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Environmentally sustainable and climate neutral health and care systems

NetZeroAICT

Digital Contrast for Computerised Tomography -Towards Climate Neutral and Sustainable Health Systems-

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= Deliverable D1.5 =

Patient and public engagement mechanisms plan

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Executive Summary

Version 1 of the NetZero AICT Patient and Public Engagement Mechanisms Plan concentrates on the development of GDPR-compliant communication channels and mailing lists, prioritizing data privacy and transparent data management. A key element of the strategy is the formation of a Public Advisory Group, which will consist of patient representatives from a minimum of five European countries. The comprehensive plan includes the following components:

1. Comms channel identification and mailing list creation and management: Establishing secure and compliant channels for communication and managing mailing lists that respect user privacy.
2. Utilization of d7.1 project communications materials: Leveraging developed materials for project communication to ensure consistent messaging and outreach.
3. Establish a Public Advisory Group: Setting up a group of patient and public representatives to provide input and guidance on project activities.
4. Recruitment:
 - a. Engage Patient Representative Organizations: Collaborating with organizations that represent patients to inform and involve them in the project.
 - b. Extend Outreach for Inclusive Representation: Broadening the scope of engagement to include diverse groups for a more representative advisory group.
 - c. Facilitate Submission of Applications: Streamlining the application process to make it user-friendly and accessible to all potential applicants.
5. Communication:
 - a. Adapt communication to accommodate linguistic diversity: customizing communication methods to cater to the varied linguistic backgrounds of European countries.
 - b. Promote English proficiency while encouraging non-native speakers: encouraging participation from non-native English speakers by providing support to improve English proficiency.
6. Selection Process:
 - a. Clarify Selection Criteria and Process: Defining clear and transparent criteria and procedures for selecting members of the Public Advisory Group.
 - b. Conduct Fair and Effective Interviews: Ensuring that interviews are conducted in a manner that is equitable and yields the best candidates for the advisory group.
7. Training of Public Advisory Group Members: Providing comprehensive training to members of the Public Advisory Group to prepare them for their roles.
8. Public engagement and involvement with NetZeroAICT project requirements: facilitating meaningful public involvement and ensuring that project activities are transparent and collaborative.
9. Online Discussion Forum (Discourse): Implementing an online forum to enable ongoing discussions and engagement among participants.

10. Online Mural Board: utilizing a visual collaboration tool to foster creative brainstorming and idea sharing.
11. Event planning with accessibility and inclusivity: organizing events that are accessible to all, considering the needs of those with disabilities and ensuring inclusivity.
12. PPIE representation on Intra NetZeroAICT Leadership groups: Including members of the Public Advisory Group in leadership and decision-making processes within the NetZero project.
13. Engagement with NetZeroAICT team: ensure engagement and buy in from the project team and partners through dedicated meetings.
14. Continuous Feedback Mechanism and Improvement: Establishing a feedback loop to continuously improve engagement strategies based on participant input.
15. Robust Data Protection and GDPR Compliance: Upholding strict data protection practices in accordance with GDPR standards to ensure the integrity and security of personal data.

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1. Introduction

The NetZero AICT - PPIE¹ - Engagement Mechanisms Plan represents a pragmatic approach to building broad and deep community engagement. This plan aims to create a structured approach to stakeholder engagement, enriching the NetZero project with valuable insights and ensuring that all activities are carried out with the highest standards of data protection and inclusivity. The actions in the below plan are to be undertaken by John Kellas, with support from others in the project team.

This V1 plan will be superseded by a V2 plan developed with the Public Advisory Group and published in M7.

¹ Patient and public involvement and engagement

2. PPIE - Engagement Mechanisms Plan V1.0

1. Communication Channel Identification and Mailing List Creation and Management

- Objective: Establish and maintain GDPR-compliant contact lists and communication channels.
 - Action: Develop mailing lists for interested parties, ensuring explicit consent for data retention and usage. Collect equalities monitoring data, including demographics and experience with CT scans. Focus outreach on clinical sites within the NetZero Consortium and patient advocacy groups ([link](#)).

2. Utilization of D7.3 Project Communications Materials

- Objective: Maximize engagement and understanding through the deployment of an interactive communication kit during the first wave of the project.
 - Action: The project deliverable D7.3, due in Month 4, will provide a comprehensive set of communication materials. These will be shared and refined through ongoing stakeholder co-design, emphasizing patient-friendly summaries.

3. Establish a Public Advisory Group

- Objective: Foster participation by engaging a core Public Advisory Group of circa 14 people, recruited via a transparent selection process that upholds principles of equality, diversity and inclusivity. .

4. Recruitment

- Objective: Expand recruitment efforts to achieve diverse participation.
 - Sub-goal 1: Engage patient representative organizations
 - Action 1.1: Finalise communication materials to ensure clarity and mutual understanding.
 - Action 1.2: Initiate communication with patient representative organizations across Europe to collect information on distributing project materials and associated costs - draft contact list - [link](#).
 - Sub-goal 2: Extend outreach for inclusive representation
 - Action 2.1: Analyse feedback from initial outreach and engage with at least three patient networks in each EU country.
 - Action 2.2: Send personalized invitations through email and social media, specifically targeting underrepresented groups.
 - Facilitate Submission of Applications
 - Sub-goal 3: Simplify application process
 - Action 3.1: Create an interactive Google Form for participant information, ensuring it is user-friendly and accessible, covering comprehensive demographic and experiential data. Suggested addition: Incorporate an intuitive navigation and submission process to enhance user experience.

5. Communication

- Objective: Ensure effective and inclusive communication.
 - Sub-goal 1: Adapt communication to accommodate linguistic diversity
 - Action 1.1: Utilize the primary language of each target country for initial communications, with directions to the NetZero project website for more information and multilanguage info-sheets.
 - Sub-goal 2: Enable streamlined PAG communications
 - Action 2.1: Acknowledge the PAG's working language as English but facilitate participation from those with varying levels of proficiency.

6. Selection Process

- Objective: Implement a transparent and fair selection process.
 - Sub-goal 1: Clarify selection criteria and process
 - Action 1.1: Refine and agree on a framework with PSC and ethics lead - see Annex 1 for initial framework. See Annex 1 for the initial framework draft.
 - Action 1.2: Agree and publish the selection criteria and process for interviews.
 - Sub-goal 2: Conduct fair and effective interviews
 - Action 2.1: Establish a diverse panel in the interview process.
 - Action 2.2: Prepare a structured interview plan with clear, inclusive questions and detailed scoring criteria.
 - Sub-goal 3: maintain engagement beyond the PAG
 - Action 3.1: Clearly communicate the opportunity for involvement via Discourse and mailing list/newsletter, even for those not selected for the core group.

7. Training of Public Advisory Group Members

- Objective: Enhance understanding and engagement through focused training sessions.
 - Actions: Organize three comprehensive training sessions, introducing key concepts relating to health data, health research, AI, policy and regulation, and integrating insights and detailed information on project activities and related concepts directly from Work Package (WP) leads. These sessions will cover fundamental topics such as health data, AI, research methodologies, and the overarching design of the NetZeroAICT consortium. The aim is to deepen the participants' knowledge and engagement with the project's core themes and objectives. The training curriculum will be developed by the stakeholder engagement lead, with codesign input from the PSC. Supplementary training sessions will be held if the PAG identifies a need for this.

8. Public Engagement and Involvement with NetZeroAICT Project Requirements

- Objective: Ensure meaningful transparency and facilitate co-design and co-production input via PAG meetings and remote public contributor input.
 - Action: PPIE lead to meet with all WP leads to ensure planning, decision, and evaluation stages for research instrument design, ethics applications, project architecture, IP management, and ethics by design framework development and project management are undertaken with PAG members and other public contributors as needed (decided on by the PAG and PSC). A record of these interactions and impacts will be kept and included in the project monitoring logs.

9. Online Discussion Forum (Discourse)

- Objective: Facilitate dynamic and ongoing discussions among participants.
 - Action 1: Implement a Discourse online discussion forum to provide a structured, yet flexible platform for idea sharing, questioning, and collaboration on NetZeroAICT relevant topics. Encourage active participation and ensure moderation for a respectful environment.

10. Online Mural Board

- Objective: Enhance creative collaboration and brainstorming.
 - Action 1: Utilize an online Mural board for real-time visual collaboration. Share project diagrams, questions, comments, and resources.
 - Action 2: Promote the Mural board within other project communications to facilitate cross-project team brainstorming sessions, strategy development, and creative idea sharing in a visual and interactive manner.

11. Event Planning with Accessibility and Inclusivity

- Objective: Organize accessible and inclusive online events for regular and ad-hoc PAG meetings and periodic open public meetings.
 - Action 1: Plan online events with accessibility features like closed captioning and screen reader compatibility. Align events with major project milestones and website launches.
 - Action 2: Provide regular updates through newsletters and social media to ensure broad participation. Provide large print versions and adhere to accessibility best practice guidelines.

PAG member Representation on Intra NetZeroAICT Leadership Groups

- 12. Objective: Ensure PAG representation in decision-making groups within the project.
 - Action 1: Maintain an up-to-date leadership diagram available to the PAG for clear representation.
 - Action 2: Facilitate nomination and selection processes for PAG representation in key groups such as Ethics Management Group, Project Steering Group, and IP Management Group.

- Action 3: Schedule at least one dedicated PPIE meeting with all work package leads by the end of month 4 to ensure protocol is established. Ensure ongoing engagement and representation.

13. Engagement with NetZeroAICT personnel

- Objective: Expand reach and foster interactive engagement with the project team and partners.
 - Action 1: Utilise the project team mailing list, public involvement promotion in project meetings, and interactive webinars, encouraging NetZeroAICT staff and partners to share the initiative and participate actively.

14. Continuous Feedback Mechanism and Improvement

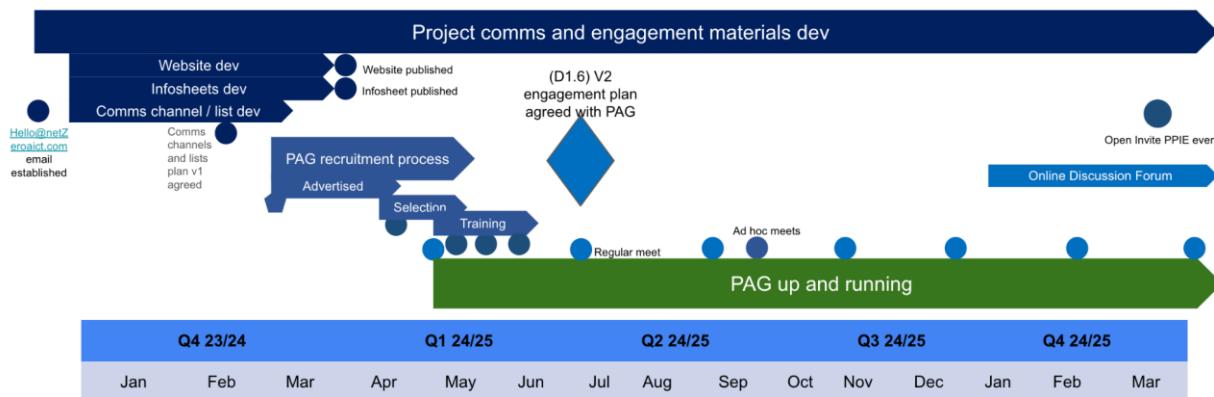
- Objective: Adapt and improve engagement strategies based on participant feedback.
 - Action 1: Implement post-event surveys and establish a continuous feedback loop for strategy adjustment and improvement. The evaluation framework is to be agreed upon with the NetZeroAICT ethics lead.

15. Robust Data Protection and GDPR Compliance

- Objective: Uphold the highest standards of data protection and Open Science standards.
 - Action 1: Regularly review and update data protection practices and conduct a Data Protection Impact Assessment (DPIA) in alignment with GDPR requirements. Ensure continuous alignment with data protection standards and practices.

Timeline

D1.5 Public and patient engagement mechanism plan V1 - draft



3. Conclusions

In conclusion, the NetZeroAICT - PPIE Engagement Mechanisms Plan balances the technical requirements of GDPR compliance with the human-centric goal of inclusive community engagement. Through a series of well-defined actions ranging from interactive data collection to event planning and continuous feedback, the plan sets a clear path for engaging diverse communities effectively.

This V1 plan will be superseded by a V2 plan developed with the Public Advisory Group and published in M7 (D1.6).

4. Degree of progress

This PPI engagement mechanisms plan marks a key first step in ensuring appropriately broad and deep engagement mechanisms and creates the foundation for an inclusive, diverse stakeholder engagement putting patients and the public at the heart of the NetZeroAICT project and enabling associated work streams to benefit from an actively engaged patient and public community.

5. Dissemination level

Across the NetZeroAICT team. To be made public on the website.

6. Annexes

Annex 1

Interview plan outline (draft)

The interviews will be held as group discussions with <8 patient / public participants and three members of the NetzeroAICT project team.

- Intro - Project leads open and lead introductions
- About the project
 - Aims
 - Schedule
 - Selection criteria
- Discussion topic -
 - Why do you think this area of work is important?
 - Are there key issues or concerns that you would like to have raised in discussions?
 - Discuss the points raised
- Next steps

Interview scoring criteria draft

This scoring system is tailored to be accessible and relevant for members of the public participating as patient and public representatives in the NetZeroAICT project Public Advisory Group. It emphasizes the importance of constructive feedback, effective group communication, and critical thinking in a respectful and inclusive manner. The additional weightings for candidates from diverse backgrounds aim to enhance the diversity and inclusivity of the group.

Interview Scoring Sheet for Digital Critical Friends

Candidate Name:

Interview Date:

Scoring Criteria

- Constructive Criticism
 - Positive Score (0-5): Capable of providing thoughtful and useful feedback. Shows an ability to identify areas for improvement and suggests helpful ideas while remaining kind and respectful.
 - Negative Score (-5 to 0): Offers criticism that is harsh, unhelpful, or personally targeted; lacks a supportive approach.
- Collaborative Communication

- Positive Score (0-5): Effective communication within a group, fostering a friendly and inclusive atmosphere. Listens well and responds thoughtfully to others' ideas.
 - Negative Score (-5 to 0): Struggles with communication in a group setting, may disrupt group harmony or overlook the contributions of others.
 - Critical Thinking
 - Positive Score (0-5): Demonstrates the ability to think deeply about topics, providing insightful and reasoned viewpoints.
 - Negative Score (-5 to 0): Shows a lack of depth in thinking through issues, unable to articulate clear and reasoned opinions.
 - Respect and Tolerance
 - Positive Score (0-5): Maintains a respectful attitude towards diverse opinions and backgrounds in discussions.
 - Negative Score (-5 to 0): Exhibits disrespectful behaviour or intolerance towards differing views and people from different backgrounds.
-

Additional Considerations

- Sociodemographic Information:
 - Provide additional positive weightings (+1 to +3) for candidates from underrepresented or marginalized groups.
- Experience of CT scans with Digital Contrast
 - Provide additional positive weightings (+1 to +3) for candidates with experience of CT scans

Total Score: [Calculate the total here]