EphMRA Committee Meeting: Minutes & Actions
24 June 2019
Hilton Warsaw Hotel & Convention Centre, Poland
13:30 – 15:30 local

Participants	Jessica Santos (JS)	Analia Revaux (AR)
	Karen Giorgio Vigo (KGV)	Matteo Cappai (MC)
	Mattias Blomgren (MB)	Alex Adams (AA)
	Camilla Ravazzola (CR) (EFAMRO - stand in chair)	Piergiorgio Rossi (PGR)
	Xander Raijmakers (XR) (via Skype)	Anne Beatrice Clidassou (AB)
Apologies	Roni DasGupta (RDG)	Bernadette Rogers (BR)
	Chloe Simmons (CS)	Christine May (CM)

Please kindly remember that all EC discussions should remain confidential

MINUTES & ACTIONS

	TOPIC	LEAD
	Introduction and apologies **Welcome by Camilla (stand-in chair)**	CR
1	**Follow ups from May 2019 call** *Ongoing monitoring US Sunshine Act (**KVG**) and general DP (**JS**): **ACTION: follow-up Sept*** *Camilla to provide update on EFAMRO/ESOMAR Code collaboration (refer section 2 below)*	CR
2	**<u>Update from EFAMRO</u>** Refer CR's slides attached to Minutes CR provided an overview of the European Data Protection Board's (EDPB) summary of the key impact and implications **one year** after implementation of GDPR. (Refer attached EDPB slide for key numbers) ➢ Number of data breach notifications >89,000 ➢ Number of queries and complaints to Data Protection Authorities >144,000 ➢ High proportion of people (57%) aware of DP Authorities (+20% since 2015) The EDPB has not provided additional guidance on GDPR although this is expected as sector level, including for market research. No time frame is available for when guidance might be available. There is little in the way of local guidance from most national supervisory authorities. However, the guidance provided by the Hungarian National Supervisory Authority on 'erasure of personal data' and 'destruction of data carriers' was too detailed and led to further confusion. It should be noted that Supervisory authorities act on an individual's complaint, not in their own right (i.e. reactive). **Examples of complaints and resulting actions:** ➢ France – fined Google €20,000 for failure to secure users' data ➢ Ireland – big tech industry and focus on investigating Facebook ➢ UK – first case law regarding anonymisation of clinical trial data. An individual submitted a Freedom of Information (FoI) request to access the trial data. This was	CR

	denied on the grounds that it could lead to re-identification of individuals who participated in the clinical trial (key part in GDPR). The large volume of data and design of the metadata would make the likelihood of re-identification high. **ACTION: CR to provide summary of UK case to EC by Sep-19** • **Key issues EFAMRO is looking at which might be relevant to EphMRA** Healthcare and market research industries are both heavily regulated, but further guidance on related topics, e.g. protection of data of children is relevant. At present supervisory authorities' focus is on social media as the area generating most complaints. • **GDPR Guidelines Update – status** EphMRA and ESOMAR initiative (open to other associations to join) is to develop a GDPR code of conduct. The objective is to provide guidance relevant to the market research industry, but not sector specific. The GDPR code will avoid duplication of existing guidance on GDPR and national references. GDPR Article 14 mentions of the possibility of a code with the EDBP providing additional guidance on codes of conduct. Neither provided sufficient clarity and this has resulted in further misunderstanding on what such a code should 'look like'. EFAMRO and ESOMAR are drafting a GDPR code which should be completed by end 2019 ready to send to the EDPB early 2020 for their review and comments. Their acceptance or approval of such a code is the first major hurdle. The next and bigger hurdle is review, comment and approval by the individual EU national supervisory authorities. It is difficult to set a timescale for these two steps in the process. EC asked for the opportunity to review and input to the working draft. **ACTION: CR to provide working draft GDPR code to EC for their comment by Sep-19.** • **Possible points of collaboration EFAMRO – EphMRA** GDPR guidance remains a central part of the collaboration.	
3	**<u>2019 Code of Conduct</u>** • Comments CR summarised main updates to 2019 code: ➢ Improved design and readability ➢ Updating key references to individual countries (avoiding duplication) ➢ Some parts are new or have moved (refer Log of Changes document) • Required by mid-July as online training must to be updated ready for September **ACTION: Urgent EC provide final comments on draft Code to BR/CR <u>before</u> end July 2019.** Main points of discussion on modifications for the next Code update, i.e. mid-2020. Two key options emerged: i. Slimmed down, core Code with separate documents for detailed key guidance, templates, etc (e.g. similar to BHBIA core code and separate guidance documents)	CR

	ii. Retain single comprehensive code but identify ways to improve usability and searching Additionally, moving to a fully online code was also raised. Overall the EC felt this was an option to include alongside a hard paper (printable) version, i.e. not a replacement. The argument reflects the general belief that it's important to retain a single hard copy of the Code to ensure consistency, correct linking of information and version control. Concern raised by EC member regarding the templates included in the Code, especially on consent. It was felt that whilst the templates were well designed and helpful, they are not 'legally' binding, i.e. mandatory to use. Examples given where clients, agencies and fieldwork agencies have adopted the templates, but others insist on using their own templates and/or wording. This highlights the ongoing different interpretations on key parts of the guidance, particularly GDPR / consent. On balance it was agreed the templates should remain within the code, but for the EC to consider how to strengthen and improve them. A further suggestion raised was to create a team of country consultants (client and agency) to provide regular feedback to the EC, i.e. once or twice a year. ***[N.B Ethics Network should be mechanism to provide input on country changes, etc. Check that this is happening]***	
4	**<u>GDPR</u>** • Topics from EphMRA London, Feb-19 meeting details attached as Topic 1 and Topic 2 (the working groups at the tables) ○ Screener Guidance: review suggested screener questions on privacy • Include simple guidance on gender identity questions (refer article) • Sample flow chart/decision tree on application GDPR for MR users • Update / guidance on most likely scenarios UK leaving EU 31 Oct 2019 Focus on developing a decision tree fell out of discussions on previous sections. Deliberation on a decision tree centred on the need for a practical tool on decision making relating to GDPR to assist market researchers and other relevant users. **<u>Starting point</u>**: level of decision making to help define the roles of controllers and processors, or 3rd party. ➢ A key consideration is who is collecting and / or processing personal data? ➢ Are the data anonymised, pseudonymised, encrypted or metadata? If yes, the data can be processed and reported. An additional complication in design of a decision tree is the transfer of data outside of the EU. It raises contractual issues with non-EU organisations (e.g. clients, agencies, etc). It requires measures that are acceptable to the EU as a legitimate means to transfer data. This is often challenging as non-EU clients might not fully comply, e.g. insist on use of their own contracts. The status of 3rd country – of which the UK will become once it leaves the EU – adds complexity to the collection and processing of personal data. How could a decision tree help? The discussion concluded without clear action or a preferred model for the flow.	CR

	ACTION: EC follow up as priority action during next Ethics (TC) meeting to agree a flow and next steps.	
5	**Country updates** Quick overview highlighting any key updates re: GDPR or other ethics issues France, Germany, Italy, Spain, UK, other European, USA or International countries (included in Code) Not discussed – see action below **ACTION: EC members to provide short update on key country issues by email to BR/CR end August.**	EC
6	**Planning for 2019/20** EC to agree key issues (3-4) to address during 2019/20. Suggest limit to 3-4 issues. Agree actions for September call, with follow-up on these for rest of 19/20. **ACTION: EC agree key issues for next year's planning in Sep-19 TC meeting.**	EC
7	**AI/Digital** AI/digital solutions from tech (e.g. Apple, Google, Amazon), and Pharma / healthcare manufacturers are increasingly being adopted for healthcare, including patient use (refer sample articles). Their use is also increasing in MR methodologies and analytical tools. This raises interesting ethics-related issues, including: • How MR industry integrates and manages GDPR (and PV) requirements into its AI/digital offerings • How tech and healthcare manufacturers meet GDPR and other compliance requirements, both through adoption of AI/digital solutions, but also for MR (primary and secondary) • Guidance and/or information (e.g. FAQs sheets) to support tech and healthcare manufacturers, MR industry and other users of AI/digital solutions • Other? **ACTION: EC agreed important and carry over as topic to next EC (TC) meeting**	EC
8	**AOB** No additional AOBs Close of meeting	EC CR