

Acronym: Anathema
Name: Technology for Ageless Sexual Health
Call: AAL Call 2020
Contract nr: AAL-2020-7-133-CP
Start date: 01 April 2021
Duration: 24 months

D1.4 Ethics: data privacy, project ethos and ethics best practices

Nature¹: P

Dissemination level²: PU

Due date: Month 2

Date of delivery: Month 2

Partners involved (leader in bold): **FhP**, SxL, INST, SPR, KBO

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¹ L = Legal agreement, O = Other, P = Plan, PR = Prototype, R = Report, U = User scenario

² PU = Public, PP = Restricted to other programme participants (including the Commission Services), RE = Restricted to a group specified by the consortium (including the Commission Services), CO = Confidential, only for members of the consortium (including the Commission Services)

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1. Introduction

Anathema is performing research and development involving human subjects, it is addressing a sensitive topic – sexual health –, it is dealing with vulnerable user groups (people with chronic diseases and older adults, among whom there is a greater prevalence of vulnerability as compared to younger demographics), and it adopts a Participatory Design approach, which implies an intense contact of researchers with research participants. The research and development process will culminate in new services and technology which, in turn, may have ethical impacts.

For all the above reasons, ethics plays a critical role in project Anathema. The research procedures will be submitted to ethics committees in Portugal and in Austria. In the Netherlands, due to National Regulation, Unie KBO and SPRIGS cannot submit requests to ethics committees. The consortium will deal with this constraint by submitting the documentation to ethics committees in Portugal and in Austria, and, if needed, to direct procedures in the Netherlands towards market research. However, the documentation to ethics commissions will describe all the processes and instruments to be used in all countries.

In this document, we outline international guidelines for ethical practices, as well as the results of the kick-off our In-Action Ethics process which led to the identification of Anathema's *ethos*.

2. Legislation and general ethics principles of Anathema

The members of the Consortium declare that the project will comply with the current legislation and regulations of the countries in which the research will be conducted. Moreover, the project will comply with all relevant EU legislation, especially the legislation described below:

2.1. The European Charter of Fundamental Rights

'The Charter of Fundamental Rights of the EU' brings together in a single document the fundamental rights protected in the EU. The Charter contains rights and freedoms under six titles: dignity, freedoms, equality, solidarity, citizens' rights and justice' (EU, 2013). The Charter became legally binding in 2009 when it was signed together with the Treaty of Lisbon. Meaning that all European legislation needs to conform to the principles of the Charter, including research policy. Several principles of the Charter are relevant in the context of research policy and are depicted below.

European Union, 2009:

- Article 3 – Right to the integrity of the person (dignity)
'Everyone has the right to respect for his or her physical and mental integrity'.
'In the fields of medicine and biology, the following must be respected in particular: the free and informed consent of the person concerned, according to the procedures laid down by law'.
- Article 7 – Respect for private and family life (freedoms)
'Everyone has the right to respect for his or her private and family life, home and communications'.
- Article 8 – Protection of personal data (freedoms)
'Everyone has the right to the protection of personal data concerning him or her'.
'Such data must be processed fairly for specified purposes and on the basis of the consent of the person concerned or some other legitimate basis laid down by law. Everyone has the right

of access to data which has been collected concerning him or her, and the right to have it rectified.'

'Compliance with these rules shall be subject to control by an independent authority'.

- Article 25 – The rights of the elderly (equality)

'The Union recognises and respects the rights of the elderly to lead a life of dignity and independence and to participate in social and cultural life.'

- Article 38 – Consumer protection (solidarity)

'Union policies shall ensure a high level of consumer protection'.

2.2. Declaration of Helsinki

The Declaration of Helsinki was developed by the World Medical Association (WMA) to lay out ethical principles for medical research involving human subjects. It is seen as the cornerstone of human research ethics in the world. Even though this is not a legally binding document through international law, most legislation of different levels have based their ethical principles on this Declaration and should therefore be highly respected. Relevant articles include (WMA, 2008):

- Article 6: 'In medical research involving human subjects, the well-being of the individual research subject must take precedence over all other interests'.
- Article 11: 'It is the duty of physicians who participate in medical research to protect the life, health, dignity, integrity, right to self-determination, privacy, and confidentiality of personal information of research subjects'.
- Article 14: 'The design and performance of each research study involving human subjects must be clearly described in a research protocol'.
- Article 15: 'The research protocol must be submitted for consideration, comment, guidance and approval to a research ethics committee before the study begins'.
- Article 21: 'Medical research involving human subjects may only be conducted if the importance of the objective outweighs the inherent risks and burdens to the research subjects'.
- Article 23: 'Every precaution must be taken to protect the privacy of research subjects and the confidentiality of their personal information and to minimize the impact of the study on their physical, mental and social integrity'.

2.3. Relevant EU Directives and other EU legislation

Directive 95/46/EC: Describes the protection and freedoms of persons with regard to the processing of personal data. Several aspects on personal data are highlighted: quality, legitimacy of processing, processing of special categories, information given to the data subject, right of access, right to object of processing, confidentiality, notification of processing to supervisory authority.

Directive 2002/58/EC: Concerning the processing of personal data and the protection of privacy in the electronic communications sector (Directive on privacy and electronic communications). Especially focused on the protection of individuals with regard to the processing of personal data and on the free movement of such data.

Nothing in Anathema may conflict the opinions of the European Group of Advisors on 'the Ethical Implications of Biotechnology and concerning respect of human person' (1991-1997) and the opinions of the European group on 'Ethics in Science and New technologies' (as from 1998).

2.4. General Data Protection Regulation

According to the Charter of Fundamental Rights of the European Union, natural persons have the fundamental right to the protection of personal data that concerning them.

The Council adopted the new Regulation on Data Protection and the Directive on 8 April 2016. The Regulation and the Directive were adopted by the European Parliament on 14 April 2016. The Regulation (EU) 2016/679 (General Data Protection Regulation), repealing Directive 95/46/EC entered into force on 24 May 2016 and is applicable since 25 May 2018. The Directive (EU) 2016/680 (Data Protection Directive) entered into force on 5 May 2016 and is applicable since 6 May 2018.

The Eurobarometer survey on protection and personal data, conducted among 28000 EU citizens in March 2015 reveals concern among EU citizens. For example, a majority agrees that “providing personal information is an increasing part of modern life” (71%), “that their explicit approval should be required in all cases before their data is collected and processed” (69%), or “that they would want to be informed should their data ever be lost or stolen”.

Further, eight out of ten EU citizens feel that they do not have complete control of their personal data. However, GDPR applies adapted regulations, which build and maintain trust. The overall change concerns the same data protection rights across EU. This means for businesses that the single, pan-European law for data protection build consistency between 28 countries. Moreover, one-stop shop involves one single supervisory authority (Data Protection Authority, DPA), which will promote clarity and make it cheaper for companies to do business in the EU. The same rules apply when goods and services are offered on the EU market. By means of a risk-based approach, rules are tailored to risks and therefore avoid one-size-fits-all obligation. Rules incentivise businesses to innovate, by means of data protection by design, meaning to build data protection safeguards into products and services from the earliest stage of development. Techniques as anonymisation, pseudonymisation and encryption are promoted to protect personal data (important in terms of big data) and thereby enable big data innovation. Transparency is core to the adapted version on data protection, stating that each organization should publish transparent and easily accessible data protection policies. "Simple icons on a website could explain how, by whom and under whose responsibility personal data will be processed" (European Commission, 2016).

In terms of controlling personal data and in order to build and maintain trust in online environment, the adopted Regulation states that easier access to personal data is ensured. Also, EU citizens have the right to data portability, which means that data can be transferred between services by the user. Thereby, trust is strengthened, and fair competition created: especially small- and medium-sized businesses can compete giants within the single market. The right to be forgotten means that if requested, data must be deleted. Moreover, users have the right to know when data have been unduly accessed. Thus, by means of clear affirmative actions, meaning that users give their consent for processing personal data. In case of data breaches, the data protection authority of each Member State as well as the user need to be informed as soon as possible – where feasible within 72 hours.

All in all, the adapted Regulation ensures:

- Enhancing transparency
- Fostering consumers' trust
- Boosting competition through new right of data portability
- Creation of a level playing field for all companies active in the single market.

The GDPR has entered into force in the Member countries through national law. The relevant national regulations are listed in the next section.

2.5. Deontological codes

Anathema crosses two scientific domains: interaction design and psychology. For this reason, the consortium is guided by professional codes of conduct elaborated by international societies and professional guilds. Regarding interaction design, researchers are familiar and compliant with the codes of AIGA³, IDSA⁴, ACM⁵ and IEEE⁶.

Regarding psychology, Anathema is guided by two professional guilds: the Portuguese and the Austrian one. The Portuguese Order of Psychologists (Ordem dos Psicólogos Portugueses) has an available deontological code since 2011, which will guide activities of psychologists in project Anathema. The equivalent in Austria is the Ethics Guideline from the Federal Ministry of Labour, Social Affairs, Health and Consumer Protection. In principle, the practice of the profession of clinical psychology and health psychology in Austria is regulated by the Psychologists Act 2013, Federal Law Gazette I No. 182/2013. The Code of Professional Conduct, in the form of an ethics guideline, supplements and concretises the professional duties laid down in the Psychologists Act 2013 and also serves to safeguard and promote the professional ethics of the members of the profession. The professional ethical principles are based on the Meta Code of Ethics of the European Federation of Psychologists' Associations (EFPA): 1) respect for the dignity and rights of the person, 2) competence, 3) responsibility and 4) integrity. The most recent version (as of 21.05.2021) was updated in February 2020.

Anathema's activities with primary, secondary and tertiary users will take place in three different countries. Therefore, Anathema not only takes into account EU regulations, which are relevant to healthcare research with human subjects, but also considers the following national legislation.

Portugal:

- Law nr. 58/2019, August 8, 2019 (Execution of the EU Regulation 2016/679)

Netherlands:

- General Data Protection Regulation Implementation Act (Uitvoeringswet Algemene verordening gegevensbescherming), dated 01.01.2020

Austria:

- Austrian Data Protection Act - Bundesgesetz zum Schutz natürlicher Personen bei der Verarbeitung personenbezogener Daten (Datenschutzgesetz – DSGVO). StF: BGBl. I Nr. 165/1999

³ <https://www.scribd.com/document/47555891/Design-Business-and-Ethics>

⁴ <https://www.idsa.org/code-ethics>

⁵ <https://www.acm.org/code-of-ethics>

⁶ <https://www.ieee.org/about/corporate/governance/p7-8.html>

2.6. General ethical principles of Anathema

Based on the above-mentioned legislation and codes of conduct, Anathema will uphold the following six general ethical principles:

- Respect for the integrity and dignity of persons (protecting them from being used for any other purpose than stipulated).
- Follow the “do no harm” principle. Any potential risks must be clearly communicated to the participant.
- Acknowledge the rights of individuals to privacy, personal data protection and the freedom of choice.
- Honour the requirement of informed consent and continuous dialogue with the participant.
- Respect the principle of proportionality: not imposing more than is necessary on the subjects, nor going beyond stated objectives (mission creep).
- Treat societal concerns seriously – listen to the participant and engage with them in a constructive dialogue, transparently, honestly and with integrity.

3. Participant recruitment

Each organisation (Unie KBO, FhP, Instahelp, SxL) will use their own contacts and recruitment methods. The recruitment method will have to comply with the methods and targets of the investigation.

Potential participants will be informed about what they can expect during the research. This information will be handed out to the participants in written form by means of an information sheet. Potential participants will be notified, in their own language and in a comprehensible way, about the research targets and methods.

Researchers will make future participants aware that their participation is completely voluntary, that they have the right to refuse to participate, and that they can terminate their participation without the need to justify their decision. Researchers will inform participants on a number of important factors that may influence their decision to participate (like risks, inconveniences, potential adverse consequences or restrictions to confidentiality) and they will elaborate on any other aspect on which the future participant may have a question. Researchers will inform participants on the feedback report method and the nature of the research results that will be reported or published. The participant shall get ample opportunity to read through the information, to ask the researchers any questions and to consider their potential participation.

The Anathema project will not approach people who are unable to give their informed consent. In case such a situation would accidentally occur, the approach will be terminated immediately.

In order to recruit participants, no unsuitably high financial compensations nor any other rewards may be used. The costs for expenditure related to participation will be paid by the organization conducting the research.

4. Data protection and privacy

Data protection and privacy are fundamental rights which need to be respected. Privacy covers the right to manage one's personal information, while being free from secret surveillance. Data protection entails the integrity and control of one's data with regard to the purposes of data processing.

As the Anathema project involves partners from different countries in the European Union (EU), personal data need to be processed across borders inside the EU. Due to the GDPR, protection safeguards will be implemented from the earliest design stage of the project and will be observed during the course of the project. Personal data will be pseudonymised during research and encrypted during development and trials in order to protectively process large datasets. Core to the data protection and privacy regulations in the Anathema project is transparency, meaning that data protection policies will be published. In order to comply with the GDPR and to build trust between the services provided by the Anathema project and its end-users, data accessibility will be applied. This means that users will get access to their personal data, if requested. Further, users can ask for their personal data for data portability use, enabling them to easily transfer their data to other services. If requested, personal data will be deleted once and for all. Particularly in terms of data protection, the data protection authority of each Member State as well as the user will be as soon as possible – where feasible within 72 hours, informed in case one's personal data have been unduly accessed.

4.1. Processing of personal data

Personal data refer to any information which relates to an identified or identifiable natural person. In terms of privacy, personal data are treated in a confidential way, which is ever more critical in Anathema due to its treating of health-related data.

- The consortium will handle personal data confidentially and will abide by all applicable legislation.
- The privacy of all participants is respected by giving control over the processing of personal data. Personal data that may lead to the identification of a participant will be disconnected from the research data.
- Personal data gathered for Anathema will only be used for its assigned goals defined in advance, or for objectives that are consistent with these defined goals.
- Members of the consortium will not hand over any personal data to any third party, without the participant's prior written and clearly stated consent. Even so, passing personal data to any third party is only allowed if this would serve Anathema's research.
- If a database with directly identifiable personal data will be constructed within Anathema, the researcher must provide its registration according to national rules.
- The researchers will take all suitable precautionary technical and organisational measures to prevent any loss of data or illegitimate access or processing.

5. Informed consent

Informed consent involves a voluntary agreement with an action proposed by another and should be communicated in clear and plain language. This proposal should include the nature, significance, implications and risks of the trial and should be either handed written or in exceptional cases orally. It should also include the participant's right to withdraw from the study at any time and a contact point to obtain further information. For the collection and use of personal data, informed consent should be asked for and include a simple explanation of who is collecting data and why, how to obtain a copy of the data and details of who will have access to the data.

In case of Anathema, the consortium shall ensure that participants are capable to make rational and voluntary decisions of participating. As Anathema will treat health data – which must be treated as sensitive data –, this will be communicated explicitly.

The informed consent document covers:

- Purpose of the project
- Research procedures and purpose
- Duration
- Benefits for participants, society and economy
- Potential risks
- Alternatives to participation
- Incentives for participation
- How data will be processed and by whom
- Participation rights: Refuse or withdraw of participation
- Data protection and privacy
- Research results and publishing
- Recording, pictures and videos
- Emergency care, compensation for injury or damage

6. In-Action Ethics

All the above sections consist of principles, guidelines and law, which can be grouped into a concept of normative ethics practices. However, given the Participatory Design approach used in Anathema, the consortium is prone to finding unexpected ethical dilemmas during project execution which may even, in some cases, require researchers to make quick decisions in the field. In order to support these decisions, we have decided to adopt an *In-Action Ethics* framework, which was originally proposed by Frauenberger, Rauhala and Fitzpatrick [1].

The authors note that there are several occasions in Participatory Design work, in which normative ethics may not suffice, such as full protection of participants; informed consent forms not accounting for all the activities, since new activities are designed in the course of the project; risks of deep involvement of researchers; or unplanned data collection when researchers spend a significant time in the field in contact with participants.

Therefore, the authors suggest *In-Action Ethics*, which begins by collectively defining a *Project Ethos*, i.e., the set of values the research project stands for. From this point onwards, the authors suggest keeping a continuous activity related to ethics. Whilst the authors have not defined a set of fixed activities, they have provided examples of relevant activities, such as an Ethics Bug Tracker.

6.1. Methods and participants

We have initiated an In-Action Ethics approach by beginning to elicit ethical dilemmas with the consortium in the project's kick-off meeting.

FhP led a remote group session with a total of 13 participants to elicit ethical dilemmas. The session had two parts: an initial presentation of project Anathema's general ethics concerns, followed by collective elicitation of ethical dilemmas associated with the project.

The session was held using Microsoft Teams and the group activity for ethics dilemmas elicitation was made using MURAL. Participants were presented with a Venn diagram showing the intersection of 'Participants', 'Researchers' and 'Business' and were asked to place the ethical dilemmas they thought of in the respective circle or intersection of circles. Participants were given 15 minutes to complete the exercise.

The results were analysed by three coders in two steps: first, each dilemma was associated with the most common applied ethical concerns by two coders, as defined by the Internet Encyclopedia of Philosophy⁷. The coders then discussed the associations and moved items until they reached consensus. The result was shared with a third coder and discussed among the three to reach consensus. Following this step, each group of dilemmas associated with an applied ethics concern was given a short description by one of the coders.

As final steps, the description along with the grouped dilemmas will be shared with the consortium, who will be asked to elicit values that Anathema should stand for to address each group of dilemmas. Then, individual members of the consortium will be asked to select the five values they found more important

⁷ Available at: <https://iep.utm.edu/ethics/#H3>

to consider in the project, ranking them by order of importance. The goal will be to identify the top three values which would configure the Ethos of project Anathema.

6.2. Results

6.2.1. Dilemma elicitation

The exercise of dilemma elicitation resulted in a total of 80 potential dilemmas (Figure 1). At first sight, after analysing the diagram, we noticed that there were more dilemmas associated with researchers and participants rather than with business. However, it is crucial to denote that more researchers participated in the exercise, likely explaining this occurrence.



Figure 1 Venn diagram of dilemma elicitation

6.2.2. Dilemma grouping

6.2.2.1. Ethical concerns

The following step stood for the analysis of the results by one coder, who identified several groups of dilemmas as similar ethical concerns. For instance, many obstacles were elicited regarding participants' protection and safety, expressing the need to keep them safe from harm or other risks. Other dilemmas emerged concerning the inclusion and exclusion criteria, recognizing the need for an inclusive approach,

fostering equal access to opportunities and resources for those who, otherwise, might be excluded. Subsequently, other ethical concerns groups arose, yielding a sum of ten categories, displayed in Figure 2.

- **Power and Authority** — Imposing a position of power and authority by doing or acting in a particular way, directly influencing others' behaviour or the course of events.
- **Reliance and Dependency** — The state of relying on, being controlled, or trusting in someone or something.
- **Training and Qualification** — A must fulfil condition before acquiring the right of perform an action, a particular skill, or a type of behaviour through a practice.
- **Approaches and Methods** — A way of dealing with a problem or situation that was initially proposed or requested about a particular procedure to accomplishing or approaching something, especially a systematic or established one.
- **Privacy and Confidentiality** — The state in which one is not being observed or disturbed by other people, being kept secret or private.
- **Inclusion and Exclusion** — The action or state of including (or being included) within a group or structure. The practise or policy of providing equal access to opportunities and resources for people who might otherwise be excluded or marginalized (people with physical or mental disabilities and members of other minority groups).
- **Communication** — The imparting or exchanging of information by speaking, writing, or using some other mediums while successfully conveying or sharing ideas and feelings.
- **Outcomes and Expectations** — The way a thing turns out, the consequence, the firm belief that something will happen or be the case, or the belief that someone will or should achieve something.
- **Protection and Safety** — The condition of being protected from or keeping others safe from harm or abuse, unlikely to cause danger, risk, or injury.
- **Discrimination, Bias and Prejudice** — The unjust or prejudicial treatment of different categories of people (especially due to race, age, or sex); recognition and understanding of the difference between one thing and another; cause to feel or show inclination or prejudice for or against one person or group, especially in a way considered to be unfair; a preconceived opinion not based on reason or experience.

In short, this step focused on the impact dilemmas will have on each of the upper mentioned categories, being some cross-cutting across sections. For instance, *Not designing an inclusive solution* is a dilemma that crosses three different parts such as discrimination (not including all potential users), expectation (not reaching an inclusive solution), and inclusion (not being able to design for everyone).

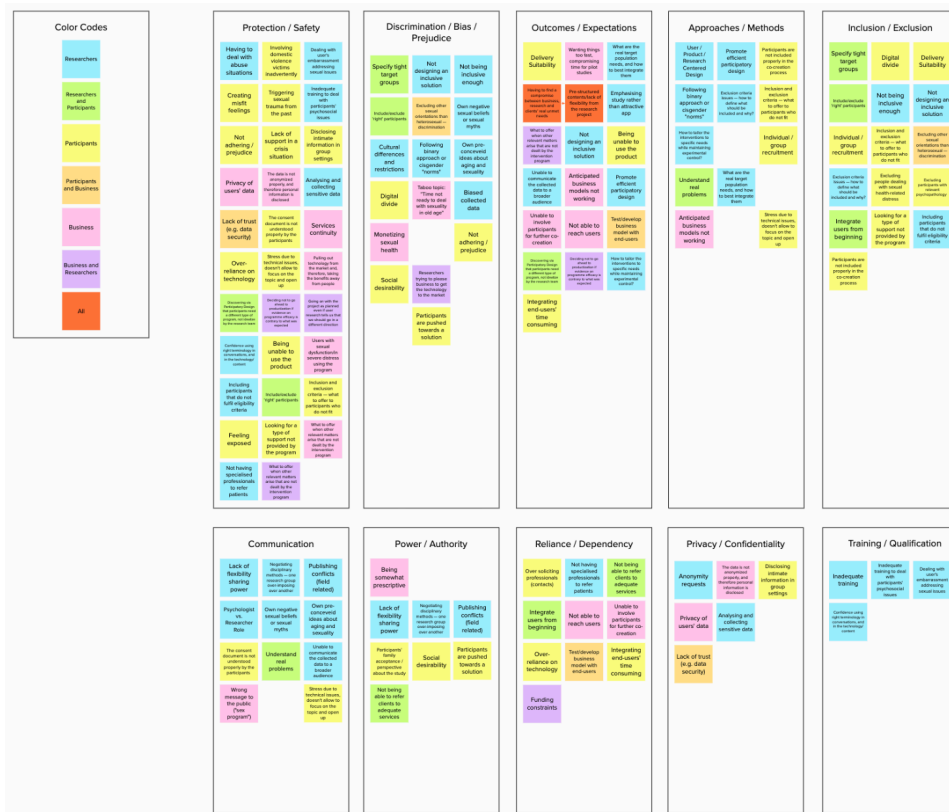


Figure 2 Affinity diagram of ethical concerns

6.2.2.2. Ethical principles

Moreover, three coders analyzed the results from dilemmas elicitation. First, each sticky note was associated, by two coders, with the most common applied ethics. Individually, the coders linked 80 dilemmas, prospecting to understand their interrelations. Later, the coders discussed their suitability and moved items until they reached consensus by associating them to another category or duplicating it due to their ubiquitous nature.

Different perspectives and interpretations gave value and significance to each dilemma, sustaining its implications on distinct ranges. Hence, a third coder analysed the results, which, in turn, promoted the associations' discussion, better suiting some dilemmas to ethical principles. Together, but individually, all three coders looked at the results, noticing some adjustments to carry. The third coder's perspective with a different academic background sustained a better framing of the outcomes, showcased in Figure 3.

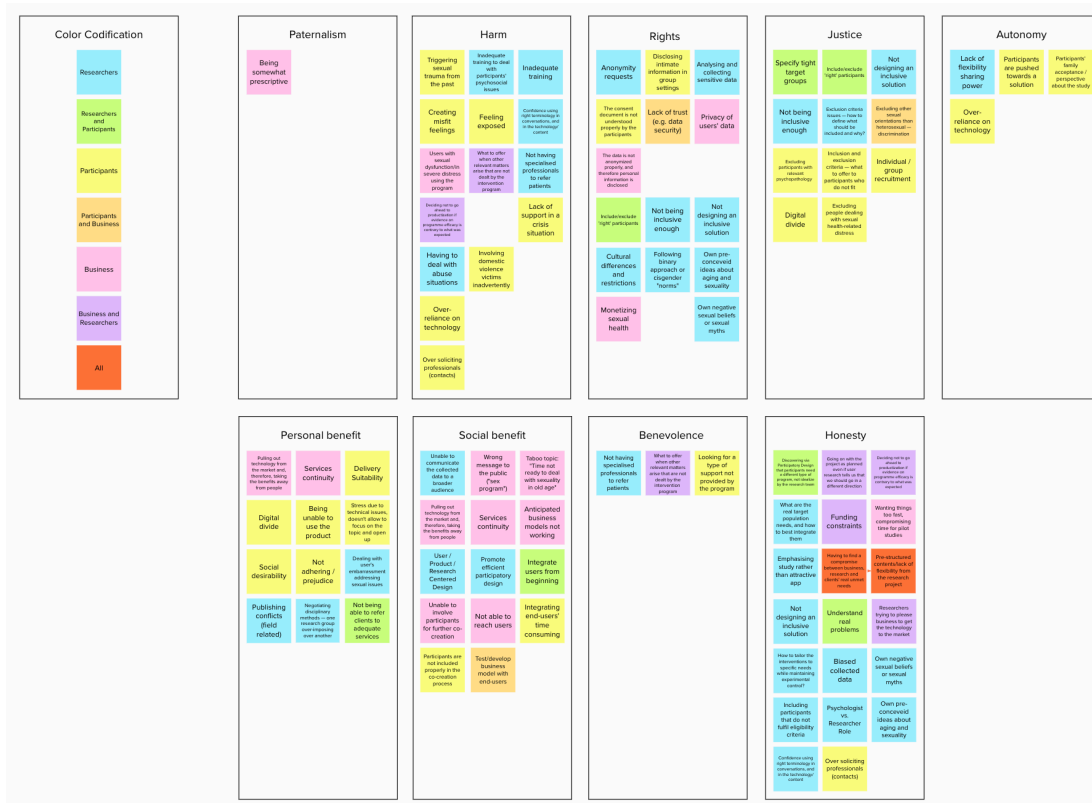


Figure 3 Affinity diagram of dilemma grouping

In the end, each group of dilemmas associated with an applied ethics concern was given a short description by one of the coders, intended to provide all consortium members with a brief overview of ethical issues that arose during dilemmas elicitation. Therefore, this eased the elicitation of project Anathema’s ethos and values.

The description provided for each group intends to provide all consortium members with a brief overview of the concerns that arose during the dilemma elicitation. Hence, this will help elicit Anathema’s values and ethos of the project.

The summary of these relationships sustained the following nine short descriptions, labelled as the ethical principles:

- **Rights** — defend peoples' rights of privacy and confidentiality. Defend individuals' (who will use and co-develop the solution) rights not to be discriminated against in the inclusion criteria. Finally, defend peoples' rights to sexual health support, meaning that we should not monetize sexual health.
- **Honesty** — be honest about the investigation course. About users’ real problems and needs, and about finding a compromise between business, research, and customers’ unmet needs. About financial and restrictive business concerns. About potential biases, inclusivity, and possible harms we can cause.
- **Justice** — fairness in the inclusion and exclusion criteria will guarantee an inclusive solution. There is also a need to be fair in seeking to fill the gap of digital divide.
- **Harm** — do not harm others due to the lack of researchers’ training or qualification addressing some issues that may arise. Do not harm others due to the theme’s sensitivity. Adapt the

product to the users' needs. Do not harm users (and participants) due to the excessive demand for technology use or the extreme solicitation of health professionals.

- **Social Benefit** — recognize that the community will benefit from the services' continuity. The withdrawal of technology might prevent social benefit. The acquired data must be public and able to be communicated as broadly as possible. We must pass on the right messages regarding sexual health, online intervention programs and end-users' value. The involvement of participants and end-users in user research, co-design and testing sessions will guarantee social benefit.
- **Personal Benefit** — recognize that people should benefit from the continuity of services, so we should not withdraw technology which is being beneficial. We must adequate the product and fill the digital divide gap to ensure that users will be able, and will accept, to use it, regardless of prejudice. Better adapting the services provided will eliminate the stress and constraints of participants and users during their involvement with Anathema (project and product). Finally, we must recognize the benefit that researchers will have in sharing methods and producing publications in various fields.
- **Benevolence** — help those in need, ensuring that we seek help to those looking for specialized professionals and support not addressed by the Anathema sexual health promotion program.
- **Autonomy** — recognize individuals' freedom over their actions or physical body. In this case, acknowledge researchers' sharing power, participants' freedom not to rely too much on technology, participants' right not to be directed towards a solution, and the participants' autonomy to participate in the study regardless of their significant others' acceptance.
- **Paternalism** — help others pursuing their best interests if the market is persistently prescriptive, imposing standard rules or methods.

Later, one coder summed these nine descriptions, reinforcing their meaning under negative impacts, facilitating participants' ease when eliciting values to address those ethical dilemmas:

- **Rights** — Hurting participants' rights of:
 - Privacy and confidentiality.
 - Non-discrimination in inclusion criteria.
 - Having non-monetized sexual health support.
- **Honesty** — Dishonest about:
 - Investigation course.
 - Users' real problems and needs.
 - Compromise between business, research, and customers' unmet needs.
 - Financial and restrictive business concerns.
 - Potential biases, inclusivity, and possible harms we can cause.
- **Justice**
 - Unfairness in the inclusion and exclusion criteria.
 - Digital divide.
- **Harm** — Harming participants due to:
 - Lack of researchers' training or qualification addressing some issues that may arise.
 - The theme's sensitivity.
 - Failure to adapt the product to the users' needs.
 - Excessive demand for technology use.
 - Extreme solicitation of health professionals.

- **Social Benefit**
 - Withdrawal of technology might prevent social benefit.
 - Non-disclosure of data.
 - Communicating wrong messages regarding sexual health, online intervention programs and end-users' value.
 - Users not properly involved.
- **Personal Benefit**
 - Withdrawal of technology might prevent personal benefit.
 - Digital gap.
 - Making participants uncomfortable during the project.
 - Conflicting paper publishing views (partners).
- **Benevolence**
 - Not providing adequate support to those who's needs fall out of project scope.
- **Autonomy** — Participants' autonomy threatened by:
 - Over-reliance on technology.
 - Being directed towards a solution.
 - Not being able to decide whether to take part in the project
- **Paternalism**
 - Being prescriptive.

With this step, we aimed to summarize results and draw conclusions considering bidding and impactful ethical dilemmas. Hence, it is easier to denote a primary need to protect all participants involved in the project, mainly protecting from harm, being end-users, researchers, health professionals, or others. A need to be honest, helpful, respectful of rights and personal benefits throughout the project development. A need to protect people's rights, not discriminating against those that might personally or socially benefit from Anathema. Finally, a need to help those in need yet acknowledging their independence to govern their decisions.

6.2.3. Values elicitation

Following the dilemmas grouping and analysis, individual consortium members (7 in total) received nine descriptions outlined at the end of section 2, point B. We asked them to elicit values that Anathema should stand for to address each group of dilemmas. This exercise rendered a sum of 133 values. Later, those were grouped in an affinity diagram, prospecting to aggregate all complementary values as a group. Figure 5. showcases the interrelationships between ethical principles and elicited values, resulting in a total of 23.

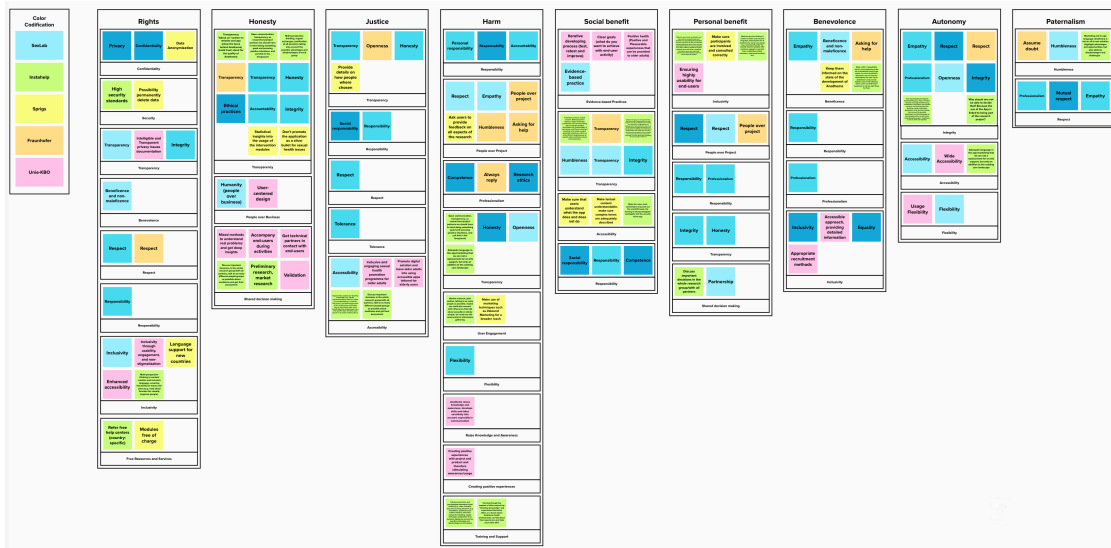


Figure 4 Affinity diagram of values elicitation

6.2.4. Values selection and hierarchy

As a final exercise, we asked individual members of the consortium (7 in total) to select five values they found more relevant to consider in the project and to rank them by order of importance. The goal was to identify the top three values which would configure project Anathema's ethos. After each participant selected and ordered the five values, we attributed points for each value. The most crucial gather 5 points and subsequently decrease until it reaches 1 point for the less relevant value, as showcased in Table 2. The points criteria helped distinguish values importance weight, resulting in the following board displaying elicited values and the corresponding score.

	5 (points)	4 (points)	3 (points)	2 (points)	1 (point)
P1	Transparency	Inclusivity	Shared decision making	Creating positive experiences	Responsibility
P2	Benevolence	Transparency	Inclusivity	Flexibility	Shared decision making
P3	Respect	Inclusivity	Responsibility	People over business	Accessibility
P4	Inclusivity	Accessibility	Flexibility	Evidence-based practices	Transparency

P5	Respect	Inclusivity	Accessibility	Transparency	People over business
P6	Respect	Responsibility	Shared decision making	Accessibility	Inclusivity
P7	Inclusivity	Respect	Responsibility	Transparency	Flexibility

Table 5 Values selection and rank

Hence, the hierarchy and importance rank of each value resulted in the following board. Table 3 showcases the hierarchy of values, denoting Inclusivity, Respect and Transparency as dominant and central ethical values for Anathema.

Values	Points
Inclusivity	26
Respect	19
Transparency	14
Responsibility	11
Accessibility	10
Shared decision making	7
Flexibility	6
Benevolence	5
People over business	3
Creating positive experiences	2
Evidence-based practices	2
Confidentiality	-
Security	-
Benevolence	-
Free resources and services	-
Tolerance	-
People over project	-
Professionalism	-
User engagement	-
Raise knowledge and awareness	-
Training and support	-
Integrity	-
Humbleness	-

Table 6 Values hierarchy

6.2.5. Values and project Anathema’s ethos

At the end of the second part of our General Assembly meeting, we asked the consortium to discuss if they envisioned themselves in unison with the top 3 values — Inclusivity, Respect and Transparency —

to which they responded that they would comply with these aims, envisaging to address, use and promote those values throughout the project.

Further, we asked them if they accepted the order of importance and wanted to add other values to the top. Accordingly, mostly psychologists (and sexologists) told us that Confidentiality is crucial and part of their deontology. Moreover, addressing Security could mitigate this sense of a confidential application. However, we asked if this could be a part of the value of Respect as they told us that it must be distinct due to its importance as a fundamental value for Anathema's ethos.

In the end, all members reached a consensus defining Anathema's ethos and values as **Inclusion, Respect, Transparency, Security** and **Confidentiality**, which allowed us to seek a framework to address the several dilemmas that may arise during the fieldwork studies, user research, participatory design, and project delivery, striving to defend throughout the project's extent.

6.3. Conclusions

The results of this exercise so far denote a primary need to protect all participants involved in the project. Mainly, to protect all from harm, be them end-users, researchers, health professionals, or others. There seems to be a concern for all to be honest, helpful, respectful of rights and personal benefits throughout the project development. Protecting people's rights and not discriminating against those who might personally or socially benefit from Anathema also emerged as a general theme. Finally, there is a concern to help those in need, yet acknowledging their independence to govern their decisions.

Bibliography

1. Frauenberger C, Rauhala M, Fitzpatrick G. In-Action Ethics. *Interact Comput.* 2017 Mar 8;29(2):220–36.