# GDPR News - Impact of naming the end client – August 2018

## *Update on findings of the BHBIA member survey (July 2018)*

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As many members will be aware, the BHBIA alongside the MRS and EphMRA has been in discussions with the Information Commissioner's Office (ICO) about the interpretation of GDPR/DPA 2018 requirements on the determination of data controller(s) and the implications of naming the market research end client.

The questions we raised during our discussions are under consideration internally at the ICO and within the European Data Protection Board's (EDPB) Key Provisions subgroup and we are awaiting formal EU-wide guidance. In the meantime however, some of our members have been feeling the impact of this issue.

Consequently, in July, the BHBIA's Ethics & Compliance Committee surveyed members on the impact naming the end client as data controller is having.

Thank you to all those who provided feedback.

**On the next page you will find a short report summarising the survey findings.**

As you will see, naming the end client as a data controller is resulting in fewer market research projects being commissioned in the UK and in Europe.

We are using this information to show the ICO (and other European DPAs) that if an interpretation of requirements that determines an end client is generally a data controller is formalised it will have a significant impact on the aims, integrity, and viability of healthcare market research in the UK and the EU.

We have shared this evidence with:

- The ICO in order to help them to understand the very real impact this is having and to provide them with evidence of this as they consider the issue and discuss it with their EU counterparts;
- Jeremy Wright QC, Secretary of State for Digital, Culture, Media and Sport to draw his department's attention to the impact on UK business;
- The MRS, EphMRA, ESOMAR and EFAMRO so that they can use the information to support their discussions with data protection regulators.

It is expected that controller/processor guidelines are on the agenda for an EDPB September meeting and it's likely that the production of formal guidelines will allow the EDPB view to be formalised.

The BHBIA will continue to work with the MRS and ICO in the UK on this issue and with EphMRA and ESOMAR to support our European counterparts. We will keep members updated of any further developments.

# Assessing the impact of naming the end client as data controller

# Summary of the feedback to the BHBIA's GDPR questionnaire

## Introduction

The British Healthcare Business Intelligence Association (BHBIA) represents organisations involved in healthcare market research and data analytics work. This work supports the measurement and understanding of disease, physician and patient needs and informs drug development.

In 2017 market and social research suppliers generated turnover in the region of £5 billion[1] and employed about 45,000 individuals[2], many of them in smaller businesses[3]. It is estimated that healthcare research on prescription medicines accounted for over £300 million of research supplier turnover[1]. We are a very significant 'niche' in the business world providing a valuable service.

Interpretation of GDPR and UK DPA 2018* requirements with regard to the definition and determination of Data Controllers is having a serious adverse impact on research work as this requires the commissioning client to be named.

Whilst we are currently awaiting further guidance from regulators, members have been talking to us about the difficulties this presents. Rather than relying on anecdotal evidence, powerful though it is:

"*we are now up to 6 projects we have had pulled because of the decision to name the end client*"

UK Fieldwork Agency (employing 5 people), 11 July 2018

we decided to survey members and find out what impact the need to name the end client as data controller is having on research.

The information we collected is presented below.

**The BHBIA believes that it's important that the impact of a disproportionate, non-risk based determination of Data Controller is clearly understood. If applied to companies that commission research but who:**

- **do not determine the purpose <u>and</u> means of data processing;**
- **and who do not themselves process any personal data;**

**this approach will damage the research industry.**

## Headlines

- **As one of the respondents said "*no one is comfortable naming the research sponsor*" as it "*violates research best practice*". It introduces bias, undermines the rigour of the methodologies we use and opens the work up to being considered promotional.**
- **It *may* be a legal necessity, but we are ethically and technically compromised by the requirement.**

**The requirement to be named as a data controller is resulting in fewer market research projects being commissioned in the UK and the EU.**

As a direct result of the requirement to be named as a data controller:

- Around half of pharmaceutical companies surveyed are:
  - Sending out fewer requests for proposals (46%)
  - Commissioning fewer projects (54%)
  - Bypassing the UK or EU more often (54%)
- Consequently, almost half of market research agencies are seeing:
  - Fewer projects being commissioned (38%)
  - The value of their market research work decreasing (41%)
  - More projects commissioned that bypass the UK and EU (46%)

**The damage is being felt already.**

Already this requirement is hurting UK healthcare market research and the impact is expected to worsen over the next year – this is not a short-term issue that will resolve as the new requirements bed in.

- Two thirds of market research agencies (68%) and half of pharmaceutical companies surveyed described the impact as significant (53%).
- They expect the impact to get worse in the next 6 to 12 months, by then almost three quarters of market research agencies (71%) and 9 out of 10 pharmaceutical companies surveyed expect the impact to be significant (92%).

**We will collect less information and less valuable information**

Pharmaceutical companies and agencies greatest concerns are that naming the sponsor of the research will:

- Undermine the assessment of awareness (~85%) and tracking/longitudinal work (~70%), so the means by which we can effectively monitor healthcare initiatives and products are compromised.
- In the healthcare field we are particularly sensitive to market research not being misinterpreted as the disguised promotion of drugs; being forced to name the sponsor of the work increases this risk and is a very widespread concern (80-90%). In Europe prescription medicines cannot be promoted to the public and there are strict regulations about promotion to healthcare professionals, it is essential that market research work does not appear to breach these rules.

**Source**

These results are based on 53 completed questionnaires. The agency base of respondents was 39 and the pharmaceutical company base of respondents was 14. These bases represent 29% of the BHBIA's agency members and 21% of pharmaceutical company members.

The data were collected between 6 and 18 July 2018.

We are happy to share further detail of the source material. For more information please contact the BHBIA Secretariat admin@bhbia.org.uk

## References

[1] UK Market Research Survey 2017
[2] Business Register and Employment Survey 2016 (BRES)
[3] ONS' Annual Business Survey (ABS), 18 May 2018
* General Data Protection Regulation and Data Protection Act 2018

**The BHBIA's Ethics & Compliance Committee is providing this guidance as general information for its members. It is not legal advice and should not be relied upon as such. Specific legal advice should be taken in relation to any specific legal problems or matters. Whilst every reasonable effort is made to make sure the information is accurate, no responsibility for its accuracy or for any consequences of relying on it is assumed by the BHBIA.**

**We do expect to update our guidance on the GDPR as more information becomes available**.

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