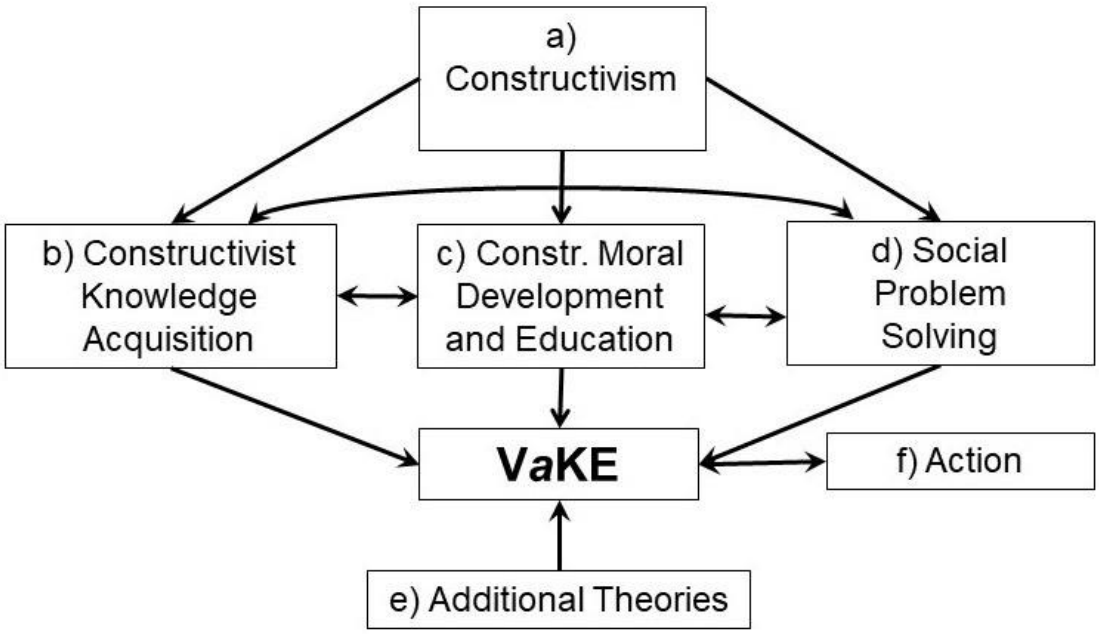


Figure 1: Theoretical framework of V*a*KE (adapted from Patry & Weyringer 2022, Figure 2.1[1])

V*a*KE follows the epistemological principles of *constructivism*, which means that human beings construct their interpretation of instead of perceiving the world "as it is". It is impossible to find out or to test whether there exists a real world, and if so, how it is. All what we, the human beings, know about the world are products of assumptions, which we have tested with respect to their reliability, validity, and viability (i.e., whether they satisfy the needs for which they have been conceived) in selected areas of environment. Established concepts of truth, objectivity and reality must be seen with these restrictions.

---

[1]Patry J.-L., Weyringer S. (2022). V*a*KE: Theory, Prototype, and Variations. In: The V*a*KE Handbook: Theory and Practice of Values *and* Knowledge Education (2022). Sieglinde Weyringer/Jean-Luc Patry/Dimitris Pnevmatikos/Frédérique Brossard Børhaug (Editors). BRILL, Leiden, The Netherlands, p. 12 – 42.

The *constructivist* answer to the question "What can I know?" is: Knowledge is not acquired passively; rather, it is constructed by the learner. This knowledge can be conceived as subjective theories; these have the same function for persons as have scientific theories for the scientific community, but they differ in several regards (explicitness, communication, testing, etc.). Learning as constructing means that information is integrated into the learner's system of subjective theories, either by assimilation (direct integration) or by accommodation (integration after the learner has adapted his or her subjective theory to comply with the new information). Constructivist learning means that the learner takes responsibility for his/her learning. It is appropriate to change the concept of truth into viability. A concept is viable if it can be used successfully to achieve the aims it is designed for. The viability of a concept is judged according to some viability criteria. There might be antinomies between viability criteria (e.g., in a dilemma). Both factual issues (knowledge; see b) as well as normative issues (values; see c) are relevant viability criteria. Checking for the viability (viability checks) are crucial when searching for a viable way to deal with a conflictual situation (e.g., a dilemma). One important means for viability checks is getting feedback from the peers (see d). Constructive teaching, then, consists in providing a situation to the learners where they can construct their subjective theory optimally, and to ensure the implementation of viability checks.

(a) Constructivist knowledge acquisition means that the learner generates the knowledge him- or herself. One possibility is inquiry-based learning: The learners ask questions they are really interested in and search themselves – possibly with support – for answers, whose viability they check with their peers and other means.

(b) Constructivist *moral development and education* do not address the values themselves, but their justification ("*Why* is it good or appropriate to do x?" – this has been conceived by Kohlberg[1], but V*a*KE goes beyond Kohlberg's theory, hence it is a post-Kohlbergian perspective. One can distinguish several modes of justification ("stages") which form a hierarchy, from a unilateral perspective ("good is what I have been told") through a group oriented one ("good is what my reference group thinks is good") to one led by principles ("good is what is in agreement with principles I embrace"). Higher stage judgments are ethically more appropriate than lower ones, because they involve more people and are more autonomous.

(c) *Social problem* solving refers to the attempt to come to a collaborative proposition how the protagonist/person should act in the given dilemma situation. This means that the participants give mutual feedback about the viability of the respective concepts (both about knowledge, see b, and about values justifications, see c). This way, they develop also a collaborative and common framework of subjective theories while still keeping individual concepts.

(d) Many additional *theories* can be used and capitalized on, such as theories of motivation, of critical thinking, etc.

In conclusion, the process has (or aims at having) an impact on actions: While the dilemma discussions address how one *should* act in a given situation, action deals with what one actually *does* in such a situation. For example, participants in a V*a*KE process may get sensitized on moral issues that then play a role in their actions, and hence they need to

consider more such issues in their decisions for action. Hence, action theories (and theories about moral actions) need to be considered.

[2]Power F. Clark, Higgins Ann and Kohlberg, Lawrence, 1989: Lawrence Kohlberg's Approach to Moral Education. New York: Columbia University Press.

1.2. Prototypical course, possibility for adaptions and variations

Table 1 shows a prototypical course how to do V*a*KE step-by-step. This is based on many years' experience with diverse groups of participants, in diverse formal, non-formal and informal educational settings aiming at diverse educational and trainings objectives, and finally with diverse cultural backgrounds (for further information and details see Weyringer, Patry, Brossard Børhaug and Pnevmatikos, 2021[3]). We recommend varying the steps and adapting the course to the needs of learners, to the obligatory requirements of a curriculum and based on the teacher's personal attitude towards learning and teaching.

Furthermore, based on experience with implementation, we recommend that prospective users of VaKE take a training course in order to experience the effect on themselves as learners. AVaKE – Association for Values and Knowledge Education (https://avake.iliauni.edu.ge/) – the representative association legally registered in Austria, offers training courses and accompanying supervision during the implementation.

[3]Weyringer, S., and Patry, J.-L. (2021). V*a*KE als Ansatz zur Förderung der Demokratiekompetenzen. Pädagogische Horizonte. Ein Journal der Privaten Pädagogischen Hochschule der Diözese Linz, Austria, 5(1), 99-113.

	Step	Action	Group
0	Preparation of the students	Introduce V*a*KE course Process, underlying theoretical issues, goals of activity, output / outcome	Plenum / All
1	Introduction of dilemma story	Understand dilemma! "What should the person do?" Fields of problems, values at stake, useful and relevant knowledge, proposals for answer	Plenum / All
2	First decision	Vote! Who is in favour? Who is against? Who does not know?	Plenum / All
3	*First dilemma discussion*	Discuss! Exchange arguments: Why am I in favour, why against? What are my values priorities for decision? What are the values priorities of the others? How acceptable are the values priorities of the others for me? Why? *(moral viability check)*	Plenum / All or in groups
4	Exchange of knowledge	Collect questions! Collect knowledge! What do I know? What do I need to know further to be able to argue? Asking for missing information	Plenum / All
5	Looking for evidence	Collaborate! Get the information, using any source available!	Groups
6	Exchange of results	Inform the other students! Result of information search; is the information sufficient? (content related viability check)	All
7	*Second decision and dilemma discussion*	Vote and discuss! What is my decision now? Why? Do we agree with each other? Why? *(moral viability check)*	Plenum / All
9	*Synthesis of discussion process and argumentation*	Collaborate! Summarize the process within the group! Present conclusions to the plenum! Product of the group (moral and content viability check)	Group and Plenum / All
9	*Repetition: 4 through 8*	… *if necessary*	
10	*General synthesis*	Collaborate! Capitalize on the whole process	Plenum / All
11	*Generalization*	Transfer! Discussion about other but related issues Actions based on the results of the discussions	Plenum / All

Table 1: Prototypical steps in V*a*KE; *in italics: values education*; underlined: knowledge education (adapted from Patry & Weyringer, 2021)[2]

The prototypical course can be varied in many ways, e.g.

- by adding steps done by the individual participant, such as a reflection on personal beliefs and convictions or anticipation of consequences;
- by adding steps for all: presenting specific relevant content, training specific competences (e.g. using technical tools and digital programs) and negotiations on discussion rules or how to organize the information search and the collaboration;
- by adding steps to address specific audiences, such as checking for understanding for foreign-language or illiterate participants;
- by adding steps for specific research purposes, etc.

In a V*a*KE course, a dilemma story is presented to the participants, which depicts a person in a dilemma situation and ends with the questions "What should the protagonist/person do? And why?" The latter question, "why?", is the crucial one as it asks for the justification of the decision, which is then submitted to the viability check.

A dilemma is characterized by the conflict between two or more values, which both / all equally are meaningful and sensemaking to the person. Therefore, whatever the protagonist decides, one value is favored to the detriment of the other. As a consequence, the conflict cannot be solved ultimately and finally – there is no "right" or "wrong ", only better or less good argued for. Only a temporary solution can be found. This impossibility of finding a final solution to a dilemma is the central distinguishing feature from a problem for which final solutions can be found.

The question "Why should the protagonist decide in favor or against a possible solution?" comes into the focus of the participants' considerations. This is the moment when the person consciously perceives his / her individual hierarchy of preferred values. This system is the hierarchical order of immaterial and material values, which affects decisions as points for orientation, and it develops effective power for motivation and action.

The vote offers three possibilities: "in favor", "against", or "don't know". By voting, a personal point of view is determined each time, which has to be justified in a values- and knowledge-based way in the subsequent discussion. Postponing the decision opens the possibility for the conscious confrontation with both the lack of reliable knowledge about facts and the knowledge about one's own criteria for evaluations. By repeating the voting (with the possibility of changing the position) and the subsequent discussion, on the one hand, the provisional nature of a position is shown; on the other hand, it is still possible to change the point of view with corresponding justification. Thirdly, the processual nature of the training as a learning and development process becomes obvious.

Getting to know the personal values preferences is combined with getting to know trustworthy information about facts for strengthening the argumentation, why the favored position is "better" than the opposing one. Any possible source can be used to establish facts and knowledge. The sources used have to be documented.

The knowledge explored (the sources together with the references) is shared with all participants in appropriate presentation formats. The aim is to establish a common knowledge base shared by all.

Voting, discussing, and searching for information can be repeated.

The course culminates in a collaborative product that both represents the working process within the group as well as meets predefined evaluation criteria for the output.

In a closing session, all participants give feedback, share their experiences during the course and reflect together on the transfer on related issues and actions in their professional daily life.

1.3. Challenges

There are several challenges for participants.

The conception of the dilemma story is the most crucial part of preparing a V*a*KE session:

- The dilemma is a conflicting situation, which cannot be solved peremptorily/definitely, and in which the protagonist usually has two options, each of which is linked with certain values – the two options are in conflict with each other
- The protagonist is the person who is in a dilemma situation and has to decide what to do
- The story is conceived in such a way that for a competent discussion some knowledge is required
- The question is: “What should the protagonist do? And why?”, asking for justification of the answer proposed by the participants
- The dilemma must address issues that are relevant to the participants
- Both options for the protagonist must be plausible for the participants; small changes in the formulation can have a great impact on the likelihood of support or opposition by the participants – the dilemma should be designed to make both support and opposition to a certain decision likely

There are substantial differences between V*a*KE and traditional teaching–learning settings. The first difference relates to the concept:

- The constructivist teaching approach means: ”open teaching – autonomous learner”
- The collaborative learning approach means: ”working in groups – sharing workload – exchanging information”
- The aspect of values means: “which values?” and “why these values and no other ones?”
- Questions by lecturers aim at stimulating further information search – not testing and assessment of existing knowledge

There are also challenges for the lecturer who:

- is responsible for the process – not for the outcome
- takes diverse roles and acts as:
  - manager and facilitator of the learning process – not the organizer – by leading the V*a*KE course; watching the process dynamics; organizing grouping; keeping the time frame; caring for access to the resources
  - moderator of the discussion – not as the chair
  - expert by request – not as the provider / presenter of knowledge without being asked
  - supporter of the participants who cannot express themselves easily

- advocatus diaboli (with open disclosure of playing this role) if appropriate
- any other role that complies with the theoretical base

There is:

- no competition, but cooperation and collaboration between participants
- The achievement is a group achievement
- The lecturer / trainer / moderator exerts only minimal control, as far as necessary

The challenges for the participants:

- The participants unexperienced with V*a*KE are often insecure and do not know what to do with the leeway they get
- The required knowledge: Participants ask content questions related with the dilemma and try to answer them by searching for evidence
- The outcomes are, among others, conceiving consequences for own actions

1.4. Frequently asked questions

- **I use already teaching-learning approaches similar to V*a*KE. Why should I learn about V*a*KE?**
  V*a*KE is a complete package that combines different concepts, in particular open teaching, inquiry-based learning, and constructivist values education. Practicing only one of these principles may be highly valuable but does not comply fully with the concept of V*a*KE. Open teaching, for instance, does not mean to let the students do whatever they want, but rather to create and implement situations in which the students are motivated to learn and given the possibility to learn in a constructivist way, as achieved by V*a*KE. And conveying values is not the same as fostering values justifications.

- **Will the participants abuse the freedom they get in this teaching-learning situation, e.g., for misbehavior and discipline problems?**
  Experience shows that they abuse the situation very rarely, since the students generally are interested in the dilemma. If such problems arise, it has usually reasons outside of the teaching-learning situation, such as issues that the participant regards as more urgent. However, sometimes, the students are not yet ready to discuss according to the discussion rules (discussing contents and not people; listening to the other person whoever he or she is; giving appropriate, not-offending feedback; not interrupting the other person; etc.). In such cases, more preparation of the students for such discussions is needed (see step 0 in the process, table 1).

- **Are less engaged students able to cope with the open teaching-learning situation?**
  We found that students who seemed less engaged during traditional teaching – and who were regarded as “low level students” – often bloomed in V*a*KE and became very active in the group. V*a*KE is appropriate for heterogeneous groups since each participant can bring in his or her competence; often, arguments of presumably lower quality are triggers for intense reflections and challenges for arguments of presumably higher quality. Finally, there are students who might need more structure due to specific individual characteristics of personality. This can be provided with adding steps of explicit viability checks.

- **In an open teaching-learning situation, the students are free to choose their goals. How can I then achieve the curricular goals?**

  There are at least three possibilities to focus the students on the curricular goals:

  (1) The formulation of the dilemma determines to a great deal the direction of the discussions;

  (2) One can focus the participants from the very beginning on the issues one wants particularly to be dealt with (e.g., by saying to rather avoid certain topics and to concentrate on others; or to make explicit which knowledge will be tested - for this the mandatory reading should be provided by the teacher);

  (3) During the discussions, one can intervene if one notices that the students address issues that deviate from the curricular goals – however, often such deviances can be very fruitful by adding interesting issues to the topic addressed.

- **Is VaKE very time-consuming?**

  (1) For the teacher, the most time-consuming part of VaKE is preparing the dilemma. Once the process is launched, the teacher needs to follow it carefully to be able to intervene, but to do this only if necessary.

  (2) Within a semester program, VaKE can take some time. It is the teacher's responsibility to decide how much time to allow for a VaKE unit and to ensure that the time frame is not transgressed. It must be emphasized that many of the tasks – such as searching for information – can be done in homework and some discussions can be done outside of class, e.g., virtually using appropriate platforms.

- **Should V*a*KE replace all traditional teaching?**

  In school and university, V*a*KE is one teaching tool among others. It can be used for some topics, and for others, one can use traditional teaching. For instance, in the course of one semester, one can use V*a*KE for a quarter of the time (depending on the time structure) and teach the rest traditionally.

- **The curricular pressure focuses on knowledge acquisition. How can I integrate values education in the schedule of lessons, which is very tight already?**

  All studies show that after a V*a*KE unit, the students know at least as much as the students of control groups getting traditional teaching. Hence, the students do not lose knowledge compared to traditional teaching, rather they gain, and the knowledge is usually on a higher level and better cross-linked with other knowledge issues.

- **If I do values education, I will get into conflict with important stakeholders of values, like political parties, the church, etc., and possibly with parents and representatives of the education system who might defend other values than those addressed in V*a*KE. How shall I deal with this?**

  V*a*KE does not focus on the values themselves (which would be indoctrination), but on their justification. We found that after discussing the justification of values often the participants

brought values discussions in their families or in classes of other teachers – we regard this as quite positive, as it extends the values discussions and benefits both the participants and their discussion partners.

- **What if the participants come to a decision that the workshop leader does not agree with on ethical grounds?**

  It is not excluded that the participants come to a decision that is inacceptable from an ethical standpoint, and that all arguments of the teacher are rejected. In this case it is recommended:

(1) to discuss the issue with a group of experts who are, preferably, independent or representatives from different orientations (e.g., if the issue is against church positions, the experts should not only be representatives of the church). In particular, the experts have to judge whether and to what degree the participants' decision as well as their own priorities comply with Human Rights, and if not, whether this can be justified. It is important, then, not only to scrutinize the participants' decision, but also, and just as carefully, the solution they prefer themselves.

(2) Our experience is that if the participants are given sufficient time to discuss the issues, they come up with a proposition that complies with the Human Rights and that considers the whole and not only specific groups (and neglects the needs and interests of other groups).

(3) If the decision is rejected on ideological grounds without accepting any justification against the teacher's position, other educational instruments than V*a*KE should be applied.

2. From a case story, through the dilemma to the virtual exercise: the process

2.1. Case story definition

As indicated in Section 1.2, dilemma construction and discussions are cornerstones of the V*a*KE method. Accordingly, during organization of the Schools and engaging of speakers, the organizers should clearly define the learning objectives for the students/attendants to the School. Once these objectives have been defined, a story including the selected topics can be proposed. This story may be based on a real and usually controversial case, or a fabricated story related to the School's topics. Participants with V*a*KE experience might conceive a V*a*KE story themselves. In any case, care has to be taken to avoid personal involvement of any participant in such a case; if necessary, changes should be made so that any personal involvement is removed.

Each story deals with questions and looking for answers and solutions. The difference between a case and a problem is briefly illustrated based on the expertise that is in the foreground for the clarification: when clarifying a case, the focus is on specific knowledge of a specialist discipline, e.g., oncology. For a problem solution, additional non-case-related factors, which should nevertheless be taken into consideration, become relevant for decisions, e.g., personal factors. In a V*a*KE dilemma, a person and his / her values priorities together with considerations on professional ethos are the main influencing factors for decisions, e.g., saving life.

Both the problem and the dilemma have a common main component: the conflict of a person who has to make a decision. The difference between them is the possibility or impossibility of a solution: for a problem a final solution, which is definitely the best, can be found and thus a corresponding decision can be evaluated as "right" or "wrong". This is not true for a dilemma: a person decides, but a perfect decision and thus a right solution is not possible – the conflict remains. But the decisions can be justified that are better or not so good from the point of view of the participants.

A V*a*KE story combines the characteristics of a case, a problem and a dilemma. In order to end the examination of the story, provisional solutions or answers are sought, since, as already mentioned, the dilemma conflict cannot be solved. Thus, the dilemma is transformed into a provisional problem, but the provisional nature of the solution is emphasized: there are several different points of view possible on what can be a viable solution, with several viable justifications for each point of view. Unanimity is not the goal of the whole process. Majority votes are inappropriate, since each participant has his or her own position, which must be respected.

2.2. Dilemma construction

Transforming a case into a V*a*KE story needs to meet some requirements and has to follow V*a*KE principles[4]:

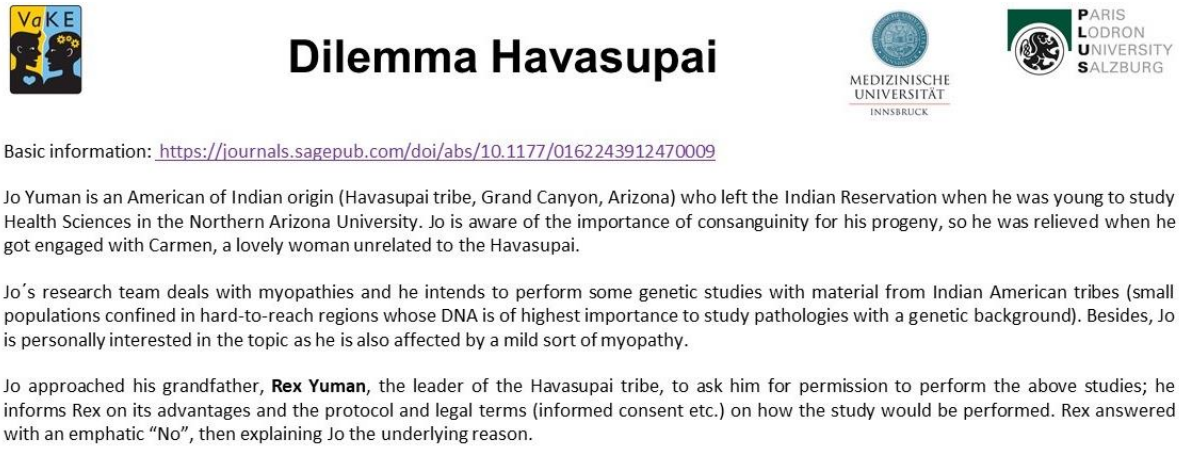
- V*a*KE stories must describe a dilemma situation. In a dilemma situation, a protagonist has to take a decision; whatever he or she may decide, he or she will break some values that are regarded as important
- The story has to address a controversial topic, real or fabricated
- It takes into account values that are involved and knowledge that will be acquired
- It has to be personalized: main character is a protagonist; other persons are involved; motivations, conditions, relationships are described
- Only a part, but not all available information is included
- It offers two or more options from which the protagonist has to choose one, and asks: "What should he/she do? Why should he/she do that?"
- The parameters of the dilemma can be slightly adjusted to make it more likely that one of the options will be chosen (if it is assumed that most participants will opt for the other option)
- The text is personalized by focusing on the personal and affective state of the protagonist and not on abstract "cases". Give names to the persons involved in the story!
- V*a*KE stories can never include all potentially relevant details; rather, they leave some characteristics for instance of the patient and his or her situation open, to be filled by the discussants of the V*a*KE process
- The story stops at a certain moment, and the discussants have to take a decision on behalf of the protagonist. In contrast to typical real cases, the continuation of the story is not known, so the consequences of the protagonist's action remain open
- Further, the text may contain technical terms that must be understood by the learner (in general they are part of the lectures) to account the problem at stake, to find a decision how to act, and to have arguments for the decision proposed to be best

The stories also show the different domains of responsibility and the transdisciplinary relationships and thus offer learning opportunities for different decision types

An example is the Dilemma Havasupai used in one of the Schools (Fig. 2).

---

[4]The V*a*KE Handbook: Theory and Practice of Values *and* Knowledge Education (2022). Sieglinde Weyringer/Jean-Luc Patry/Dimitris Pnevmatikos/Frédérique Brossard Børhaug (Editors). BRILL, Leiden, The Netherlands.



Dilemma Havasupai

Basic information: https://journals.sagepub.com/doi/abs/10.1177/0162243912470009

Jo Yuman is an American of Indian origin (Havasupai tribe, Grand Canyon, Arizona) who left the Indian Reservation when he was young to study Health Sciences in the Northern Arizona University. Jo is aware of the importance of consanguinity for his progeny, so he was relieved when he got engaged with Carmen, a lovely woman unrelated to the Havasupai.

Jo´s research team deals with myopathies and he intends to perform some genetic studies with material from Indian American tribes (small populations confined in hard-to-reach regions whose DNA is of highest importance to study pathologies with a genetic background). Besides, Jo is personally interested in the topic as he is also affected by a mild sort of myopathy.

Jo approached his grandfather, **Rex Yuman**, the leader of the Havasupai tribe, to ask him for permission to perform the above studies; he informs Rex on its advantages and the protocol and legal terms (informed consent etc.) on how the study would be performed. Rex answered with an emphatic "No", then explaining Jo the underlying reason.

The Havasupai had bad past experiences with this kind of studies. In 2003, Carletta Tilousi (Havasupai Tribe) discovered that DNA samples that she and other members had donated for a genetic research project on type 2 diabetes in 1989 were used in non-diabetes-related genetic studies by researchers at Arizona State University (ASU). The DNA samples were used for studies on schizophrenia, ethnic migration, and population inbreeding, which are highly charged topics and taboo in their culture. To obtain informed consent, ASU researchers had made oral statements recruiting the tribal members, and when participants agreed, they were asked to sign informed consent documents written in English. The Tribe filed a lawsuit against the Arizona Board of Regents in 2004.

In 2010, the case reached a settlement in the tribe's favor. They received different compensations and most significantly, the return of the tribe's DNA samples; this allowed them to properly dispose of them in a culturally appropriate ceremony (for the Havasupai any part of their bodies is sacred and DNA is part of the essence of a person).

After the clarification, Jo and Rex are taking some reflection time before speaking to the tribe members. On one hand, it is now accepted that Havasupai people, and other tribes, are affected by diseases that perhaps could be avoided if there would be more scientific information about them. On the other hand, this topic is touching the very core of their religious beliefs and traditions, and formerly it was handled in a non-sensitive way. Jo´s descendants could benefit from the acquired knowledge, but can he guarantee that the wishes of the tribe on how to proceed with the DNA samples will be respected, and if the affected people do not have really interest in participating, should Rex, their leader, try to convince them?

What should Rex do?
-Support the research studies.
-Not to support the research studies.
-Don´t know.
Why?

Figure 2: Example of a dilemma story as used in the DATAETHICS Summer School 2022.

2.3. Introducing the students to the dilemma

During the first day of the School, the students should be taught what the V*a*KE process is, what a V*a*KE (dilemma) story is, and which dilemma story they will discuss during the School. If it is the students' first experience with V*a*KE, they need to be prepared since most of them are not familiar with open teaching and the freedom it provides. They must be informed about the principles of V*a*KE (including the 11 steps indicated in Table 1) and possibly learn to deal appropriately with each other, to argue and to focus on arguments, to search for information on the internet and elsewhere, etc.

Finally, the dilemma is presented in a form adequate for the target group, and the teacher ascertains that the students know what values are at stake.

2.4. Dilemma discussions

Discussions are embedded in a structural process that is organized in steps that follow predefined rules on which the group has to come to an agreement. The following list is a proposal for the hands of the trainer:

- All discussions should be led by mutual esteem and appreciation
- The argument counts, not the person who utters it
- Any statement must include the position that is defended and its justification
- Feedback must be specific, descriptive (not evaluative) and factual or refer to a normative position. The peers must understand it. The feedback must not be personal. It must be expressed in a way that one would accept if one would receive feedback in that manner
- The trainer has to nurture small-groups discussions and discussions in the plenum
- In the Plenum, values and arguments have to be noted on a whiteboard
- In the group, the student has to add values, thinking of the different stakeholders (people who are involved in some way) and discuss and argument about them
- The student doesn´t need to come to an agreement within the group. There is no right or wrong. It may well be that new values and valid arguments arise
- When in the course of the discussions the students need more information, this has to be written down
- Every day, the V*a*KE work starts in the plenum before going into the groups (breakout rooms)
- Among others, there will be a vote at the beginning of the respective sessions. Students are free to change their minds at any time, however having in mind that they have to present their arguments for this change

Taking a first decision: students have to explain what they think the protagonist should do. The students take this first decision based on their common knowledge and common sense before acquiring additional information; it is the first opportunity for them to recognize that more facts have to be acquired to support their decisions.

First arguments (dilemma discussion): the students argue in favour or against the different proposed solutions to the conflict; this corresponds to the dilemma discussion in the Blatt and Kohlberg (1975)[5] tradition. It includes a moral viability check with respect to addressing the dilemma.

Exchange of experiences and missing information: the group experiences concerning the results of the argumentation are exchanged, although the discussion on the conflict may not be finished yet. More importantly, at this stage of learning, there is an exchange about what kind of knowledge is necessary to be able to discuss the dilemma more deeply. The students set their individual learning.

Looking for evidence: the students organize themselves to obtain the necessary information and to exchange the evidence they have acquired, while the teacher is a manager and counsellor of the whole endeavor; in this phase, the teacher can also serve as source of information and respond to the students´ content questions as an expert among others.

Exchange of information: after the phase of information acquisition, there is once again a phase of exchange of information in the whole course so that all students have the same level of knowledge. The previous steps correspond to the constructivist knowledge development and include a viability check of the acquired knowledge with respect to its contribution to addressing the dilemma.

Second arguments (dilemma discussion): with this new knowledge in mind, the students turn back to the dilemma discussion itself.

Synthesis of information: a general discussion with the presentation of the results (current state of the negotiations) follows. This can be done in anticipation of the task to be performed in the next step.

Exchange of information, exchange of experiences, looking for evidence and synthesis may be repeated if necessary and depending on the time constraints of the course and interest of the participants.

After/during the dilemma discussions the students should be able to:

- develop possible options for dealing with the dilemma conflict
- vote - to decide in favor or against or even to postpone their vote
- discuss - to argue
- reflect - to anticipate consequences
- collaborate - searching and sharing information

---

[5]Blatt, M. M. & Kohlberg, L. (1975). The effects of classroom moral discussion upon childrens' level of moral judgment. Journal of Moral Education, 4, 129-161

2.5. Output of the group discussions

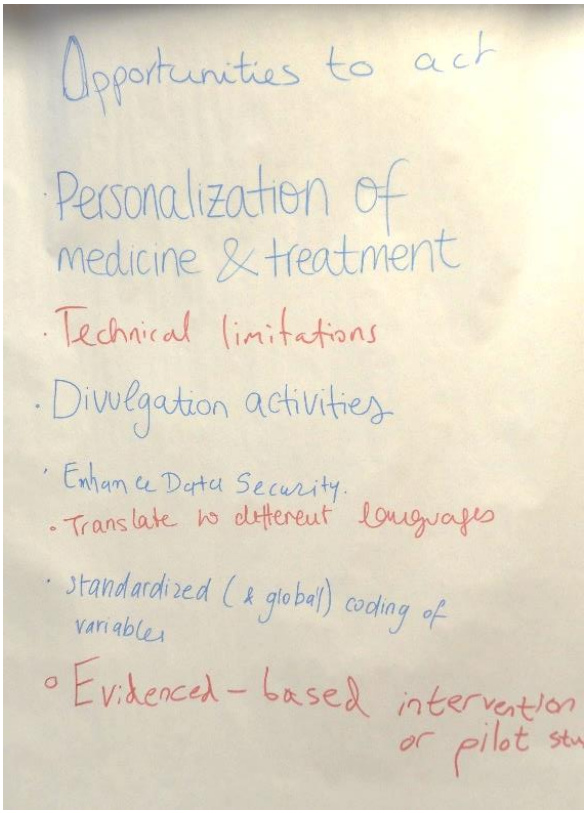
As with the discussion process, the output is generated in defined steps: general synthesis, generalisation, and final presentation.

General synthesis: the final synthesis addresses the current state of the discussion of the conflict (including, if appropriate, new problems) of the group. This can be done in didactically sophisticated ways such as through role-plays (with a possible change of perspectives), writing a newspaper, etc.

Generalization: the generalization consists in dealing with similar issues to broaden the perspective. Very often, this does not need to be conceived; rather the students do it

spontaneously. Sometimes they decide to act in some way (e.g., writing letters to newspapers or politicians, collecting money for a certain cause, etc.).

Final presentation: in a final session, each group will present their respective outcome to the other participants including trainers and supervisors and possibly other guests. The mode of the presentation shall be chosen by the group itself and should depict the creative process that was used during the discussion and output production process. Possible formats include but are not limited to role-plays, podium discussion, theatre plays, court scenes, TV-shows etc.; "classical" presentations or lectures should be avoided. The presentation should not be longer than 15 minutes. It is important to keep a tight time schedule since otherwise attention may fade away. Supervisors and trainers will provide feedback. For some examples of presentations see Figure 3.



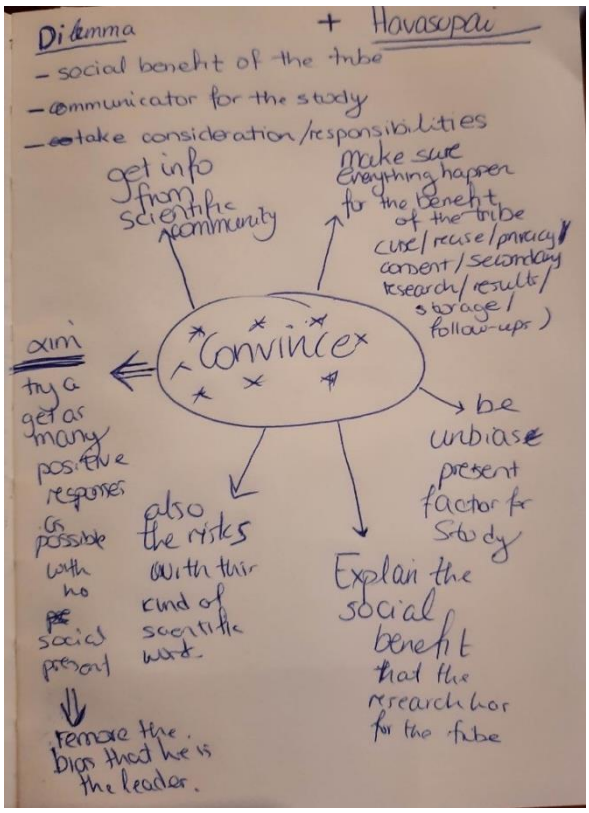


Figure 3: The upper panels show two charts summarizing the elements brought up during small-group discussions. The bottom panels show two groups during their final presentation. Left: Winter School 2023-Leiden; Right: Summer School 2022-Barcelona.

2.6. Design and execution of the virtual exercise

In order to settle the knowledge and the capabilities acquired during the School, the students are invited to complete a Virtual Exercise (VE), a group exercise that can be performed online after finalizing the School. It is advisable to design a VE that is meaningful for the students. Different formats are possible: Either the trainer provides a dilemma story that will have to be discussed in additional online-appointments, or he/she encourages the students to select one topic from the themes taught or discussed during the School. The students will design themselves a dilemma story based on principles of VaKE on that topic, and they will repeat the V*a*KE process afterwards.

2.7. World Café (Special case)

The World Café is a common activity in which students (guests) hold discussions in groups gathered around a virtual Table. There is a Table Host and a Virtual Tablecloth (a whiteboard) on which the guests can make notes. On each Table, a specific question is discussed. Everyone notes what he or she thinks is important on the Tablecloth. After twenty minutes, the guests change tables while the host remains; the host briefly summarizes the last discussion, using the tablecloth as reference; then the discussion continues with the new guests. At the end, the host summarizes the discussion for the whole plenum, using the tablecloth as reference. In preparation of the Virtual World Café, each group is responsible for one table as follows:

- Nominate a Table Host for the World Café: Each group nominates one person who will host a table. The task of the table host will be to initiate the discussion by asking the question, summarizing previous discussions for subsequent guests and for the plenum, and manage the discussion with as little intervention as possible; he or she can also participate in the discussion on the same level as all guests.
- Formulate a question for the Table discussion: Each group formulates one question to be discussed at the World Café Table. Possible questions are collected; one question is selected to be discussed in the World Café Table.

3. Monitoring progress and quality control.

Karolinska Institutet (KI) in collaboration with the coordinator, University Medical Center Göttingen (UMG), have developed a comprehensive set of tools to dynamically measure the effectiveness of the adapted and applied V*a*KE principles and methodology throughout the DATAETHICS project. These tools were specifically designed to investigate how participants, including students and teachers, experienced the course. To achieve this, the focus was on measuring the perceived quality of the course based on various parameters such as the course syllabus, learning outcomes, content, teaching and learning activities, and assessment tools. Figure 4 shows examples of questions used for the evaluation.

A combination of quantitative and qualitative methods was used to create and analyse the data, ensuring that the results were both comprehensive and nuanced. By using this approach, valuable insights were gained into how the Schools could be improved to enhance the learning experience for both students and teachers.

The virtual exercise and the pilot School designed in the framework of the Intellectual Output 1 (IO1), were excellent opportunities to pilot the tools, gather important feedback, and adapt them ahead of the Summer and Winter Schools.

The methodology developed to ensure the effectiveness of the tools included the following steps:

- Defining the objectives of the tools
- Developing survey questions based on the project outcomes
- Testing the survey questions through cognitive interviews
- Revising the questions based on the results of the cognitive interviews
- Piloting the survey in a pilot school
- Analyzing the pilot survey data
- Finalizing the survey questions
- Administering the survey
- Collecting and analyzing the data
- Reporting the survey results

By following this methodology, the survey questions were made clear, concise, and easy to understand, and the data collected was effective in achieving the project objectives.

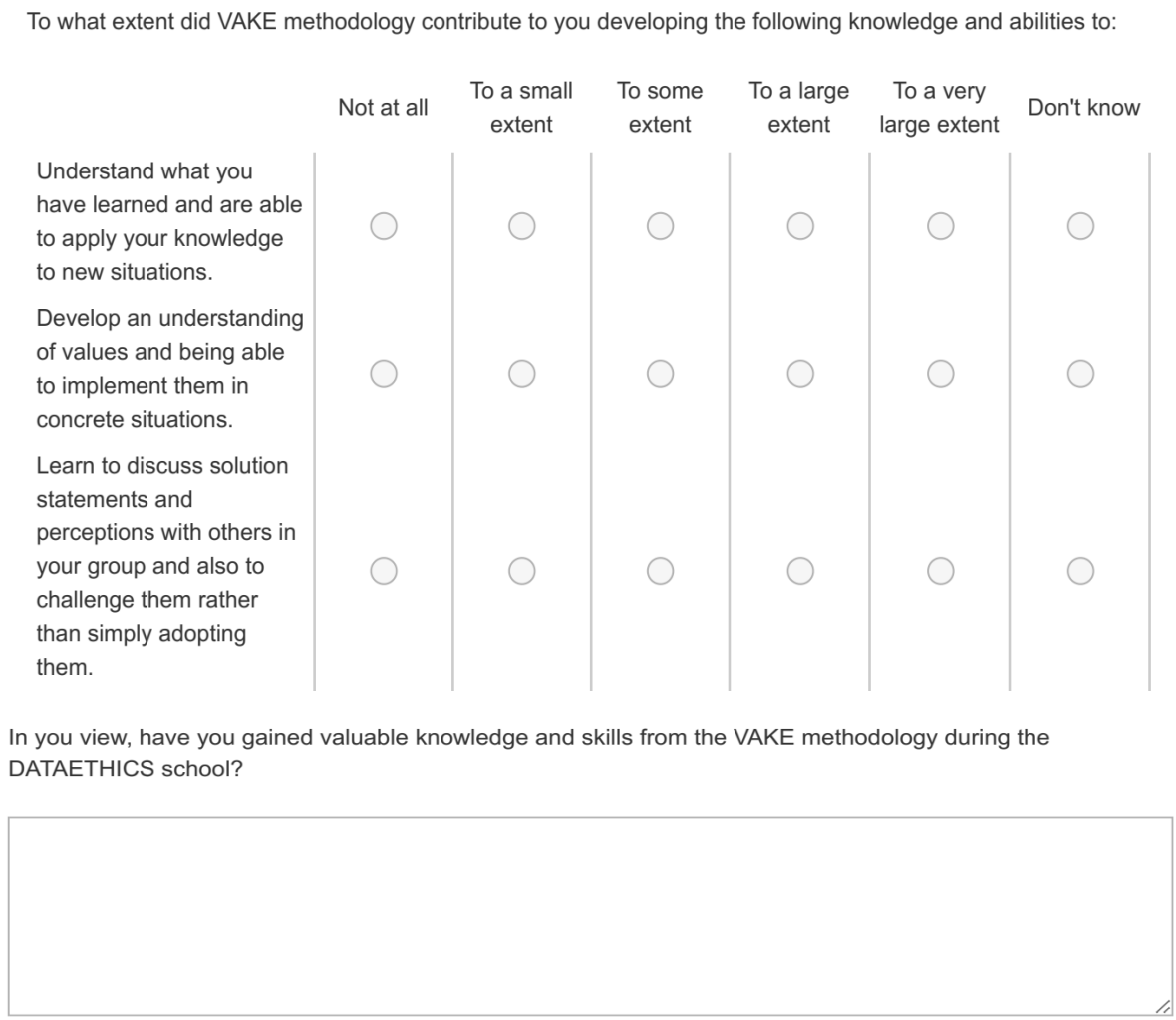
The DATAETHICS evaluation framework focused on four key aspects:

1. Participant experience of the V*a*KE methodology during the DATAETHICS Schools. For evaluation, students were asked to complete an evaluation survey at the end of each School, and a follow-up survey was sent to all students several months after the completion of each School. The survey questions assessed the students' experience of

V*a*KE, including questions about the knowledge and skills they acquired and whether they had an opportunity to apply them after completing the DATAETHICS School.

2. Student and teacher learning estimation. Students' learning success will be rewarded: Participants will receive a DATAETHICS Open Badge based on an assessment of their learning outcomes.
3. Evaluation and estimation of what teachers learned from teaching the course, including any new skills, knowledge, or attitudes gained after using the pedagogical framework. A survey was sent to the speakers who participated in the V*a*KE introduction on the first day of each School to assess this.
4. Estimation of the application of the knowledge gained by students in their local university practice by teachers/professors. The implementation of DATAETHICS activities by teachers/professors in their universities will serve as the indicator for this level.

The data generated served as a self-evaluation method of the project and for process improvement purposes.


To what extent did VAKE methodology contribute to you developing the following knowledge and abilities to:

	Not at all	To a small extent	To some extent	To a large extent	To a very large extent	Don't know
Understand what you have learned and are able to apply your knowledge to new situations.	○	○	○	○	○	○
Develop an understanding of values and being able to implement them in concrete situations.	○	○	○	○	○	○
Learn to discuss solution statements and perceptions with others in your group and also to challenge them rather than simply adopting them.	○	○	○	○	○	○

In you view, have you gained valuable knowledge and skills from the VAKE methodology during the DATAETHICS school?

Figure 4: Examples of questions posed to the students attending the meetings in order to evaluate the quality of the Winter/Summer Schools.

4. How to organize meetings/hybrid events

The organization of a meeting is a process that has to be initiated well in advance and has to consider external factors such as pandemics and limited availability of lecturers and trainers. A guideline with items to consider is shown in Table 2. For every step of the organization process, alternative solutions have to be taken into account.

Item	Time (Month)
Put together an organization board (appoint a project leader)	T-9
Set a date	T-6
Create a program; Items to consider: Budget (should be known in advance) Duration of the course (according to budget or other considerations) Interest for the subject, possible participants interested, expertise in house/external	T-6
Decide the format (in person, virtual, hybrid) and plan accordingly	T-5
Based on the program and the format Make lecture room reservations (and reservations for study rooms) Make reservations for accommodation Make catering reservations (coffee/thee, lunch)	T-5
Make an inventory of the technical assistance needed (hire a third party for audio- recording/streaming of the lectures)	T-5
Choose the right online meeting and webinar platform that can support both virtual and in-person attendees (Zoom, Teams, Meet, etc.), specially needed for virtual or hybrid events	T-5
Come up with a social event (escape room, beer/chocolate tasting, diner, visit a museum, gamification,..)	T-5
Come up with a theme and a title for the Winter/Summer School	T-5
Make an inventory of possible speakers (in consultation with each of the 9 Eurolife institutions)	T-5
Invite 12-14 speakers based on the team.	T-4
Develop with V*a*KE colleagues, 1-3 central case dilemmas according to student number	T-4
(Fine) tune the content with respect to the central theme (and available time) with each speaker	T-3
Winter/Summer School with A3 online and offline channels – minimal three month in advance	T-5
Select the candidates (Master students, PhD students, others)	T-3
Come up with Giveaways	T-3
Create online platform to share data, save presentations and chats/meeting rooms (Google drive etc)	T-3
After selection inform participants and speakers over (travel information to) accommodation flights etc.	T-2
Inform participants regarding the concept program	T-2
Finalize program and inform participants and speakers	T-2
Inform participants on the platform chosen, how to register and basic use, provide WIFI, etc.	T-2
Inform speakers about timings, talks, discussion times, talks recording, data protection, etc.	T-2
Inform Cleaning and Security	T-2

Regular organizational team meetings (whole period)	Every month
Administrative work: apart from the above offers, honoraria etc., document activities	Every month
Financial administration	Every month
Regular updates with Eurolife administration	Every month
Attend the Winter/Summer School for Q&A and troubleshooting	0
Have technical support ready for audio/video problems or network failures	0
Obtain Informed consent document from the participants (including the speakers)	0
Record participants' attending	0
Evaluation	T+1

Table 2: List of items to be considered during the planning process.

Possible drawbacks to be considered:

- Limited budget for accommodation participants
- Limited budget for accommodation speakers
- Limited budget for classrooms or other spaces if not provided free by the institution
- Limited budget for meals or coffee breaks during the course

Attention points that have to be taken into account:

- Dietary needs of participants
- Hot snack should be included in the lunch
- Mobility limitations and accessibility for participants and speakers, including patients from patient organizations

Finally, it is recommended that the organization of this type of meetings is guided by one or two appointed project leaders. One project leader with managerial skills focuses on the administrative tasks and the budget. The second (scientific) project leader focusses on the academic content of the meeting. Occasionally these skills are combined in one person and in this case one project leader will suffice.

5. Troubleshooting

During the development and planning process of the Schools, courses and post-School virtual exercises, several critical issues arouse that had to be taken into consideration:

- Choice of e-learning platform, recruiting e-platform administrator
- Availability of virtual rooms for discussion among of 30 participants,
- Creating stimulating and appealing tasks in Schools and virtual exercises, in which students are willing to take part
- How to motivate students to participate in virtual exercises
- Impact of Covid-19: Since the whole School was conducted virtually in times of the pandemic, the relevance of a virtual exercise after the pandemic was found questionable; after the end of the pandemic, students enjoyed a School in presence and were deterred of having to take virtual classes again.
- Coordination: A clear description of how the week is organized is important; it has to be clarified that theoretical parts (teaching/lectures) and practical elements (V*a*KE course, World Café) are linked together and are interrelated;
- The School must be supervised and monitored with regard to keeping the schedules and keeping the participants focused without overstraining them.
- For Summer and Winter School a social (bonding) event is highly recommended.

6. Students feedback on the School

During the Summer School 2022, student´s feedbacks were recorded in a video that is now publicly available in YouTube in full length[6]. Here, we present some extracts of their comments.

"Great to see. We scientists are kind of focused in our fields, so to get a greater perspective on some ideas for DATAETHICS has been really incredible (…) especially the context of GDPR and understanding and focusing on how we really protect and manage our data".
DATAETHICS student, Trinity College Dublin, Ireland.

"It was really thought provoking and food for fun, a really good overview of unresolved problems and challenges that we face in the field, but then again it was really inspiring because we can turn these challenges into opportunities".
DATAETHICS student, Karolinska Institutet, Sweden.

"A lot of ideas about AI, bioinformatics but also the ethical considerations belonging to that".
DATAETHICS student, Medical University Innsbruck, Austria.

"Gaining new ideas will be too short a term to explain my experience in a nutshell, I just did not gain new ideas but I gained new perspectives new approach new understanding new thought process and, along with that, new friends that I will cherish for through the years to come."
DATAETHICS student, University Medical Center, Göttingen, Germany.

[6]https://www.dataethics-eurolife.eu/2022/11/03/hear-from-the-participants-to-the-dataethics-summer-school-2022-and-learn-what-they-have-to-say-about-the-dataethics-school/