HEREDITARY Advocacy Workshop: Mockup Policy Exercise Instructions – 30/06/26

Welcome to the Mock-up Policy Exercise! During this session, you will step into the shoes of key stakeholders to navigate real-world tensions in cross-border harmonization, data access, and healthcare ethics.

1. Session Flow

16:00 | Introductions and Icebreaker

- Quick intros: Share your name and professional background.
- Icebreaker discussion: “In an ideal world without constraints, what is the most effective policy to support better cross-sector collaboration or ethical AI health tools?”

16:15 | Stakeholder Simulation

- Role assignment: Your moderator will assign you to one of five stakeholder roles (see below).
- Deliberation: Work through your group’s assigned scenario (A or B) to surface ethical and regulatory tensions.
- The deliverable: Formulate a short, defensible policy recommendation based on your scenario’s task.

16:45 | Plenary & Presentations

- Return to main room: All groups reconvene.
- Consensus pitch: Your group’s designated spokesperson will present your final recommendation to the room in under 30 seconds.

2. Stakeholder Role Cards

Embrace your assigned perspective during the deliberation. Your goal is to advocate for your role’s specific priorities while working toward a group consensus.

Role	Your Perspective	Your Primary Goal

Research Scientist	You are the lead scientist on the project. You care deeply about scientific accuracy and continuity. You must advocate for the scientific evidence to the rest of the group.	Ensure the science is not oversimplified or dismissed in the final decision.
Patient Advocate	You represent patients and their families. While not a scientist, you hold the most important lived experience factor in the room.	Ensure patient voices, safety, and needs remain the absolute centre of the discussion.
EU Policymaker	You work for a health ministry or EU agency. You understand the legislative process and must balance innovation, safety, and fairness.	Land on a recommendation that is both legally defensible and politically realistic.
Legal Expert	You specialize in health and data law (like GDPR). You aren't here to block progress, but to ensure rules are followed safely.	Identify obstacles and suggest pathways forward.
Industry Representative	You represent a biotech or health-tech company. You have resources and believe that delaying innovation costs both lives and investments.	Push to move forward quickly while genuinely engaging with the ethical concerns raised.

3. Policy Scenarios

Your moderator will let you know whether your group is tackling Scenario A or Scenario B. These scenarios deliberately lack a single "right" answer.

Scenario A: Multiple Sclerosis – Real-World Data & Treatment Access Equity

(Gut-brain axis / neuroinflammation / health data governance)

The Context: A Horizon Europe consortium has been studying over 4000 MS patients across seven EU member states. By combining gut health data, brain scans, and medical records, researchers discovered that patients with certain gut bacteria profiles respond much better to one type of MS medication than another; a finding that could help doctors choose the right treatment for each patient.

The Tension: A major health insurance company wants access to these research findings to update the rules on which treatments it will pay for. In practice, this could mean patients without the "right" gut profile are denied access to the more effective – but more expensive – treatment. Patient groups say this is unfair: patients never agreed to have their data used this way, and being refused a treatment based on their gut bacteria is a new and worrying form of discrimination. The research consortium's data agreement does not allow for insurer access, and getting new consent from all 4000 patients is not realistic.

The Task: Should the consortium share its findings with the insurance company? Your group must agree on one position: Yes / Conditional Yes / No – and name one rule or policy that should exist to make this kind of decision clearer and fairer in the future. Your recommendations should be readable aloud in under 30 seconds.

Scenario B: Stroke – AI Triage & Liability at the Clinical Frontier

(AI diagnostics / medical device regulation / clinical urgency)

The Context: A research consortium has developed an AI tool that helps doctors make faster decisions when a patient arrives at hospital with a stroke. In test hospitals, the tool helped get

patients into treatment 22% faster, which can mean the difference between recovery and permanent disability. However, under EU rules, this type of AI tool must go through a lengthy approval process before it can be used widely. Three hospitals want to start using it right now.

The Tension: There is an important question no one has answered yet: if the AI recommends against a treatment and the patient gets worse, who is responsible – the hospital, the company that built the AI, or the doctor who followed (or ignored) its advice? EU law does not currently give a clear answer. The official approval body has asked for 18 more months of data before giving the green light. But doctors argue that waiting 18 months costs lives since the evidence they already have is strong.

The Task: Your group must agree on one position: Use the tool now under close supervision / Wait for full approval / Ask the European Commission for urgent guidance – and agree on one change to EU rules that would make it clearer who is responsible when AI is used in life-or-death medical decisions. Your recommendations should be readable aloud in under 30 seconds.