

**EphMRA Committee Telephone Meeting: Minutes & Actions**  
**19 September 2019**

<b>EC members</b>	Jessica Santos (JS)	Analia Revaux (AR)
	Xander Raijmakers (XR)	Matteo Scaringi (MS)
	Roni DasGupta (RDG)	Bernadette Rogers (BR)
	Christine May (CM)	Mattias Blomgren (MB)
	Karen Giorgio Vigo (KGV)	Matteo Cappai (MC)
	Chloe Simmons (CS)	Alex Adams (AA)
	Anne Beatrice Clidassou (AB)	Piergiorgio Rossi (PGR)
<b>Please kindly remember that all EC discussions should remain confidential</b>		

**MINUTES & ACTIONS**

	<b>Topic</b>	<b>Who?</b>
<b>1</b>	<p><b>Introduction and apologies</b></p> <p><b>Follow up actions from June 2019 Warsaw conference meeting</b></p> <p>Actions from Warsaw included in September agenda topics discussed during TC</p>	
<b>2</b>	Reviewed Camilla's Basel 24 September slides from EFAMRO for comments/feedback, and to address topics below	
<b>3</b>	<p><b><u>Code of Conduct</u></b></p> <p>Review Decision Tree (<i>refer slides 6, 10</i>) – comments / feedback</p> <ul style="list-style-type: none"> <li>Agreement that the flow is good and as a starting point for (GDPR) roles and responsibilities. It's not answering the main questions people (commissioning company, agency, and fieldwork) are asking.</li> <li>Key question: who is (joint) controller? This is a significant question for the commissioning company, especially when the company is a (joint) controller. Disclosure of the name of the commissioning company is required. Raises issues, e.g. bias, ethical (e.g. require subject's name disclosed for MR fee received?), subject's withdrawal on disclosure of company name.</li> <li>Similar concerns for agencies. Commissioning companies vary in how they define the roles of controller. Reflects differing interpretation on GDPR in MR by companies and their legal departments. Agencies must respect the company's decision on who is controller and if they are identified or not during MR.</li> <li>Camilla provided a clear explanation at Warsaw (EC and main meeting) on this. If the sponsor company doesn't want to be named and doesn't want to be controller, they are not interested in anything during the MR study.</li> </ul> <p><b><u>Three key scenarios:</u></b></p> <ol style="list-style-type: none"> <li>Company determines they are the controller</li> <li>Company determines that the agency is the controller</li> <li>Company determines both they and the agency are joint controller</li> </ol> <p><i>Only scenario 2 allows for sponsoring company not to be identified.</i></p> <p>The main issue on role of controller requires specific guidance for MR.</p> <p><b>Action:</b> EC to now develop the flow chart to meet its own needs - particularly the need for clarity and guidance for MR.</p>	BR

4	<p><b><u>GDPR Research Code</u></b></p> <p><i>Refer slides 3-13</i></p> <p>Slides provide the main scope and focus but <u>no timeframe</u> for when it will be available</p> <p><b>Action: Ask Camilla when the code will be available; update EC on expected timing</b></p>	BR
5	<p><b><u>AI/Digital</u></b></p> <p>Discussed key issues relevant to Ethics and Code for EphMRA members and other external stakeholders.</p> <p>A key issue is the lack of clear ethics on the use of AI generally and specifically MR</p> <p><b>Concerns:</b></p> <ul style="list-style-type: none"> <li>Global tech companies', e.g. Google, Apple, &amp; Amazon's smart devices can listen and record peoples' conversations without their being aware this is happening. Will EU regulators apply GDPR more stringently to tech companies, or everyone? How does this affect MR? Implications for audio and/or video MR recordings?</li> <li>The <b>correct consent</b> to collect and use personal data must ethical. Consent for future uses? Future use not defined? Need clear ethics and guidance.</li> <li><b>Risk of bias:</b> unintended bias in data collection and processing gives biased results. Combining bias in different data sets will compound the problem. The algorithm might be good, but output will be biased, unethical or rubbish ('garbage in, garbage out').</li> <li><b>Risk of re-identification</b> of a data subject: analysis by AI of anonymised data set, or combining different sets, creates the risk of identification of an individual(s).</li> <li><b>Evolving AI/digital technologies</b> poses further risk and questions, e.g. analysis of voice to text.</li> </ul> <p><b>Action: Provide EC feedback to Camilla to follow-up on.</b></p>	BR
6	<p><b><u>Oct 2019 – Sep 2020 Planning</u></b></p> <p>Agree top 3 – 5 priority topics to work on during the year, e.g. Code of Conduct, Decision Tree, AI/Digital, Webinars, etc.</p> <p><b>Priorities</b></p> <ol style="list-style-type: none"> <li>Restructure (streamline &amp; user-friendly) Code of Conduct</li> <li>GDPR Research Code (ERDAA) (incorporate in 2020 Code)</li> <li>Develop Decision Tree to provide a clear, practical flow, especially role of Controller</li> <li>Adapt Code templates to improve practical usability (Action: for AR)</li> <li>Healthcare Outcomes studies in 'Differences between MR, PSP and NIS' table (Code of Conduct 2019, p18 – for 2020 Code update)</li> <li>Assess impact of EU e-Commerce Directive</li> <li>Screening guidance to cover GDPR related issues, e.g. questions on disclosure</li> <li>Assess impact of CCPA on US MR (and globally) (Action: for RDG)</li> </ol>	AR       RDG
7	<p><b>AOB</b></p> <p>None – meeting closed</p>	