

# U-TOPIA

## Towards Empowering Older Persons Living with HIV

*D2.1 Format and workplan for co-creation (format only)*

*D2.2 Needs analysis, Navigation co-creation toolkit & concepts for sustainable supportive technology on self-management (toolkit only)*

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**Impressum**

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# 1 Introduction

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## 1.1 Purpose of this document

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This document is meant as shared learnings about both the chosen format, and the toolkit used in the AAL U-topia project. This document is provided as a public source of information for other parties willing to learn and understand the chosen methodology. In this document, the timeline and planning of the session is provided as the format for the sessions. In addition to this, the toolkit actual toolkit that we deployed is also provided. This toolkit is the collection of individual exercises and energisers that have been used in these sessions, or that have been introduced to the consortium during the project.

## 1.2 Introduction of original project

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Before continuing, we provide some information about the origin of the project that the format and toolkit have been extracted from. This origin is the U-topia project focussing on elderly persons living with the Human Immunodeficiency Virus (HIV).

Infection with HIV, thankfully, is no longer an inevitable, terrifying death sentence. With the advent of effective antiretroviral therapy, HIV has been turned into a chronic illness that can be managed in the context of a life expectancy that is pretty close to normal. Living longer, however, is not the same as living in good health with a good quality of life: The lives of the growing population of older persons living with HIV are disproportionately affected by a serious number of physical, mental and social challenges. Project U-topia sets the first step towards the empowerment of older HIV patients.

The project has been designed to develop, through co-creation and explorative market analysis, sustainable concept(s) for supportive technology that match the needs of older persons living with HIV to manage and improve their quality of life. Based on the collective results, a plan and consortium for further development and commercialisation will be delivered.

The consortium includes four end user group organisations in three countries involving primary (older HIV patients) and secondary end users (HIV physicians, social workers, HIV nurses, relatives, formal carers, general practitioners). With the expertise of co-creation leader Waag, Institute for Art, Science & Technology, establish co-create ICT concepts that meet the needs and aspirations of older HIV patients once implemented.

## 1.3 Scope of this document

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This document will only provide insights into the approach and tools used for the co-creation sessions related to the Utopia project. By doing so, this project provides the public part of deliverable 2.1 and 2.2 from the original project proposal.

## 1.4 Related documents

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Before reading this document it is recommended to be familiar with the grant agreement of the project. This enables the reader to better understand the origin of the project.

This document includes references to a wide diversity of documents (tools) that can be deployed to successfully organise a co-creation session. However, the reader should keep in mind that, in its current form, this report contains information that is tailored to the needs of the U-topia project, but that can also be adapted to fit other contexts.

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## 2 Introduction to co-creation

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This brief chapter introduces the concept of co-creation and the co-creation session design for this project. The next chapter will go on to further introduce the actual content of the co-creation sessions themselves.

### 2.1 On the co-creation workshop design

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Discussing the overall health and well-being of HIV-positive people, HIV care providers (collaborating in BREACH, the Belgian Research AIDS & HIV Consortium), admit having to concentrating their activities on pharmaceutical interventions and medical care. Embracing the PozQal scale<sup>1</sup> we created an approach to structure health challenges in an understandable way, and in a way that goes further than merely looking at medical and pharmaceutical challenges. The PozQal categorisation of questions were used as a starting point to do so.

In co-creation within the U-topia project we emphasize the role of the user of individual and the needs of that user of individual. Further understanding of co-creation can be achieved by turning to the following definition of Cottam and Leadbeater (2004)<sup>2</sup>

*“Co-creation is not a one off event, like a referendum in which the community decides what should be done. [...]”*

Nor is co-creation just a question of formal consultation in which professionals give users a chance to voice their views on a limited number of alternatives. It is a more creative and interactive process which challenges the views of all parties and seeks to combine professional and local expertise in new ways.”

This definition shows that co-creation is a method for engaging users in design processes. Through co-creation (thinking, designing and creating together in multidisciplinary teams), personalised and unique experiences emerge.

But do users really have the ability to articulate their needs? Critics claiming the user is not able to do so, often quote Henry Ford who stated:

*“If I’d asked my customers what they want, they would have asked for a faster horse.”*

However, co-creation goes further than merely asking users what they want. In an early phase of the process it is already valuable to explore and discuss the question behind the question. By using co-creation methods to get input from end-users, we expose crucial and more tacit information and ideas on needs, wishes, ideas and concepts in the development process. This introduces ideas that we might have overlooked if we had limited our perspective to a developer’s or researcher’s point of view and to their assumptions about reality.

For the U-topia project, two types of sessions were organised between February and April 2019. These sessions took place in Amsterdam, Lisbon and Brussels and focussed on needs of, and solutions for elderly (50+) people living with HIV. Waag led the process of developing structure and content of these sessions. The actual sessions themselves were hosted by the three groups of patient organisations that are represented in the project-consortium. Partners were introduced to co-creation in a project meeting in Brussels, and were able to further

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<sup>1</sup> Brown, G. et. Al. (2018). Development and validation of PozQoL: a scale to assess quality of life of PLHIV. Public Health. 18:527

<sup>2</sup> Leadbeater, C. and Cottam, H. (2008). [The User Generated State](#)

experience this approach in a two-day workshop in Amsterdam in February 2019. This workshop also elaborated more on the soft skills regarding co-creation. That specific information is beyond the scope of this document.

The co-creation session consisted of two separate events. The first session focussed on the actual needs of people with HIV. The second session took those needs as a starting point. With these needs in mind existing solutions were aimed to be discussed, and possibilities for further development or development of new tools were considered. The project partners' intent was to letting this exploration be the starting point for a further jointly written project proposal for developing a specific solution.

To further validate the reliability and power of the co-creation sessions, an additional survey was spread amongst a broader population in Portugal. This survey is beyond the scope of this public report on the co-creation methodology.

### **3 Session one setup // Understanding needs**

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The next two pages contain an overview of the setup of session one. This overview was used by workshop leaders coordinating the meetings. Besides this planning, a wide range of elaborate documents and materials were provided to the consortium by Waag. The main question of the session is listed above page one.

Moderator notes // Co-Creation Timeline // Session 1

**Q: What are the most relevant and urgent needs for improving lives of people living with HIV?**

**Introduction (15-20 min)**

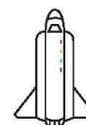
1



Introduce yourself  
 What is the Utopia project and why are we here (talk about central question)  
 Who are partners in this project? (optional)  
 Questions?

**ENERGIZE 1 // Portrait Drawing (15 min)**

Suggested energizer is portrait drawing  
 Feel free to choose another format if you want  
 Use the explanation A4 as a guideline for you as a host for this section



2

**Today's goals (5 min)**

3



1. To find out what, according to you as experts, are the most relevant and urgent needs for improving your life as a person living with HIV.  
 2. To map these needs which leads to more thorough understanding of their origin and reason for being.

**EXERCISE 1 (part 1) // Dialogue or Triologue (30 min)**

Depending on your group size, you can organise this in di-alogue. or tri-alogue  
 Remember; participants share intimate personal information here  
 Use the explanation A4 as a guideline for you as a host for this section



4

**EXERCISE (1 part 2) // Structuring and rating input (30 min)**

5



Remember; participants share intimate personal information here  
 Use the explanation A4 as a guideline for you as a host for this section

**Break (15 min)**

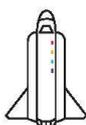
Take a break. Nice to let everyone relax for a second



6

**ENERGIZE 2 // Quadrants (or other) (15 min)**

7



Suggested energizer is quadrant exercise  
 Feel free to choose another format if you want  
 Use the explanation A4 as a guideline for you as a host for this section

## EXERCISE 2 // Story Puzzle (60 min)

Reserve time for making the puzzle (20 min) and (40 min) group reflection  
 Use the explanation A4 as a guideline for you as a host for this section



8

### Wrapup (10 min)

9



Thank people for participation and openness.  
 Tell: Next step is to reflect on needs and start thinking of solutions.  
 Questions: What did you think about the session?  
 Does it meet expectations?  
 Have you been heard?  
 What is needed for next session about solutions and will you join?

### Preparation:

Hang sheets on wall for catering needs (before participants arrive)  
 Arrange coffee, tea Water, something nice to snack.  
 Check the assignment A4 descriptions (before session)  
 Ensure timely sending of need category cards to participants for preparation.  
 (way before session)  
 Get participants to bring and sign non-disclosure agreements.

### Notes and Advice:

Mind the seven mindsets.  
 Allow for time to delay. Time pressure should never be a thing  
 Think of "the Art of Hosting" and setting the scene.  
 Empathy is key for this session.  
 Check the presentation document provided by Waag for some more background info.  
 Print some sheets of the presentation to show if you think they add to your story  
 Customise the session to a version you feel comfortable with  
 Guarantee and protect safe atmosphere at all times.  
 Consider ending the wrapup with cooldown (see A4 Instruction)

### WishList:

#### ENERGIZER Rollercoaster

- A1 print rollercoaster
- Color Marker

#### ENERGIZER QUADRANTS

- Tape to make a cross for on the floor
- A4 sheets with quadrants

#### ENERGIZER PORTRAITS

- A4 paper
- Color markers

#### ENERGIZER PICTOGRAM

- Printed Pictogram documents on A4
- Color markers

#### EXERCISE 1 // Dialogue or Triologue and rating

- Probe cards
- Sticky notes
- Color markers

#### EXERCISE 2 // Story Puzzle

- Every group needs a story puzzle set (cut and ready)
- Sticky notes
- Color markers

#### COOLDOWN

- Sticky notes

In this session we introduced different co-creation formats. Different organisers were allowed freedom to alter this setup based on their personal preference, and perception of fit of the method with the group's preference. The exercises that are central in this format, focussed on yielding the actual insights that we needed to answer the main question that we aimed to address.

Before the session took place, the participants were asked to prepare themselves. They did so through an exercise with different cards. These card were designed to highlight different categories of needs. By offering these cards, we aimed to do two things:

1. We allowed participants to better understand what we were asking for. Asking if the participants were dealing with any type of personal challenges related to HIV, is such a broad question that people might not be able to answer it. By offering sub questions in different categories, we aimed to suggest areas of thought, that could better enable the participant to identify personal challenges.
2. We aimed to give them time to prepare. By offering a card set like this in advance, we allowed the users to prepare for the sessions, and to take some time to properly answer the suggested areas in which they could formulate needs.

The card we used in preparation of session one can be found in the first appendix of this document.

For the first session, Waag has collaborated with the partners to provide multiple tools and resources to successfully host the co-creation event. These tools and resources were partly sourced from the co-creation navigator<sup>3</sup>. The co-creation navigator is an online source in which Waag shares several co-creation tools. However, the project has also generated additional tools. The complete list of tools can be found as appendices of this report.

### 3.1 Toolkit for this session

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The co-creation format described above provided a structure for workshop leaders to follow. This structure refers to a number of energisers and exercises that have been named below, and that have been further described in the appendixes of this document. If relevant, we have also provided templates needed to carry out these energisers and exercises. Besides the preparatory card probe exercise, that has been mentioned already, we have provided:

- **Portrait Energizer** // Explanation // Appendix 2
- **Pictogram Energizer** // Explanation // Appendix 3
- **Quadrant Energizer** // Explanation and Template // Appendix 4
- **Rollercoaster Energizer** // Explanation and Template // Appendix 5
- **Interview Exercises** (based on the card probe method\_ // Explanation // Appendix 6
- **Storyboard Exercise** // Explanation and Template // Appendix 7

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<sup>3</sup> <https://waag.org/en/project/co-creation-navigator>

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## 4 Session two setup // Considering existing solutions and conceptualising possibilities

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The next two pages contain an overview of the setup of session two. This overview was used by workshop leaders coordinating the meetings. Besides this planning, a wide range of elaborate documents and materials were provided to the consortium by Waag. The main question of the session is listed above page one.

For session one, we partly relied on the tools and resources that had been provided for session one. Additionally, we provided two more exercises that suited the goal of this second session. The first exercise was the People Value Canvas<sup>4</sup>. The second was the Tech Tryout evaluation method. These exercises that are central in this format, focussed on yielding the actual insights that we needed to answer the main question that we aimed to address.

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<sup>4</sup> <https://waag.org/en/project/people-value-canvas>

## Moderator notes // Co-Creation Timeline // Session 2

**Q: What (other) solutions to the needs can we conceptualise. What do we think about existing solutions? What should be created or improved?**

### Introduction (15-20 min)

1



Introduce yourself

What is the Utopia project and why are we here (talk about central question)

Who are partners in this project? (optional)

What happened in session 1? Which needs did we identify (be specific)

Questions?

### ENERGIZER 1 // Free choice (15 min)

Suggested energizer is the rollercoaster

Feel free to choose an other format if you want

Use the explanation A4 as a guideline for you as a host for this section



2

### Today's goals (5 min)

3



1. To explore and discuss what solutions should do to fit our identity and needs as identified in session 1

2. To present and talk about some presented solutions that somewhat fit the needs that we identified in session 1

3. To find out what should be created (or improved)

### EXERCISE 1 // People Value Canvas (60 min)

Use the template for doing this

Fill in the needs (if different needs then different colour) in the overview(s)

An instruction has been provided to guide this process



4

### Break (15 min)

5



Take a break. Nice to let everyone relax for a second

### ENERGIZER 2 // Free choice (15 min)

Suggested energizer is Rollercoaster

Feel free to choose an other format if you want

Use the explanation A4 as a guideline for you as a host for this section



6

### EXERCISE 2 (part 1) // Tech Tryout (30 min)

7



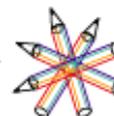
In this part, people can experience and discuss some existing solutions

The amount of groups depends on amount of participants, and the amount of solutions that will have to be considered

Use the explanation A4 as a guideline for you as a host for this section

## EXERCISE (2 part 2) // Tech Tryout (structuring) (30 min)

In this part people are presented with a structure to organise their input  
 This leads to a clustering of findings which they themselves will present to each other  
 Use the explanation A4 as a guideline for you as a host for this section



8

### Wrapup (10 min)

9



Thank: people for participation and openness  
 Conclude: What have we learned, what should be created or improved?  
 Question: What did you think about the session?  
 Did it meet expectations?  
 Have you been heard?  
 What is needed to take this proces further?  
 Tell: We will send a survey to get some more info for scientific study

### Preparation:

Hang sheets on wall for rollercoaster (before participants arrive)  
 Arrange coffee, tea, water, something nice to snack.  
 Check the assignment A4 descriptions (before session)  
 Ensure timely preparation of fitting solutions. Can people try these out? Or are these presented in a powerpoint presentation? (prepare way before session)  
 Get (new) participants to bring and sign non-disclosure agreements.

### Notes and Advice:

Mind the seven mindsets (shared in material for session one).  
 Mind the risk of healthcare professionals dictating the session.  
 Allow for time to delay. Time pressure should never be a thing  
 Think of "the Art of Hosting" and setting the scene.  
 Allowing for flexibility is key for this session.  
 Customise the session to a version you feel confortabe with  
 Guarantee and protect safe atmosphere at all times. Don't just TELLto new group members what identified needs are. Instead, let earlier participant tell their own stories on their own terms.  
 Consider ending the wrapup with cooldown (see A4 Instruction) or last Rollercoaster

### WishList:

#### ENERGIZER Rollercoaster

- A1 print rollercoaster
- Color Marker

#### ENERGIZER QUADRANTS

- Tape to make a cross for on the floor
- A4 sheets with quadrants

#### ENERGIZER PORTRAITS

- A4 paper
- Color markers

#### ENERGIZER PICTOGRAM

- Printed Pictogram documents on A4
- Color markers

#### EXERCISE 1 // People Value Canvas

- a3 printed template
- Color markers
- Additional paper

#### EXERCISE 2 // Tech Tryout

- Post it
- a3 printed template
- Color markers

#### COOLDOWN

- Sticky notes

In this session we introduced new formats. Different organisers were allowed freedom to alter this setup based on their personal preference, and perception of fit of the method with the group's preference. The main tools that had been suggested by Waag, were a People Value Canvas<sup>5</sup> exercise, and an exercise that was aimed at evaluation of existing solutions. We called this the Tech Tryout tool. This tool was developed based on scientific sources proposed by project partners.

When explaining about the methodology to the different consortium partners that were hosting the sessions, the partners looked for ways to slightly customise their approach based on earlier insights from session one. For example, the Dutch group used a video fragment that introduced so called "blue zones" in which people seemed to live healthier and enjoyed longer lives. This was used as a starting point for a discussion about determinants of quality of life.

#### 4.1 Toolkit (additional) for this session

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The co-creation format described above provided a structure for workshop leaders to follow. This structure refers to a number of energisers and exercises that have already been mentioned as part of session one. However, we have also provided multiple additional exercises. If relevant, we have also provided the templates needed to carry out these exercises. For session two, we added the following exercises to the toolkit:

- **TechTryout Exercise** // Explanation and Template // Appendix 8
- **PeopleValueCanvas Exercise** // Explanation and Template // Appendix 9

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<sup>5</sup> <https://waag.org/en/project/people-value-canvas>

## 5 Appendix 1: S1 Card probe overview.

**Other Challenges**

5. Do you experience any other challenges in living with HIV? You can think of things like:

- Anything else that doesn't fit within any of the other categories.
- For every other challenge you can think of, also write down if you can think of a new category-name for it.

**5**

**Functional challenges**

1. Do you experience any functional challenges living with HIV? Functional challenges are things like:

- Ways in which HIV prevents you from doing what you would like
- Ways in which HIV limits opportunities in your life
- Ways in which living with HIV wears you out

**1**

**Health Challenges**

2. Do you experience any health challenges living with HIV. Health challenges are things like:

- Ways in which you worry about your health
- Ways in which you worry about HIV's impact on your health
- Things your fear about HIV while growing older
- Ways in which you are effected by HIV related medication

**2**

**Psychological challenges**

3. Do you experience any psychological challenges living with HIV? Psychological challenges are things like:

- Ways in which HIV limits enjoyment in life
- Ways in which HIV limits your control over life
- Ways in which HIV limits your optimism about the future
- Ways in which HIV limits you feeling good about yourself

**3**

**Social challenges**

4. Do you experience any social challenges living with HIV? Social challenges are things like:

- Ways in which HIV limits your personal life
- Ways in which you experience a lack of belonging with people around you
- Ways in which you fear rejection when people learn you have HIV

**4**

**+**

**Extra challenges**

U-TOPIA TOWARDS EMPOWERING OLDER PERSONS LIVING WITH HIV




## Instructions:

View the cards with a picture on the front periodically to identify challenges that are relevant for you. Do so multiple times whenever you like. Decide yourself how often you want to do so before the workshop.

Look at each card and ask yourself: Do I experience a specific challenge in this category? You can also discuss this with friends or family. Write down the challenges you identify on the back of the cards, or on the extra (grey) answering cards.

The suggestions below the image on every card are added to help you think about various challenges.

The list of challenges you create will be later be the starting point for the workshop. So write down exactly what your specific challenges are.







## Points of attention:

- You are asked to think about challenges you experience in your life. Don't worry. You don't have to come up with the solution for these challenge yet. Just writing down the challenges is fine for now.
- If you experience challenges that don't fit one of the category cards, then write it down on card 5: "Other challenges". We really like to hear about these other things as well.
- Write down the needs that you think about on the back of the cards. Describe the challenges accurately, but do not make the description too long. If you need more writing space, use one of the grey extra cards, or just grab a blank paper.
- Think of your own daily routines when thinking about challenges you deal with in your life.
- Please also mark the categories that apply to you on the front of the cards.
- Please take all cards and additional paper with you to the workshop.

Good luck!!!




## **6 Appendix 2: S1 Portrait Energizer. (EXPLAINED)**

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## **7 Appendix 3: S1 Pictogram Energizer. (EXPLAINED)**

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## 8 Appendix 4: S1 Quadrant Energizer. (EXPLAINED / TEMPLATE)

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## 9 Appendix 5: S1 Rollercoaster Energizer. (EXPLAINED / TEMPLATE)

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## **10 Appendix 6: S1 Interview Exercise. (EXPLAINED)**

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## **11 Appendix 7: S1 Storypuzzle Exercise. (EXPLAINED / TEMPLATE)**

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## **12 Appendix 8: S2 TechTryout Exercise. (EXPLAINED / TEMPLATE)**

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## **13 Appendix 9: S2 PeopleValueCanvas Exercise. (EXPLAINED / TEMPLATE)**

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