

The outlook for scientific research under the Data Protection and Digital Information Bill

The proposed Bill removes the need to define the ultimate research purpose before collecting personal data, as further processing activity can take place in certain circumstances.

By **Victoria Hordern** of Taylor Wessing.

In recent times the UK government has frequently promoted the UK as a scientific superpower. On one of its latest front covers, the *Economist* magazine hailed the life science industry as providing vital lessons in growth for the British economy. Therefore, it's no surprise that enabling scientific research is part of what the recently introduced bill to reform data protection law aims to do¹.

The draft Data Protection and Digital Information Bill amends existing data protection law following the UK government's consultation *Data: A New Direction*². In its consultation and response, the government indicated that it would make changes in order to bring existing provisions together in one place in the law, as well as to make other aspects of the law clearer. For a number of the changes concerning scientific research purposes, there is no substantial change to the law as we currently have it – the changes are more cosmetic. However, other changes appear more significant.

of “scientific research” in its Definitions section (Article 4). However, recital 159 indicates how the term should be interpreted – broadly to include technological development and demonstration, fundamental research, applied research and privately funded research. The European Data Protection Board (EDPB) in its April 2020 guidelines on processing health data for the purposes of scientific research in the context of Covid-19 stated that the term scientific research should not be stretched beyond its common meaning but comprised “a research project set up in accordance with relevant sector-related methodological and ethical standards, in conformity with good practice”³. This interpretation covers both public and private research activity.

The bill inserts a new definition in the UK GDPR which states that references to processing personal data for the purpose of scientific research in the UK GDPR are “references to processing for the purposes of any research that can reasonably be described as

standards referred to by the EDPB.

ANONYMISATION – A HELPFUL REFORM

In reforming the law, the government is keen to help organisations that struggle to determine when data is anonymous. Clause 1 of the bill attempts to tackle this debate head on and move away from absolutist interpretations of the law. While the bill does not define anonymous data, it does define when a living individual is identifiable by inserting a new Section 3A into the Data Protection Act 2018. The amendments are designed to set a reasonable standard when determining whether data is personal data i.e. the data is personal data where the controller reasonably knows that another person who obtains the data is likely to have reasonable means to identify a living individual. In the context of processing data for scientific research purposes it can be critical to know whether the data is personal data or anonymous data given that anonymous data is not subject to data protection law. This addition should, therefore, be helpful.

LAWFUL BASES – NOT MUCH CHANGE

Any organisation processing personal data for scientific research purposes needs to identify the lawful basis it will rely on under Article 6 and, where relevant, Article 9. While the government originally proposed introducing a new lawful basis for research under Article 6, it has now decided not to proceed. Partly this seems due to the concerns raised by consultation respondents that any new lawful basis would be open to abuse. In the absence of a new research lawful basis, an organisation is likely to rely on either consent or legitimate

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DEFINING SCIENTIFIC RESEARCH

Processing personal data for scientific research purposes has always been afforded special treatment and flexibility under EU data protection law. This is partly due to the recognised public and societal good that scientific research can bring. An increase of knowledge (recital 113) is a legitimate expectation of a society. The GDPR does not currently include a definition

scientific, whether publicly or privately funded, including processing for the purposes of technological development or demonstration, fundamental research or applied research”. There is considerable similarity between recital 159 and this proposed definition. But the concept of research that can “reasonably be described as scientific” suggests a wide scope and is potentially without the emphasis on ethical

interest under Article 6. Again, the GDPR already allows (in recital 33) that individuals can provide their consent to ‘certain areas of scientific research when in keeping with recognised ethical standards for scientific research’. The bill takes this concept and includes it in Article 4 of the UK GDPR so that it does not deviate from what is already in the GDPR.

The government consulted on whether to shake up the lawful basis of legitimate interest by setting out processing activities where a controller did not have to carry out a balancing test. As part of the original consultation paper one of the activities mooted was using personal data for internal research and development purposes, or business innovation purposes aimed at improving services for customers. However, this processing activity has not been included in the new Annex 1 to the UK GDPR which sets out recognised legitimate interests. Consequently, for any research that an organisation pursues on the basis of legitimate interest, it will still need to carry out the balancing test.

Processing special category data requires reliance on a condition under Article 9. Article 9(2)(j)’s reference to Article 89 is replaced under the bill by a reference to new Article 84. New Article 84 provides a definition of Research, Archives and Statistics purposes (RAS purposes). Any processing for RAS purposes must be carried out with appropriate safeguards. It must also be carried out primarily in a manner that does not identify a living individual (i.e. anonymised following the new test in the bill) although this does not apply either (i) when the data is collected or (ii) where the RAS purposes cannot be fulfilled if the data was anonymised. The remainder of Article 84 sets out the appropriate safeguards which are broadly in line with current UK law i.e. reflecting current provisions from s.19 of Data Protection Act 2018 and Article 89. Consequently, the new Article 84 doesn’t change any of the fundamentals that are already in place today.

FURTHER PROCESSING – GREATER CLARITY NEEDED

The government indicated that it would propose new provisions to clarify further processing i.e. where a controller

that decides to use personal data for a purpose (a ‘new purpose’) other than the purpose for which the controller collected the data originally (the ‘original purpose’) is able to argue that the new purpose is compatible with the original purpose. For the most part, the amendments (new Article 8A) mirror the existing test under the UK GDPR for where further (or ‘new’) processing is compatible with the original purpose (under Article 6(4)). This confirms that processing for a new purpose is compatible where processing is in accordance with Article 84B for RAS purposes. However, one aspect which reflects the position currently under the GDPR does not provide greater clarification. As drafted, where an organisation collects personal data based on consent, processing for a new purpose is only compatible processing if it falls within certain conditions but RAS purposes is not one of them. Therefore, if a research organisation originally relies on consent as its lawful basis and then wishes to use the data for further processing, it cannot automatically argue that such processing is compatible. The organisation would therefore need to identify a new lawful basis. Presumably this remains the case where the organisation has relied on ‘broad consent’ to areas of scientific research and therefore consent under Article 6. This can be confusing – broad consent to scientific research suggests greater flexibility for further processing but new Article 8A indicates that, in such circumstances, the ability to carry out further compatible processing could be limited.

TRANSPARENCY – SIGNIFICANT CHANGE

The bill includes a significant change in one aspect of transparency even though most respondents to the consultation disagreed with the proposal. The bill amends Article 13 so that an organisation does not have to provide a new privacy notice where (i) it has already collected personal data directly from an individual, (ii) it decides to use the personal data for a further research purpose, and (iii) providing a new notice is impossible or would involve a disproportionate effort (guidance is now provided on what is a disproportionate effort). This exception currently only exists in Article 14. The bill also

amends Article 14 to replace the disproportionate effort exception wording with a broader scope for when all organisations are exempt from providing a privacy notice. These changes could lead to greater concerns that organisations proceed with new processing activities without being sufficiently transparent. Additionally, while the amended Article 14 retains the requirement on a controller to take appropriate measures to protect the rights of individuals including by making the privacy notice information publicly available, the amended Article 13 does not include these additional safeguards. This may be because the new disproportionate effort exemption in Article 13 must also comply with new Article 84 which includes appropriate safeguards at Article 84C (albeit with no requirement to ensure transparency information is publicly available).

ACCOUNTABILITY REVISED

One of the significant changes under the bill is recasting the accountability requirements as part of a privacy management programme. Certain mandatory obligations have been diluted in the bill though not wholly abolished. For instance, the requirement to appoint a Data Protection Officer (DPO) has been removed. But there is now a new requirement on controllers and processors to designate a Senior Responsible Individual (SRI) where the processing activities are likely to result in a high risk to individuals. The explanatory note that accompanies the bill indicates that an example of “high risk” processing is where organisations process special category data on a large scale. Therefore, effectively any organisation that has appointed a data protection officer because they process health data on a large scale, will still be expected to appoint an SRI. The main difference between the DPO and SRI provisions appears to be that an SRI doesn’t have to attain a certain level of data protection expertise and the requirement for absolute independence to avoid conflicts is omitted. This should make it easier for organisations to appoint a SRI.

Additionally, the bill amends Article 35 dealing with data protection impact assessments. The renamed process – “an assessment of high risk

processing” – is now required only where there is processing likely to result in a high risk. Given the explanatory note’s guidance on how to interpret “high risk” an assessment would be required for any processing of health data on a large scale. What the assessment must contain is amended to be slightly less detailed from the current requirements and with no obligation to obtain the views of affected individuals.

CONCLUSION

The bill is going through the Parliamentary process and should become law by Spring 2023. Many of the amendments proposed are not strikingly different from the current framework for processing personal data for scientific research purposes. However, the bill sets out a looser regulatory framework in the UK for organisations engaged in processing personal data for scientific research.

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DP and Digital Information Bill: Organisations will face mostly cosmetic changes

Alison Deighton of HelloDPO assesses the practicalities of the UK Data Protection Reform.

The Data Protection and Digital Information Bill (referred to as the Bill in the rest of this article) proposes a number of changes to the UK data protection regime which the Government hopes

will make data protection compliance more straightforward in the UK. In this article we review some of the proposals from a practical perspective to consider how they will

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The regulation of AI in the UK

The lighter touch regulation of AI in the UK, and arguably drastic differences from EU plans may pose issues that require further attention from the UK government in due course. By **Gareth Oldale** and **Georgía Philippou** at TLT.

The UK government's journey to reform data protection in the UK has reached another milestone with the recent release of the Data Protection and Digital Information Bill¹. The proposed legislative change amending the Data

Protection Act 2018 and the UK GDPR reflects the UK government's efforts to boost British business and use its post-Brexit freedoms to depart from European law.

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PL&B Roundtable on International Data Transfers in the UK's Data Protection and Digital Information Bill

3 October 2022

See p.22 for details

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New UK DP Bill starts its passage in Parliament

As we are going to print, the Data Protection and Digital Information Bill was due to have its second reading at the House of Commons. Some of the original proposals have been dropped, but new ones have emerged. A completely new area has been added to the Bill, namely digital verification services. This makes sense from the point of view of enabling the use of digital identities with confidence, but for those used to navigating the UK GDPR and the Data Protection Act 2018, additional change may be unwelcome.

Much of the proposed reform concentrates on the existing accountability framework, which the government sees as burdensome. Many of the changes would affect the day-to-day work of DPOs; even their own status is threatened by the proposals (p.1).

There are changes to come in the field of the Privacy and Electronic Communications Regulations (PECR), for example on banners and cookie pop-ups. PECR fines would be elevated to GDPR levels.

The government also seeks to win companies' approval in terms of scientific research and AI. Unlike the EU, the UK is not, at the moment, legislating on AI. The Bill proposes to widen the concept of scientific research. Read our correspondents' analysis of the proposed changes on pages 1, 10 and 13.

The DCMS says that the reform is "evolution rather than revolution". However, much depends on whether all these proposals are adopted. In the worst case, UK's EU adequacy decision could be threatened. The question about the UK's own adequacy decisions is an interesting one. *PL&B* has organised a Roundtable in London on 3 October so that you can learn from the DCMS about the proposed future framework for international transfers from the UK, and put your questions to the speakers from that department who have been drafting the Bill's clauses and advising the Data Minister. See p.22

Laura Linkomies, Editor

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