



Q1: On a scale of 1-5, to what extent do you agree or disagree that the guidance is clear and easy to understand? Please explain your reasoning for your choice.

- 1 – Strongly disagree
- 2 – Disagree
- 3 – Neither agree nor disagree
- 4 – Agree
- 5 – Strongly agree

Comments:

The scientific research provisions in the UK GDPR and DPA 2018 are complex, dispersed, and layered. The IPMPC supports efforts by the ICO to provide centralized guidance to researchers on the application of the law. The draft guidance uses straight-forward language and includes a number of helpful examples. The table of contents allows readers to quickly locate relevant content.

Q2: Do you think the draft guidance will help you to carry out your research while complying with your obligations under data protection law? If no or unsure, please explain why.

- Yes
- No
- Unsure

Comments:

Q3: To what extent do you agree or disagree that the guidance gives a useful definition of archiving purposes in the public interest?

- 1 – Strongly disagree
- 2 – Disagree



3 – Neither agree nor disagree

4 – Agree

5 – Strongly agree

Q4: To what extent do you agree or disagree that the guidance gives a useful definition of scientific or historical research purposes?

1 – Strongly disagree

2 – Disagree

3 – Neither agree nor disagree

4 – Agree

5 – Strongly agree

Q5: To what extent do you agree or disagree that the guidance gives a useful definition of statistical purposes?

1 – Strongly disagree

2 – Disagree

3 – Neither agree nor disagree

4 – Agree

5 – Strongly agree

Q6: Do the definitions of these terms fit with your understanding of these concepts? If unsure or no, please explain why.

Yes

No

Unsure



Comments:

Q7: Do the definitions capture the key features of each of the types of research-related purpose? If unsure or no, please explain why.

Yes

No

Unsure

Comments:

Q8: Do these definitions help you determine whether your processing can make practical use of the research provisions in your day-to-day work? If unsure or no, please explain why.

Yes

No

Unsure

Comments:

Q9: Are there any factors that you use to determine whether processing is for research-related purposes which you expected to see in the guidance? If yes, please give details.

Yes

No

Unsure



Comments:

Q10: Is the section of the guidance on appropriate lawful bases when processing for research-related purposes helpful? If unsure or no, please explain why.

Yes

No

Unsure

Comments:

Q11. Is the section of the guidance on the compatibility of research with your original purpose helpful? If unsure or no, please explain why.

Yes

No

Unsure

Comments:

Q12. The guidance provides a definition of when processing for research-related purposes is in the public interest. Does this definition help you determine whether or not your processing is in the public interest? If unsure or no, please explain why.

Yes

No



Unsure

Comments:

Q13. Does the section on exemptions help you determine when you may apply the exemptions for research-related purposes? If unsure or no, please explain why.

Yes

No

Unsure

Comments:

Q14. Does the section on appropriate safeguards contain sufficient detail for your processing? If unsure or no, please explain what else you think this section should cover.

Yes

No

Unsure

Comments:

Q15: Does the guidance contain enough examples? If unsure or no, please give details of further scenarios you would like us to consider.

Yes



No

Unsure

Comments:

Q16: Did you find the examples in the guidance useful or not useful? Please give details as to why/why not.

Useful

Not useful

Unsure

Comments:

The examples are clear and practical. They do a good job of illustrating the operation of the guidance.

Q17: Is there anything that you think hasn't been covered that should be? If yes, please give details.

Yes

No

Unsure

Comments:



Q18: Please provide any further comments or suggestions you may have about the drafts.

The International Pharmaceutical & Medical Device Privacy Consortium (“IPMPC”) welcomes the ICO’s guidance on the research provisions within the UK GDPR and the DPA 2018. The IPMPC is comprised of chief privacy officers and other data privacy and security professionals from a number of research-based, global pharmaceutical companies and medical device manufacturers. The IPMPC strives to be a leading voice in the global pharmaceutical and medical device industries to advance innovative privacy solutions to protect patients, enhance healthcare, and support business enablement. More information about IPMPC is available at [www.ipmpc.org](http://www.ipmpc.org).

The IPMPC strongly supports the ICO’s efforts to provide clear, practical guidance to the biomedical research community on the application of the UK’s data protection laws. The biomedical industry has a long history of respecting patient privacy and data confidentiality in our R&D and commercial activities. Members of the IPMPC have built sophisticated privacy compliance programs, and we take our data protection responsibilities seriously. As indicated by our responses to the questions in this survey, we are supportive of the guidance document as drafted.

We are compelled to also note that pharmaceutical and medical device research and development activities in the modern age are rarely confined to a single jurisdiction but rather typically involve patients and scientists around the world. While we recognize that this guidance document only covers UK data protection law, we note that the UK GDPR largely mirrors the EU GDPR, and we hope that the ICO, through its membership in the Global Privacy Assembly, as well as the UK’s membership in the Council of Europe and other regional and international organizations, will continue to promote sensible interpretation of data protection law across Europe and around the globe. The IPMPC is mindful that most of our members approach privacy compliance in a centralized manner. Where privacy requirements are harmonized across jurisdictions, IPMPC members are able to focus their efforts on taking practical compliance steps rather than on simply trying to understand local interpretations and variations.

## About you

Q19: Are you answering as:

- An individual or professional acting in a private capacity
- A data protection professional acting in your professional capacity or on behalf of an organisation
- Other



If you state 'Other' please ensure that you specify here:

Q20: Please specify the name of your organisation:

Q21: Please provide a contact email address:

Q22: What sector are you from?

Q23: How did you find out about this consultation?

- ICO website
- ICO Twitter account
- ICO Facebook account
- ICO LinkedIn account
- ICO staff member
- Colleague from your organisation
- Person outside your organisation
- Other

Comments: