**Terms of Reference for the Research Participant Toolbox Workshop**

**1. Background and rationale:**

In August 2024, the Director-General of the World Health Organization (WHO) declared that the recurrence of monkeypox a public health emergency of international concern (USPPI) under the provisions of the International Health Regulations (IHR) 2005. In the same month, Africa CDC declared the event a Public Health Emergency of Continental Concern (PHECS) for the African continent. Since August 2024, cases of transmission have been reported in all six regions of the world. The African WHO region is the most affected, with the Democratic Republic of Congo (DRC), Burundi and Uganda (1) being the most affected countries in the region.

The WHO has issued recommendations for the control of monkeypox. These recommendations advise member states to invest in meeting evidence-based needs. As communities are at the center of all research, they must have a clear understanding of their rights. Without this knowledge, their consent could be based on incomplete information, misunderstanding of risks and benefits, or undue influence. Informed consent, a fundamental pillar of research ethics, is mandatory.

It is within this framework that the toolbox on research ethics developed by partners will be implemented during workshops in the DRC to enable people with limited education and those with no prior experience to understand and decide whether to participate in any research that respects their rights and ethics.

**2. Workshop objectives**

To better equip communities in understanding and evaluating their decisions to make an informed choice about their participation in health research.

**4. Expected results:**

* 20 participants are better equipped to make a fully informed decision about taking part in any research, while respecting their ethical rights;
* 20 workshop participants are able to pass on what they have learned to members of their communities.

**5. Target audience:**

Participants will mainly come from affected communities in all their diversity (PLHIV, PS, LGBTI,).

**6. Workshop content (Topics to be covered):**

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| **Time** | **Activity** |
| 8:00–8:30 | Registration / Arrival |
| 8:30–8:45 | Welcome and program of the day |
| 8:45–10:00 | Reflexivity exercise 4 (Facilitator's Guide, p.95)Topic: Personal and community values, and the value of health research* Small groups deliberate on 4 questions (Agree/Disagree/Why) (35 minutes)

(p. 95 Nouvet* Research is useful
* Research conducted in (country) does not necessarily benefit the population of (country)
* Participation in research benefits participants
* Participation in research benefits others
* Large-group sharing of small-group discussions and facilitator's reflections (30 minutes)

- Statement of workshop objectives: building confidence in assessing the usefulness, benefits and risks of research (10 minutes) |
| 10:00–10:15 | Coffee/tea break |
| 10:15–11:30 | How and why do clinical trials appear in public health emergencies?* Orientation to theme 1/Ch. 1 of the Facilitator's guide + film: The difference between clinical research and health care (30 min)
* Orientation to theme 2 / Ch. 2 + film: Stages in drug development (30 min)
* Orientation to theme 3/Ch. 3 + film: Key players and decision-makers (30 min)
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| 11:30–12:30 | Rights of research participants* Presentation of the flipbook and posters (p. 89, PRET Facilitator's Guide) + Discussion/brainstorm on the use/clarity of the workshop in/for the DRC context

(30 min)* Orientation to topic/chapter 4 + film: To participate or not to participate in research (30 min)
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| 12:30–1:30 | Lunch break |
| 1:30–2:30 | The decision to participate in research* Activity 1, Chapter 4 (PRET Facilitator's Guide): Staging decision-making scenarios
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| 2:30–3:00 | Bio-samples* Overview of films in the toolbox (not screened in session)
* Activity 1, Chapter 5 (PRET Facilitator's Guide: Anticipating questions about bio samples)
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| 3:00–3:15 | Coffee break |
| 3:15–4:15 | Reflexivity exercise 2 (Facilitator's Guide, pp. 92-94)Identity categories and facilitation, or the importance of diversity of experience, position and power. |
| 4 :15-4:30 | Questionnaire/feedback* Participants are invited to give their feedback via a questionnaire
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| 4:30–4:45 | Closing the session* Certificate distribution
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**7. Methodology:**

* Introductory and interactive presentations.
* Practical demonstrations on how to use the toolbox.
* Individual and small-group exercises.
* Discussions and exchanges personal experiences.
* Case studies or concrete examples.
* Q&A sessions.

**8. Workshop duration and date:**

The workshop will take place over two days, from June 24 to 25, 2025 in the conference room of the AFRICANA PALACE hotel in Kinshasa, DRC.

**9. Facilitators:**

* Prof. Elysée Nouvet
* Prof., Felicien Munday
* Prof. Mandy Kader Kondé
* Mr. César Mombunza

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