

EphMRA Committee Telecon: Minutes & Actions  
27 September 2018

Participants:	Analia Revaux	Georgina Butcher – Chair
	Xander Raijmakers	Roni DasGupta
	Matteo Cappai	Piergiorgio Rossi
	Jessica Santos	Bernadette Rogers
Apologies	Christine Mai	Jayne Blanshard
	Kate Barber	Anne Beatrice Clidassou
	Mattias Blomgren	
Please kindly remember that all EC discussions should remain confidential		

**MINUTES & ACTIONS**

<b>1</b>	<p><b>Minutes Follow ups from June meeting</b></p> <p>Some outstanding actions which Bernadette has only just started to sort out once the MRS/EFAMRO service has got going. But confident that EFAMRO will provide a great service. EphMRA working with a newly appointed EU Policy Manager at the MRS to provide additional resource to support Ethics.</p> <p>EphMRA to ensure that it is clear to Members and external stakeholders that Ethics guidance, tools and communications reflect a wider European/International healthcare market research perspective. Care will be taken to avoid misperceptions that MRS resource is a UK centric approach.</p> <p>Feedback from members showed that we needed to provide more frequent and relevant Ethics communications and so there will be a regular (monthly) Ethics newsletter to highlight GDPR and related DP topics (wider perspective) from Oct-18 onwards. EFAMRO will draft the content using their wider network of resources and send to EphMRA for approval.</p> <p>We will also encourage people to share any linkedin contact and to forward the email to other colleagues and internal stakeholders (not just MR/BI colleagues).</p>
<b>2</b>	<p><b>GDPR and Members Survey</b></p> <p>The EphMRA members survey echoed the feedback from the BHBIA.</p> <p>Members are encouraged to share the results with legal, privacy and PV departments to increase awareness.</p> <p>EphMRA should be working on guidance (not guidelines). Emphasise the importance of discussing this with appropriate legal input.</p> <p>GDPR</p> <p>Actions:</p> <p>EphMRA press release and to maximise the GDPR survey findings to Members and wider MR community – end Oct-18.</p>

	<p>Communication: simple, clear Press Release reminder of key points in guidance that not automatic to determine end client as Data Controller or naming them. Emphasis on <b>reviewing on case-by-case</b> (MR project) basis and <b>documenting rationale for decision</b> to determine roles of end client and agency, e.g. in project agreement or similar. A documented rationale supports an argument on the decision to determine DC/naming end client and allows members to shape their GDPR (consent language, etc) accordingly, i.e. not one-size fits all solution by end Oct-18.</p> <p>Communication: emphasise EphMRA working with other European MR associations lobbying EDPBs and regulators to a) escalate the consequences of GDPR on MR as a greater priority to address and b) agree a suitable solution to provide clear guidance to MR community end Oct-18</p> <p>Ethics to assess country Data Protection variations. One option is to provide a simple table with links to key resources. Analia has forwarded the table at the end of the minutes – could this be developed for all countries? Action for next EC call Nov-18.</p>
<p><b>3</b></p>	<p><b>US Sunshine Act</b></p> <p>Roni and Jessica gave an update on the California Bill (similar in some ways to GDPR). In the US privacy is governed at a state as opposed to federal level. Might be useful to have a table showing state variations on data protection.</p> <p>Roni will send over the Vermont data regulation on consumers plus the analysis for the Insights Association. EphMRA can update members on what the different states position is. It would be good to have access to the Insight Association guidelines and to share with Members if possible.</p> <p>Comms to highlight state changes (not Federal level), monitoring but to-date little impact as still working through the legal system.</p>
<p><b>4</b></p>	<p><b>AER Guidelines – BHBIA change</b></p> <p>AER guidance - Actions</p> <p>BR to draft agreement on BHBIA/ABPI position (need draft statement for EG to review and agree ASAP) for EC feedback before end Oct-18</p> <p>EphMRA engage EFPIA and EU PV network – longer term – develop guidance end Nov-18</p> <p>The EC industry members to discuss with their internal PV (Global/EU) for perspective if, how and when any changes in AE reporting for patients/consumers across EU to be implemented – EU wide or country by country? EC members to provide BR with feedback before end Nov-18 latest.</p>

### Releasing client's name when Transfer of personal data (Data controller or not)

	Obligation of releasing sponsor's name	Before the interview	Option to wait until the end of the interview	Comments
Central Location viewing in person	No			This is not a transfer of personal data
Viewing Live streaming/listening Live interviews	Yes	Yes		Videostreaming/audiostreaming is a transfer of personal data
Viewing delayed streaming/ FV archive	Yes		Yes	Must be revealed before the client has access to the Archive
Access to recordings	Yes		Yes	Must be revealed before the client get access to the Recordings
Blurred FV and sim trans voice	No			This is not a transfer of personal data, however personal details can be said during the interview
No transfer of personal data (transcription, reports, contents both video and audio recording)	No			personal details can be said during the interview and therefore can be transcribed
Listening to live audio-recording	Yes			Transfer of personal data
Delayed / Archived listening to audio-recording	Yes		Yes	Must be revealed before client has access to the Recording
Access to audio recordings	Yes		Yes	Must be revealed before client has access to the Archive

### When must we release the Data controller's name?

Before the interview	Option to wait until the end of	Comments

		the interview		
Central Location viewing in person		Yes		
Viewing/Listening Live streaming	Yes	No		
Viewing delayed streaming/ FV archive		Yes		Must be revealed before the access to the Archive
Access to recordings		Yes		Must be revealed before the access to the recordings
Blurred FV and sim trans voice		Yes		
No transfer of personal data (transcription, reports, contents both video and audio recording)		Yes		
Listening to live audio-recording	Yes			Transfer of personal data
Delayed / Archived listening to audio-recording	Yes		Yes	Must be revealed before client has access to the Recording
Access to audio recordings	Yes		Yes	Must be revealed before client has access to the Archive