FORM 1

PARTICIPANTS TEMPLATE

Depending on the stage of the project, some of these activities may be already undertaken, only planned or not even applicable.

Thus, please fill in with the information planned or report; if not foreseen, please use NA, for non-applicable.

MAIN STAGES	CATEGORY	SESSIONS	PRIMARY	SECONDARY	TERTIARY
USER REQUIREMENTS	**NUMBER**	10			
	DESCRIPTION	• *In-Action Ethics* process (N=1)* • Webinar project kick-off (N=1) • Questionnaire (N=2) • Workshops (N=4) • Interview (N=1) • Project presentation and discussion (N=1) • User Experience Experiment (N=2)**	1.124	21	1
USER TESTING	**NUMBER**	4			
	DESCRIPTION	• Co-design Workshops • Surveys (planned)	9	100 (planned)	80 (planned)
PILOTS/TRIALS	**NUMBER**	3 (planned)			
	DESCRIPTION	• *Moderated usability tests (planned)* • *Pilot longitudinal waiting-list randomized controlled study (planned)* • *Post-intervention narrative interviews (planned)*	90 (planned)	NA	NA
ETHICAL DIALOGUE	**NUMBER**	1			
	DESCRIPTION	Public session with invited specialists in colorectal cancer, participatory design, bioethics, ageing, LGBTQ+, cybersecurity, sexology, human-computer interaction and mobile mental health	1	4	12***

* The start of Anathema's *In-Action Ethics* process that led to the project's *ethos* is described in *Deliverable 1.4 - Ethics: data privacy, project ethos and ethics best practices.*

** Primary users, but under 55 years of age.

*** Tertiary and other types of users, e.g. researchers.

FORM 2

A | TECHNOLOGY IN CONTEXT

1. Sketch the solution enabled by technology

In AAL, there are different kinds of solutions enabled by technologies in areas such as, health&care, living&building, safety&security. A useful taxonomy can be found here. For the dialogue it is important that all stakeholders understand what the solution is about.

Define and describe your solution here:

> Anathema will be the first smartphone-delivered sexual health promotion programme that seeks to adapt traditional face-to-face interventions for older adults, people with chronic diseases, and their partners.

2. Sketch the context where the solution will be used.

What are the main characteristics of the target group, where do they live, how do they live, what interactions do they have? What organisations are involved?

E. g., older adults, at home, in residential units, cared for by professionals, neighbours, family, a lot of life experience, not that much life expectancy, not working, maybe volunteering, …

For the dialogue it is important that all stakeholders understand where and by whom the solution will be used (primary and secondary users).

Define and describe your context here:

> Older adults, including colorectal cancer, stroke survivors, and respective partners, will use the app in a self-guided or guided fashion or in a structured consultation with a specialist.
>
> The target audience is interested in their sexual health, has a minimum of digital literacy, and is recruited through older adult associations, patient associations, and a hospital.

Method: Invite a technological expert and/or an expert of the context. Let him/her/them inform the group. Only informational questions will be asked, opinions are for later in the process.

> One expert in colorectal cancer (CRC) suggested that the app could help raise awareness the **prevention of CRC**. He has also alerted us that many patients have difficulties **using digital technologies** on their own (or adhering to tasks via digital technology). In any case, it could be important to have a **person who can help** users during the pilot.

FORM 2
B | IMPLEMENTING THE DIALOGUE

PARTICIPANTS

Invite relevant people for the ethical dialogue. This could be the developers of the solution, the users (clients), policymakers (in organisation or administration), care professionals, informal caregivers and/or others that have a role in the process or are influenced by the use of the solution. It is important that some of the participants also have the power to bring improvements. If it is impossible to get all the right people around the table, try to ensure at least that all the perspectives are considered in the group.

EFFECTS

This is the start of the dialogue.

   a) **Ask the question:** *what are the effects that could occur using this solution in this context?*

Explain that these effects can be positive or negative. Be sure to have enough room for both of them. They might be direct or indirect, and try to gather effects for the different actors.

> Anathema can have positive effects of helping to promote different types of literacy: sexual health, digital, and data protection. It can help fill the psychosexual supportive care gap there is in the National Health System, and it can help raise awareness about sexual myths, sexually transmittable diseases (STDs), and the importance of sexual pleasure (i.e., not just sexual activity) and self-knowledge.
>
> Negative effects identified by the participants were that the app itself, by imposing its presence, may be a reminder of disability. The app runs the risk of generating false expectations and, if not designed appropriately, it can reinforce negative stereotypes, namely of ability/disability, age, gender, and heteronormativity. If not designed with inclusive design in mind, it can exclude users. Participants highlighted that designing an app for people over 55 years of age may be, in itself, discriminatory.

   b) **From the answers collected, try to focus on** *what effects are most important, what are really the desired effects, what are the non-desirable effects, the ones to be avoided.*

> Promoting literacy and providing relevant information regardless of sexual orientation is a highly desirable effect, as well as breaking myths/stereotypes, which are present not only within society at large, but also among health professionals.
>
> The least desired effects are possible discrimination (regarding sexual orientation, gender, functional abilities, and age) and generating false expectations.

VALUES

Connect your reflections to values.

   a) **Ask the question:** *Which values played a role in the dialogue in the previous phases?*

This can be asked directly to the group or a co-moderator could have noted the values and bring them into the dialogue at this new stage.

The group identified the following set of values:

- Beneficence
- Autonomy (respecting and promoting it)
- Freedom of choice
- Lawfulness (namely through Informed Consent)
- Transparency
- Trust
- Acceptance
- Dignity
- Protecting vulnerability
- Justice (through Equality, Equity, and Inclusion)

b) Ask the question: *Are the main AAL values well considered in this product/service?*

The main values are being considered; however, all participants agree that believing there will be full inclusion is utopic, since there are many fringe cases.

Participants suggested using Inclusive Design (which the project already advocates for) and targeting the app content not to common categories of gender or ability, but rather to "sexual behaviour".

The question to be answered is what values are most important in this case, and how the AAL **main principles** presented below are addressed by the solution:

Figure 1 - The AAL principles

FORM 2

C | ACTION OPPORTUNITIES

Having completed the shared picture of the effects and the most important values, the last phase starts. How to make this solution have more positive and less negative effects, in accordance with the AAL values, supplemented by values of the participants. The actions shall be organised in 3 areas: the technology (ethics by design), the context and the behaviour of the individual.

ETHICS BY DESIGN (e.g., engineering, design)

a) *How can technology be improved* **- which actions will you implement?**

There were two large groups of suggestions: one related to data protection and another related to usability. On the former, informed consent can be made easy to understand and users should have the option to use the app without data traces. Regarding the latter, the app should use inclusive design.

Participants also suggested using inclusive and non-sexist language, including an SOS button for cases of harassment or abuse, and an easy access button for troubleshooting.

Examples: blurred camera's (privacy), anonymized data, data tuned on the user group, nice colours (attractiveness), washable (usability), universal design (easy to connect), accessibility, understandable information, a red button (when something goes wrong), etc.

ETHICS BY CONTEXT (e.g., agreements, policy)

b) *What can be improved in the AAL context* **- which actions will you implement?**

Participants highlighted the role of institutions on the ground, which could help mediate the use of the app. There could also be an SOS line, which could be implemented through a partnership with local institutions. Participants suggested that the content and the app could be made available free of charge in local institutions.

Examples: rules of use, agreements about who has access to data, and when, a helpdesk, technology innovation demands, standardisation, part of the payment protocol,

ETHICS BY INDIVIDUAL (e.g., behaviour, awareness)

c) *What can be improved for the users* **- which actions will you implement?**

The app can be used to raise awareness to relevant issues around sexual health. We also know, from the literature and participants' experience, that there are a myriad of aspects that users are interested in (e.g., STDs, use of medication) – therefore, the app should provide relevant links for further information on these topics, including useful contacts.

Entry into the app should be facilitated by seeking to eliminate an e-mail for login, and there could be tutorials on how to use the app.

The consortium should rethink the age limit to avoid being discriminatory.

People mostly have to learn how to use new technologies, at all different levels.

FORM 3
FURTHER REFLECTIONS

WHAT (results):

- What values and effects are newly considered?

- Which actions opportunities turned into actions?

In relation to the *In-Action Ethics* method that Anathema has implemented, the Ethical Dialogue has not raised new values or effects. It has raised a new action opportunity of targeting the content differently than we had initially foreseen, i.e., targeting sexual behaviours rather than sexual orientation, age, disease or abilities. Being now in month 13 of the project, it might not be possible to redesign the content and the technology to adapt to this, but an effort will be made to refine the technology according to this vision, whenever possible.

As this report is being written immediately after the session, no opportunities have yet turned into actions.

HOW (process):

How was the workshop evaluated?

We did not ask participants to make an assessment of the workshop. Nevertheless, participants were interested in receiving a report summarising the ideas that were gathered in the Ethical Dialogue session.

Were there new ideas presented? (yes/no, elaborate, please)

There were two main ideas presented: to make the content and app available free of charge in local institutions and to target the app to "various sexual behaviours".

Were there new connections? (yes/no, elaborate, please)

Yes, we established new connections to a specialist in security and privacy, to an LGBTQ+ organization and to a company commercialising an app which acts as a personal assistant to cancer patients.

HOW (methodology):

The ethical dialogue is a new form of getting ethics into the process of innovation. Can you help us with your reflections?

Was the methodology (not) helpful?

Considering the consortium is already using an In-Action Ethics approach, the ethical dialogue method did not significantly impact the ethos of the project. However, valuable insights were gathered on how to refine Anathema.

What functioned well?

The structure was easy to follow by the moderator and the participants.

In our particular case, there were other things that worked well: we chose an external moderator who is a specialist in Bioethics and Responsible Research, we held a public session over MS Teams and all the audience was invited to take part, and we used MURAL as a platform to gather notes from the session and contributions from the participants (Figure 2).
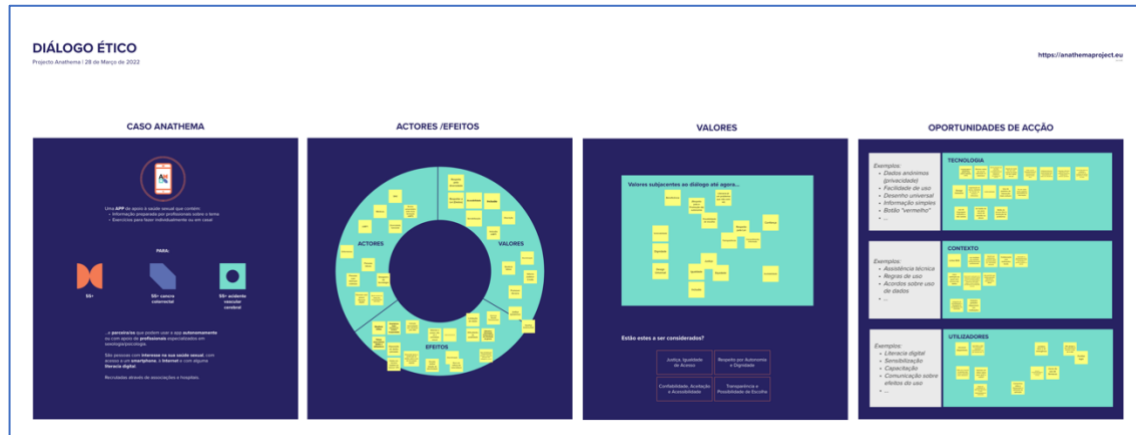

Figure 2. Screenshot of the MURAL Board

What could be improved?

The definition of "context" in the last exercise was difficult for the participants to grasp. The moderator suggested merging Ethics by Design and Ethics by Context.

We chose to hold the session online to enable greater participation, namely of geographical coverage. We believe this facilitated the presence of our guests. However, the use of MS Teams made it impossible for two older adults to join. Although they were used to videoconferencing, they had technical difficulties with this particular tool. Our choice ended up being discriminatory. Future initiatives could use more accessible software with a simpler log-in procedure.

We announced the session at large on our project website, social networks and through the National Funding Agency, but we did not have the attendance we expected.