Bridge-Health Project
Cyprus Meeting
22st September 2017

Privacy and Ethics Impact and Performance Assessment (PEIPA)

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PEIPA Questionnaire

- **Scope:**
  - To acquire detailed information on how data is processed by involved participants: EUBIROD, ECHO and EUROHOPE consortia
- **Aims:**
  - To determine the level of privacy and ethics compliance
  - To evaluate heterogeneity in the implementation of privacy-ethical principles
  - To identify key areas of concern
  - To determine an optimal level of privacy and ethics (best practices) to be used as benchmarks for privacy/data protection and ethics clearance

Privacy and Ethics Factors

- *Responsibility for Personal Data*
- *Collection and Use of Personal Data*
- *Consent,*
- *Data Sharing,*
- *Data Linkage*
- *Access and Accuracy of Personal Data*
- *Safeguarding Personal Data*
- *Anonymisation Process*
- *Openness*, Transparency and Public Engagement
- *Transparent Project Approval Processes*
- *Beneficence/Non Maleficence in Health Research Project Approval Processes*

Results

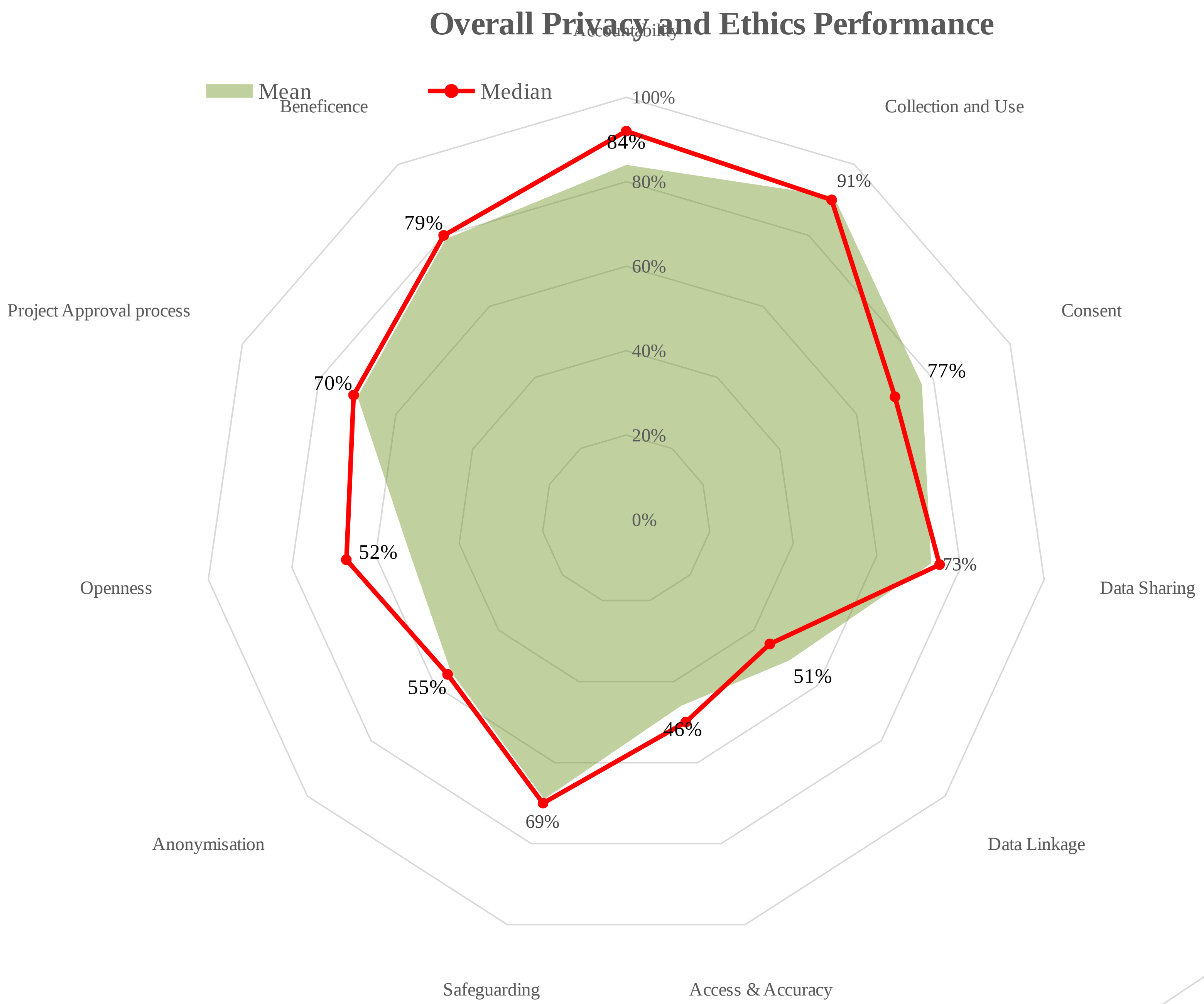
1. **Main findings from single questions:**
   - overall percentage of YES-NO-N/A responses registered by the whole sample for each of the selected questions
2. **Factors:**
   - scaled scores achieved by the whole sample in each privacy and ethics factor.
3. **Overall privacy performance evaluation:**
   - overall level of privacy/data protection and ethics achieved by the whole sample
   - Privacy/Data protection and Ethics Performance by Consortia
4. **Privacy/Data protection and Ethics Profile of Participating Centres**

Standardized Comparison of Factor Results

- **Median values indicate most problematic areas:**
  - Data Linkage (45%)
  - Access and Accuracy (50%)
  - Anonymisation (56%)
- **High variability of scores (range):**
  - Data linkage (30%-80%)
  - Access and accuracy of personal data (0%-100%)
  - Safeguarding personal data (30%-100%)
  - Anonymisation process (11%-100%)
  - Openness, transparency and public engagement (0%-100%)
  - Transparent health research projects approval process (14%-100%)
  - Data sharing (50%-100%)
  - Beneficence/Non-maleficence

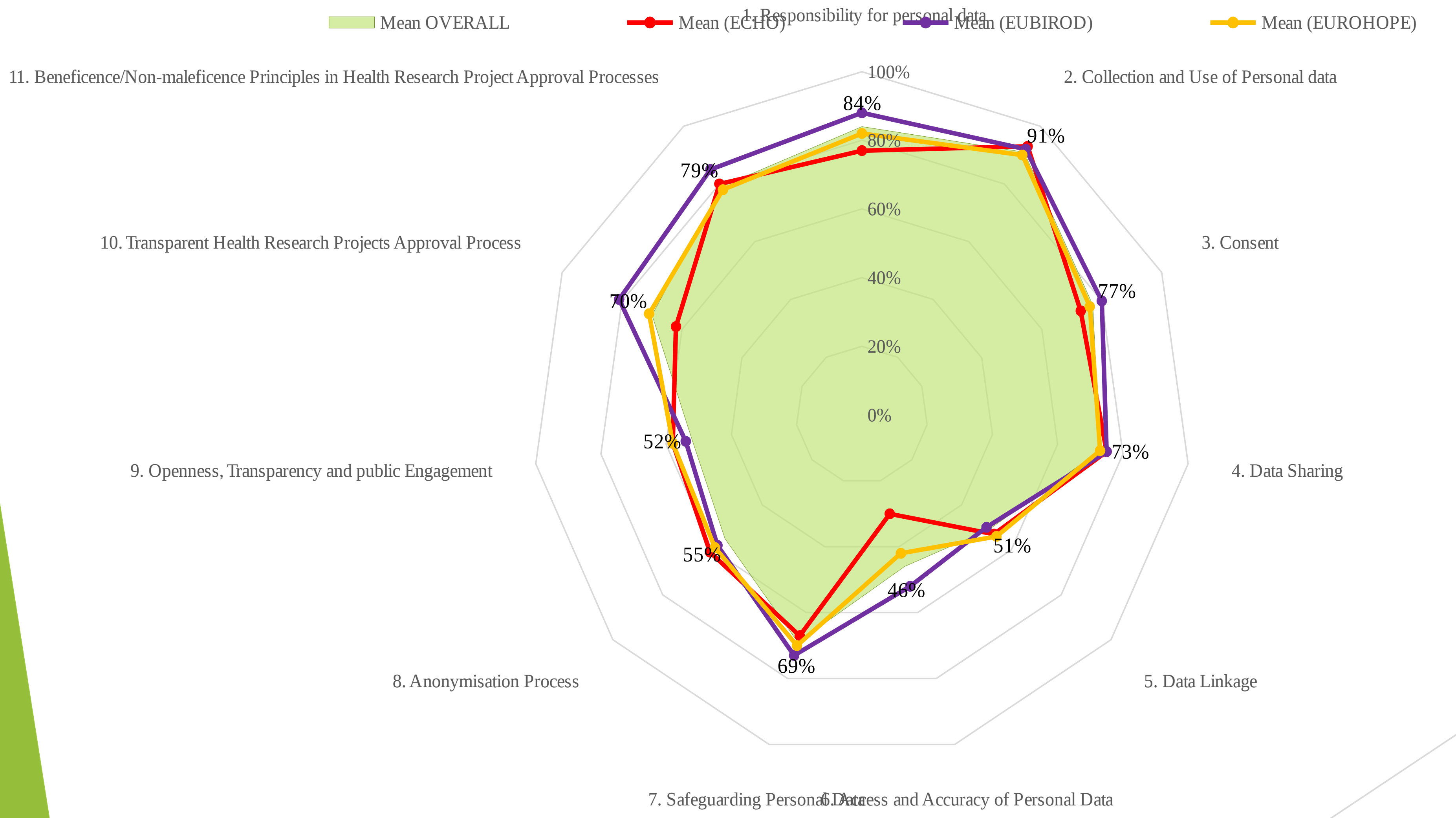
Overall Privacy and Ethics Performance

- The average and median of scores obtained by the whole sample allows:
  - the evaluation of the overall level of privacy/data protection and ethics performance of the sample
  - observed against the highest attainable level



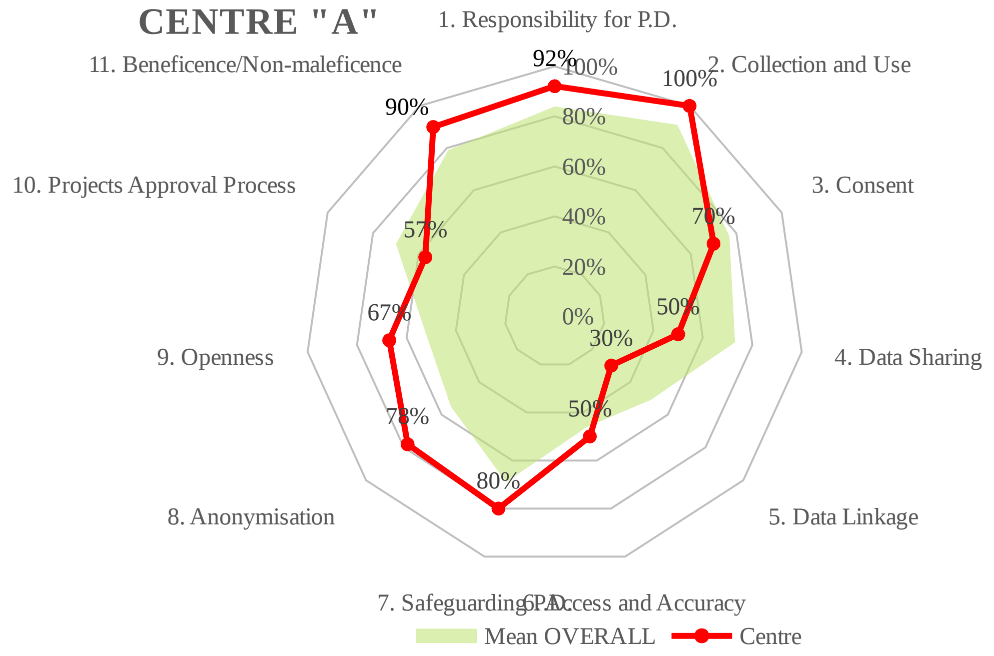
Overall Privacy and Ethics Performance

ECHO, EUBIROD and EUROHOPE Performance by Factor

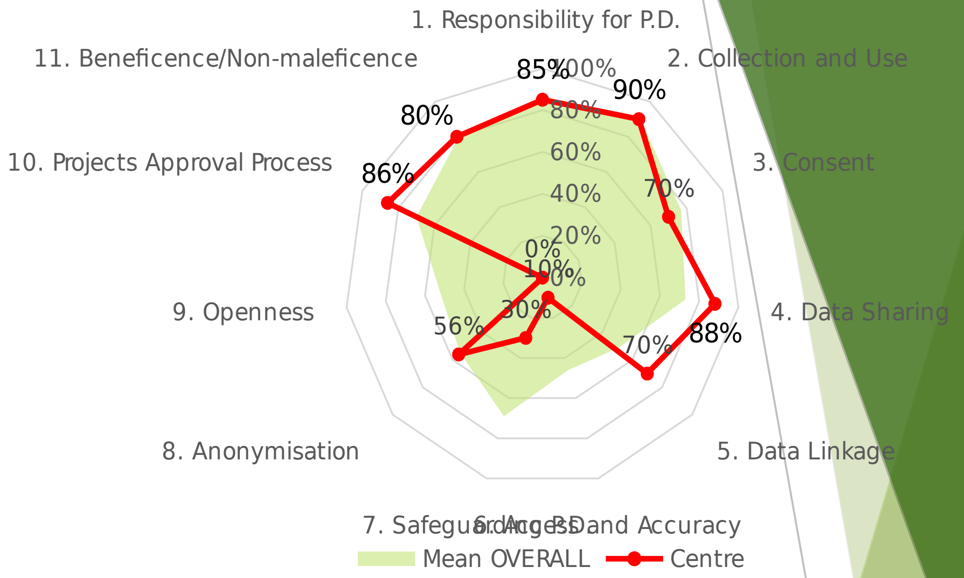


- The light green area highlights the mean results of the whole sample
- The red, violet and orange lines describe the results, by factor, of each consortia: ECHO, EUBIROD and EUROHOPE

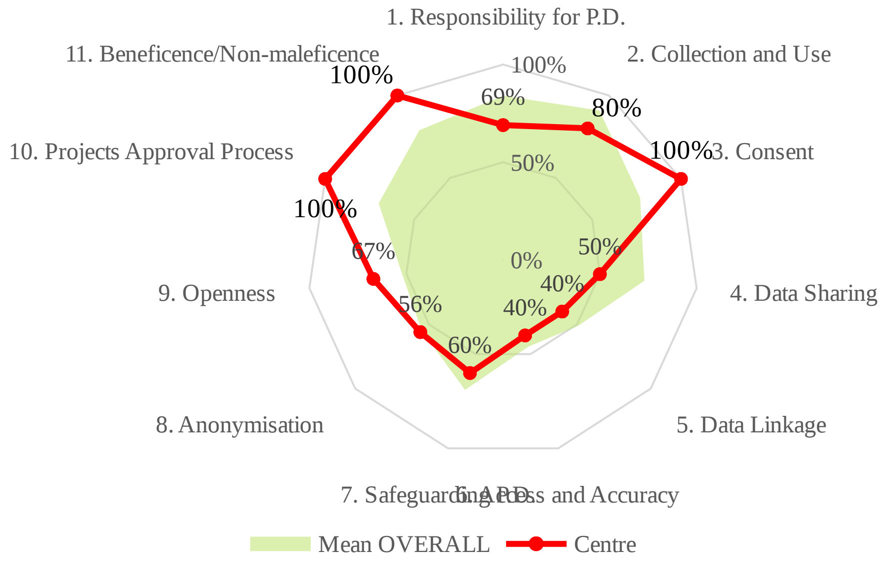
CENTRE "A"



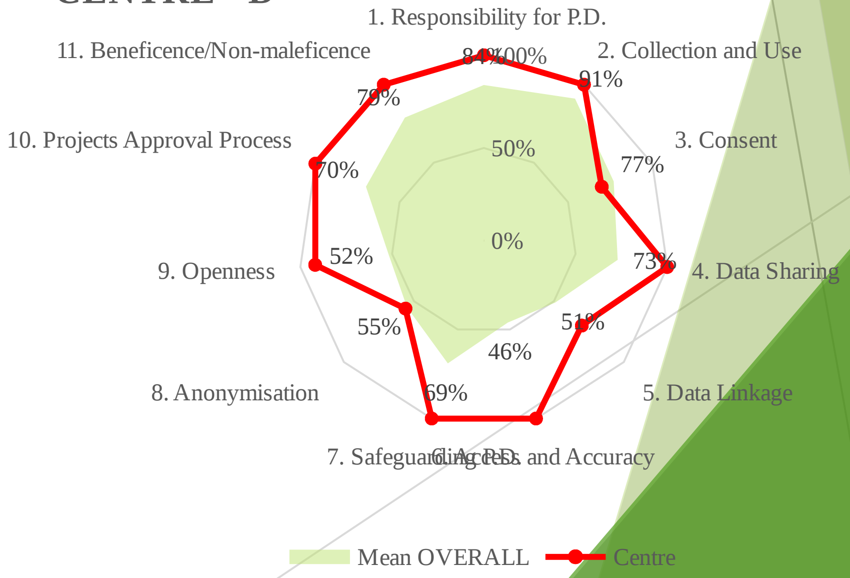
CENTRE "B"



CENTRE "C"



CENTRE "D"



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- **Table of scores relative to factors results modified:**
  - The Panel felt that a performance below 60% should be considered “poor”
  - Report to be updated accordingly
- **Questionnaire results scoring tables:**
  - Modification of score in sections 4 (data sharing) and 9 (Openness)
- **Mechanisms to avoid respondents mistakes in filling in the questionnaire:**
  - Inclusion of key questions at the beginning of sections that would detect if the section is or is not applicable to the respondent
  - Possible inclusion of an automated selection of N/A as a consequence of specific responses in a given section, if self-evaluation tool will be implemented; possibly also across some sections
- If self-evaluation tool will be implemented, the web questionnaire will have to include the latest updates on the questionnaire, as agreed with the Panel of Experts
- **Provide feedback to study participants (centres’ spider webs)**
- **Final report**
  - To clearly indicate that sections of the questionnaire include both questions aimed to assess legal compliance and best practices
- Publish article on relevant international journal

Bridge Health Deliverable Final Report

- **Final Report:**
    - describe the ethical and privacy issues involved in the management of the above information systems and
    - provide results of the Privacy and Ethics Impact and Performance Assessment
    - provision of objective benchmarks to identify best practices in the implementation of privacy and ethically compliant disease registries/information systems/databases.
- The WP11 **chapter on Privacy Impact Assessment** will be delivered at Month 30 (end of October 2017)**.**