Londonwide LMCs
The professional voice of London general practice

November 2021

Londonwide Local Medical Committees' response to "Data: A New Direction" Consultation

Londonwide LMCs welcomes this opportunity to respond to the "Data: A New Direction" consultation on data usage, storage, and privacy.

Londonwide Local Medical Committees (Londonwide LMCs) is the clinically led independent voice of general practice in the capital, supporting Local Medical Committees; bodies recognised in statute (NHS Act) which represent the interests of all local GPs and their teams. We aim to secure the future of general practice in London through our work with all partners in the health and social care sector and beyond.

We support and represent over 7,000 GPs and over 1,100 practice teams in London through our 27 locally elected committees. We ensure that London's GPs and their practice teams have access to the information and support they need to help them provide the best possible service to their nearly 9 million patients. We work with GPs across the breadth of their roles, from clinical provision to business services and patient engagement. GPs acknowledge the importance of engaging with patients in designing how to deliver services, making these as responsive as possible. We also recognise the power of information shared with patients in helping them make decisions about their health.

Summary

This response identifies concerns and queries regarding the application of the proposals to general practice and patients in the Capital as they pertain to the work of general practice. We have chosen to respond to those questions and areas that we feel are pertinent, as opposed to all questions posed.

Should you have any queries or require further information about this response please contact Sam Dowling, Director of Communications, on sam.dowling@lmc.org.uk.

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INVESTORS IN PEOPLE

Chapter 1: Reducing barriers to responsible innovation

Q1.2.1. To what extent do you agree that consolidating and bringing together research-specific provisions will allow researchers to navigate the relevant law more easily?

○ Somewhat agree

The current provisions for scientific research are in a number of different places within UK GDPR and DPA2018. Consolidating them could make it easier to navigate the relevant law but would still result in a number of pages of condensed text to navigate and understand.

Q1.2.2. To what extent do you agree that creating a statutory definition of 'scientific research' would result in greater certainty for researchers?

○ Somewhat agree

Recital 159 of the UK GDPR could be used for a statutory definition of 'scientific research' as it has inbuilt flexibility within it and is non-exhaustive as long as the safeguards are met. However, the consultation doesn't specify how the government would like to define research.

Q1.2.3. Is the definition of scientific research currently provided by Recital 159 of the UK GDPR ('technological development and demonstration, fundamental research, applied research and privately funded research') a suitable basis for a statutory definition?

○ Yes

Recital 159 of the UK GDPR could be used as a statutory definition of 'scientific research' as it has inbuilt flexibility within it and is non-exhaustive as long as the safeguards are met. However as the consultation doesn't specify how the government would like to define research it isn't possible to fully answer this question.

Q1.2.4. To what extent do you agree that identifying a lawful ground for personal data processing for research processes creates barriers for researchers?

○ Somewhat agree

It is important to identify the legal basis on which personal data processing for research purposes relies in order to protect the rights and freedoms of data subjects.

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Q1.2.5. To what extent do you agree that clarifying that university research projects can rely on tasks in the public interest (Article 6(1)(e) of the UK GDPR) as a lawful ground would support researchers to select the best lawful ground for processing personal data?

○ Somewhat disagree

Not all university research projects should be able to rely on 'public task' as a lawful ground, particularly those whose aims do not align with the wider public interest and who are not subject to the same rigorous governance, oversight, assurance and scrutiny applicable to other research projects. There is also the potential for commercial interests to influence why the research is being undertaken and the outcomes, which may not be in the public interest. There should be a case-by-case decision for each research project to determine that research projects which rely on the lawful ground of 'tasks in the public interest' are conducted in the interests of the public.

Q1.2.6. To what extent do you agree that creating a new, separate lawful ground for research (subject to suitable safeguards) would support researchers to select the best lawful ground for processing personal data

○ Strongly disagree

Existing lawful bases already provide sufficient lawful bases for research with suitable safeguards in place. The introduction of a sweeping legal basis for research would undermine the protections for data subjects, as this is likely to become the main lawful basis used and ignore the other lawful bases with suitable safeguards already in place. In UK GDPR, Article 6(1)(a) the lawful basis of consent has the safeguard that the data subject has the right to withdraw their consent without providing a reason, Article 6(1)(e) the lawful basis of public interest has the safeguard that scientific research has to be in the public interest, and Article 6(1)(f) the lawful basis of legitimate interests requires a balancing test.

Any new, separate, lawful ground for research would need to include appropriate data subject rights, particularly the right to object and the right to erasure. Public trust is important and must be secured before broadening, for the benefit of one sector, the legal bases intended to protect data subjects rights. The recently proposed GP Data for Planning and Research (GPDPR) is an example of where a lack of public engagement and understanding of how the data would be used, and the absence of appropriate safeguards in place, resulted in data subjects choosing to opt out of sharing their data on a large scale; impacting on the usefulness of that data for research purposes.

Q1.2.7. What safeguards should be built into a legal ground for research?

Current legislation already provides lawful bases for research. If a separate legal basis for research were to be introduced the current safeguards (which include controls and

restrictions around pseudonymisation, anonymisation, reuse of datasets, ensuring data minimisation, effective encryption and that subject rights are not negatively impacted) must remain. An effective way to assess that the controls are in place and to safeguard the rights of the data subject is to use Data Protection Impact Assessments (DPIAs).

Q1.2.8. To what extent do you agree that it would benefit researchers to clarify that data subjects should be allowed to give their consent to broader areas of scientific research when it is not possible to fully identify the purpose of personal data processing at the time of data collection?

○ Strongly disagree

This change is not required as the current legislation allows a data subject to give consent for processing of their personal data for one or more purposes in UK GDPR Article 6(1)(a) lawful basis for consent. UK GDPR Recital 159 defines scientific research purpose in a non-exhaustive list so if the consent is properly informed consent, then the legislation already allows for a data subject to give consent to a broader area of scientific research.

Q1.2.9. To what extent do you agree that researchers would benefit from clarity that further processing for research purposes is both (i) compatible with the original purpose and (ii) lawful under Article 6(1) of the UK GDPR?

○ Neither agree nor disagree

This would depend on the circumstances and precisely what is proposed for inclusion. It is important to ensure that the extension to use is appropriate.

Q1.2.10. To what extent do you agree with the proposals to disapply the current requirement for controllers who collected personal data directly from the data subject to provide further information to the data subject prior to any further processing, but only where that further processing is for a research purpose and it where it would require a disproportionate effort to do so?

○ Strongly disagree

This is a high-risk change as 'disproportionate effort' could be interpreted on a very broad spectrum. The consultation states [in paragraph 44] that proposals for research are to improve transparency for data subjects, but this proposal puts in place another exemption from a data subject's right to be informed, which reduces transparency for individuals.

Q1.2.11. What, if any, additional safeguards should be considered as part of this exemption.

Transparency is important to ensure that data subjects are aware of which research projects their personal data is part of. There is a possibility that this proposed exemption if applied with existing exemptions could remove transparency, which could lead to the loss of a data subjects' trust in research if they are unaware of all the research their data is used in. The UK GDPR Article 89 safeguards of anonymisation, pseudonymisation and data minimisation need to be met. Mandating that a Data Protection Impact Assessment (DPIA) be conducted provides assurance that safeguards are in place. DPIAs need to be revised/re-assessed for any further processing to ensure that data subject rights are still safeguarded. DPIAs could be revised to include ethical considerations, and provide assurance that the research is ethical.

Q1.3.1. To what extent do you agree that the provisions in Article 6(4) of the UK GDPR on further processing can cause confusion when determining what is lawful, including on the application of the elements in the compatibility test?

○ Somewhat disagree

UK GDPR Article 6(4) provides a clear list of the elements of the compatibility test. Revising the Data Protection Impact Assessment for the original processing can help to assess "the possible consequences of the intended further processing for data subjects" as per Article6(4)(d), and ensure that the appropriate safeguards can be applied to protect data subjects as per Article 6 (4)(e).

Q1.3.2. To what extent do you agree that the government should seek to clarify in the legislative text itself that further processing may be lawful when it is a) compatible or b) incompatible but based on a law that safeguards an important public interest?

○ Somewhat agree

Please explain your answer and provide supporting evidence where possible, including on:

- **What risks and benefits you envisage**
- **What limitations or safeguards should be considered**

If further processing which is incompatible with current UK GPDR Articles 6(4)(d) and (e) were to be deemed lawful when based on a law that safeguards an 'important public interest', then defining in legislation what an 'important public interest' covers is essential, particularly if the data used for further processing is special category data and there is the possibility of potential consequences for data subjects. There is a risk that further processing of pseudonymised data could lead to re-identification. The mandatory

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requirement that a Data Protection Impact Assessment be completed, or that an existing one be revised for further processing, would provide a safeguard to ensure that appropriate controls are in place for the further processing. For health data (special category data) the duty of confidentiality would need to be met or an appropriate exemption would need to be in place.

Q1.3.3. To what extent do you agree that the government should seek to clarify when further processing can be undertaken by a controller different from the original controller?

○ Strongly disagree

Please explain your answer and provide supporting evidence where possible, including on:

- **How you envisage clarifying when further processing can take place**
- **How you envisage clarifying the distinction between further processing and new processing**
- **What risks and benefits you envisage**
- **What limitations or safeguards should be considered.**

The decision on whether further processing by a controller different from the original controller is compatible and could be undertaken should be made on a case-by-case basis. The mandatory requirement for completion of a Data Protection Impact Assessment (DPIA) is an effective way to ensure that the case has been appropriately considered, including determining whether it is actually new processing or runs any risks of re-identification of pseudonymised data, or that the safeguards set out in UK GDPR Article 89, including consideration of anonymisation, pseudonymisation, data minimisation where appropriate, are in place.

Q1.3.4 To what extent do you agree that the government should seek to clarify when further processing may occur, when the original lawful ground was consent?

○ Strongly disagree

Please explain your answer and provide supporting evidence where possible, including on:

- **How you envisage clarifying when further processing can take place**
- **How you envisage clarifying the distinction between further processing and new processing**
- **What risks and benefits you envisage**
- **What limitations or safeguards should be considered.**

If the further processing is incompatible with the original purpose for which consent was obtained then further processing should not be undertaken, unless it falls under another

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existing lawful basis. In order for consent to be valid under UK GPDR when it is requested, the purpose(s) the personal data is being processed for should be absolutely clear. If any of the circumstances change then consent should be re-evaluated and clarified. There are a number of risks in further processing of personal data obtained via consent without reviewing/ refreshing consent. It is likely to reduce public trust, and therefore the usefulness of the data, if data subjects refuse to provide the data in the first instance. The mandatory requirement for completion of a Data Protection Impact Assessment (DPIA) is an effective way to ensure that where there is further processing that all the risks for the further processing have been appropriately considered, including whether it is actually new processing, risks of re-identification of pseudonymised data and that the safeguards set out in UK GDPR Article 89, including consideration of anonymisation, pseudonymisation, data minimisation where appropriate are in place.

Q1.4.1. To what extent do you agree with the proposal to create a limited, exhaustive list of legitimate interests for which organisations can use personal data without applying the balancing test?

○ Strongly disagree

This is not necessary or appropriate as the balancing test should always fall in favour of the controller if the use of the data is truly for a fair and lawful purpose. The consultation argues for this proposal as organisations, particularly in the business sector, have found the application of a balancing test complicated. The ICO has issued guidance on legitimate interests and how to apply the balancing test. Rather than amending the current legislation the ICO could provide further support for data controllers in understanding how to use/apply this lawful basis so that it is not so complicated. The completion of the balancing test and the completion of a Data Protection Impact Assessment ensures the safeguarding of data subject rights.

The introduction of a limited, exhaustive list defined in legislation would also be difficult to amend in the future.

Q1.4.2. To what extent do you agree with the suggested list of activities where the legitimate interests balancing test would not be required?

○ Strongly disagree

Please explain your answer, indicating whether and why you would remove any activities listed above or add further activities to this list

This is not necessary or appropriate, as the balancing test should always fall in favour of the controller if the use of the data is truly for a fair and lawful purpose. The consultation argues for this proposal as organisations, particularly in the business sector, have found the

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application of a balancing test complicated. The ICO has issued guidance on legitimate interests and how to apply the balancing test, rather than amending the current legislation, the ICO could provide further support for data controllers in understanding how to use this lawful basis so that it is not so complicated. The completion of the balancing test and the completion of a Data Protection Impact Assessment ensure the safeguarding of data subject rights.

The introduction of a limited, exhaustive list defined in legislation would also be difficult to amend in the future. There is particular concern regarding items 'g' and 'h' on the proposed list [paragraph 64 of the consultation] in relation to health data. It is risky to allow de-identification of personal data for data security purposes if there is no balancing test and if there isn't a mandatory Data Protection Impact Assessment (DPIA) required (if these are removed from the legislation as per other proposals in the consultation). Item 'h' on internal research is vague and could be interpreted in different ways by different controllers, and for special category data should always be considered through a DPIA to assess any risks to the rights and freedoms of data subjects.

Q1.4.3. What, if any, additional safeguards do you think would need to be put in place?

This proposal is not necessary or appropriate as the balancing test should always fall in favour of the controller if the use of the data is truly for a fair and lawful purpose. The minimum safeguards that should remain in place are retaining mandatory Data Protection Impact Assessments and the mandatory Data Protection Officer function in the legislation.

Q1.4.4. To what extent do you agree that the legitimate interests balancing test should be maintained for children's data, irrespective of whether the data is being processed for one of the listed activities?

○ Strongly agree

The balancing test should be maintained for all legitimate interests as the balancing test should always fall in favour of the controller if the use of the data is truly for a fair and lawful purpose. Children's data should always have appropriate safeguards in place, which include the completion of a Data Protection Impact Assessment to assess any particular risks to children as the data subjects, including what will happen to their data when they become adults.

Q1.5.1. To what extent do you agree that the current legal obligations with regards to fairness are clear when developing or deploying an AI system?

○ Somewhat disagree

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Fairness is integral for the processing of all personal data; it is particularly important when developing or deploying an AI system. It is agreed that there is a limited understanding of how to apply fairness in an AI system but remain concerned that any proposed changes do not remove fairness for all processing of personal data within the legislation. The limited understanding could be addressed through guidance for AI which addresses fairness across all legislation. Fairness includes both transparency and the impact on data subjects, which is particularly important when AI is developed or deployed within healthcare, as there can be significant effects/impacts on data subjects. There is a real need to increase public understanding on AI and how it is used in healthcare, when personal data is and isn't used and the likely impacts. Data Protection Impact Assessments are an extremely useful tool to clearly document the consideration for all aspects of the AI system to be deployed, they can then be reviewed and revised as the AI systems develop, as it is not possible to document and assess all impacts and risks at the start.

Q1.5.2. To what extent do you agree that the application of the concept of fairness within the data protection regime in relation to AI systems is currently unclear?

○ Somewhat agree

In relation to AI systems, the application of the concept of fairness within the data protection regime may be unclear, but the application of fairness for AI is wider than just the data protection regime, which was reflected in the ICO's own guidance on AI and data protection. Guidance on the application of fairness in relation to AI systems needs to be developed which addresses the concept of fairness across all legislation, including the Equality Act 2010.

Q1.5.3. What legislative regimes and associated regulators should play a role in substantive assessments of fairness, especially of outcomes, in the AI context?

ICO (and any organisations/regulators independent from the government) should continue to review technological developments and advances, including what is currently happening in the assessment of fairness in the AI context, and what should be happening to ensure that there are fair outcomes for data subjects. Critically, such oversight should be on a statutorily independent basis.

Q1.5.4. To what extent do you agree that the development of a substantive concept of outcome fairness in the data protection regime - that is independent of or supplementary to the operation of other legislation regulating areas within the ambit of fairness - poses risks?

○ Somewhat disagree

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A substantive concept of outcome fairness can't exist in isolation from other legislation regulating areas within the ambit of fairness in relation to AI. However, this should not mean that the data protection regime should be changed in regard to fairness, as data protection legislation needs to continue to ensure that all processing of data subjects' data is done fairly.

Q1.5.5. To what extent do you agree that the government should permit organisations to use personal data more freely, subject to appropriate safeguards, for the purpose of training and testing AI responsibly?

○ Somewhat disagree

Please explain your answer, and provide supporting evidence where possible, including which safeguards should be in place.

This is very much dependent on the appropriate safeguards being in place. For example, there should be a consideration of whether truly anonymised data can be used for training and testing AI responsibly rather than using personal data. If pseudonymised data is used there is always a risk of re-identification through the potential linkage of other data sets. Using a proof of concept before full deployment can help to mitigate risks before deployment, ideally using non-identifiable data. Mandatory Data Protection Impact Assessments are integral to ensuring appropriate safeguards are in place and assessing risks to data subject both in the development and ongoing deployment of AI systems.

Q1.5.10. To what extent do you agree with the proposal to make it explicit that the processing of personal data for the purpose of bias monitoring, detection and correction in relation to AI systems should be part of a limited, exhaustive list of legitimate interests that organisations can use personal data for without applying the balancing test.

○ Strongly disagree

Please explain your answer, and provide supporting evidence where possible, including on:

- **the key benefits or risks you envisage.**
- **what you envisage the parameters of the processing activity should be**

This is not necessary or appropriate as the balancing test is not currently a blocker therefore it is neither necessary nor appropriate to remove it. It is not possible to know all potential future uses of AI, so to add it to a list for which organisations can use personal data without applying the balancing test is very risky. In addition, there is a complication with what happens when children's data becomes adult data. Removing the balancing test takes away the rights of the data subject, who could face distress from their use of data.

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Q1.5.11. To what extent do you agree that further legal clarity is needed on how sensitive personal data can be lawfully processed for the purpose of ensuring bias monitoring, detection and correction in relation to AI systems?

○ Strongly agree

With the caveat that clarification be sought as to whether sensitive data is the same as special category data as defined in the current data protection regime.

Q1.5.12. To what extent do you agree with the proposal to create a new condition within Schedule 1 to the Data Protection Act 2018 to support the processing of sensitive personal data for the purpose of bias monitoring, detection and correction in relation to AI systems?

○ Somewhat disagree

A new condition could be helpful to specifically address the processing of sensitive personal data, which is necessary for AI system bias monitoring, detection and correction but this should not exempt a balancing test, particularly in relation to children's data and then when it becomes adult data. There also needs to be clarification if sensitive personal data has the same definition as special category data in the current data protection regime.

Q1.5.13 What additional safeguards do you think would need to be put in place.

There are current safeguards in the UK GDPR Article 89 of pseudonymisation, anonymisation, data minimisation. The data protection principles of transparency, fairness and accountability are key, with the use of mandatory Data Protection Impact Assessments to provide effective assessment and mitigation of risks to the rights and freedoms of data subjects.

Q1.5.14. To what extent do you agree with what the government is considering in relation to clarifying the limits and scope of what constitutes 'a decision based solely on automated processing' and 'produc[ing] legal effects concerning [a person] or similarly significant effects?

○ Strongly agree

Please explain your answer, and provide supporting evidence where possible, including on:

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- **The benefits and risks of clarifying the limits and scope of 'solely automated processing'**
- **The benefits and risks of clarifying the limits and scope of 'similarly significant effects'.**

Strongly agree with the government's proposal to gather more information and evidence in this area before making any legislative changes.

Q1.5.15. Are there any alternatives you would consider to address the problem?

○ Don't know

Q1.5.16. To what extent do you agree with the following statement: 'In the expectation of more widespread adoption of automated decision-making, Article 22 is (i) sufficiently future-proofed, so as to be practical and proportionate, whilst (ii) retaining meaningful safeguards'?

○ Somewhat disagree

AI is in its infancy as a technology and there are a multitude of unknowns. Further information and evidence should be gathered before making legislative changes to Article 22 with a consideration of how the current guidance from the ICO is being applied. It is really important to ensure people understand the decisions being made about them using AI and that human intervention is built into the process where practical and proportionate and if it isn't that this is assessed in the Data Protection Impact Assessment.

Q1.5.17. To what extent do you agree with the Taskforce on Innovation, Growth and Regulatory Reform's recommendation that Article 22 of UK GDPR should be removed and solely automated decision making permitted where it meets a lawful ground in Article 6(1) (and Article 9-10 (as supplemented by Schedule 1 to the Data Protection Act 2018) where relevant) and subject to compliance with the rest of the data protection legislation?

○ Strongly disagree

Please explain your answer, and provide supporting evidence where possible, including on:

- **The benefits and risks of the Taskforce's proposal to remove Article 22 and permit solely automated decision making where (i) it meets a lawful ground in Article 6(1) (and, Articles 9 and 10, as supplemented by Schedule 1 to the Data Protection Act 2018) in relation to sensitive personal data, where relevant) and subject to compliance with the rest of the data protection legislation.**

- **Any additional safeguards that should be in place for solely automated processing of personal data, given that removal of Article 22 would remove the safeguards currently listed in Article 22 (3) and (4).**

In relation to health data, it is important that the right level of human involvement and intervention is built into the processes. If this is not possible (due to practical or proportionate reasons compliant with existing legislative requirements) the risks of this and the potential impacts on data subjects must be fully assessed in a Data Protection Impact Assessment.

Q1.5.18. Please share your views on the effectiveness and proportionality of data protection tools, provisions and definitions to address profiling issues and their impact on specific groups (as described in the section on public trust in the use of data-driven systems), including whether or not you think it is necessary for the government to address this in data protection legislation.

There is currently a lack of public awareness and understanding of how AI is being used, particularly within the health sector which impacts on transparency requirements. A clearer ethics framework for AI could be linked into data protection and implemented through a revision to Data Protection Impact Assessments, in order to introduce/capture ethical considerations.

Q1.5.19. Please share your views on what, if any, further legislative changes the government can consider to enhance public scrutiny of automated decision-making and to encourage the types of transparency that demonstrate accountability (e.g. revealing the purposes and training data behind algorithms, as well as looking at their impacts).

Increased transparency of AI and automated decision-making would provide reassurance to the public and build trust. The current legislation could be used to support this by mandating Data Protection Impact Assessments (DPIAs), revising the DPIA framework to include an ethics framework for AI so ethical consideration is considered alongside the assessment of data protection risks to data subjects, involving the public as stakeholders in the preparation and review of the DPIA, and publishing those DPIAs for further public scrutiny to provide transparency and demonstrate accountability.

A clearly written DPIA which explains how an AI system works and reveals the purposes and training data behind the algorithms can assess risks resulting from bias within the training data set, eg the data set is based on a limited cohort of individuals who are not representative of the whole population. A clear DPIA also provides data flows explaining any automated decision-making and where it is not possible (due to practical or proportionate

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reasons compliant with existing legislative requirements) identifies the right level of human involvement and intervention built into the processes. Building considerations of such risks and the impacts on data subjects into the DPIA, along with an ethical consideration of the AI system provides transparency and demonstrates accountability.

It is acknowledged that there can be potential commercial risks of sharing some of the algorithms and data used in an AI system within a published DPIA. However, any decision to not share this information should be considered carefully as it will lessen transparency and public scrutiny and impact on public trust in AI and automated decision-making, and in the ability of the organisation to demonstrate accountability.

Q1.5.20. Please share your views on whether data protection is the right legislative framework to evaluate collective data-driven harms for a specific AI use case, including detail on which tools and/or provisions could be bolstered in the data protection framework, or which other legislative frameworks are more appropriate.

The development of a clear and substantive concept of outcome fairness which addresses all relevant legislation would assist in evaluating collective data driven harms for a specific AI use case. A data flow could be legal but might not be ethical to carry out, so a clearer ethics framework for AI could be linked into the data protection framework and implemented through a revision to Data Protection Impact Assessments to have an ethical consideration alongside the assessment of data protection risks to data subjects.

Q1.6.1. To what extent do you agree with the proposal to clarify the test for when data is anonymous by giving effect to the test in legislation?

○ Somewhat agree

There isn't currently a definition in data protection legislation for what constitutes 'anonymous data', although UK GDPR Recital 26 sets out the way in which personal data can become anonymous. The proposed test would provide clarification to organisations if it was included in legislation.

Within health there are sometimes disagreements on when/ whether data is anonymous or not and a clear, supported, test would help to provide much needed clarification. Any such test must clearly address:

- how difficult it is to get the key to re-identify the data-set, and that this difficulty is kept under review as future changes in technology become available which might enable the re-identification of the data;
- that there is consideration that even when data is anonymous, large sets of data only need three datapoints to identify someone and there is the potential for linkage by patterns (eg writing style);

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- mandation of a Data Protection Impact Assessment to assess all of the risks in the process of making the data anonymous, with an assessment of the risks and potential harms to individuals resulting from re-identification, including security arrangements for the anonymous data set (whether there is a risk of the motivated intruder); and, in the event of a data breach, an assessment as to whether there are data sets available which could re-identify the breached data, and if so what the harms and risks to individuals would be if this happened;
- and that the destruction date of the anonymised data should be included under contract, particularly because future technology may become available which would enable the anonymous data set to be re-identified.

Q1.6.2. What should be the basis of formulating the text in legislation?

- **Recital 26 of the UK GDPR**
- **Explanatory Report to the Modernised Convention 108+**
- **N/A - legislation should not be amended**
- **Other**

Please explain your answer, and provide supporting evidence where possible.

Both Recital 26 of the UK GDPR and the explanatory report to the Modernised Convention 108+ have similar considerations regarding re-identification, so either option would be feasible. However translating Recital 26 into law would be the simplest approach, with the new ICO guidance on "Anonymisation, pseudonymisation and privacy enhancing technologies", currently in draft form, supporting organisations in understanding how to apply it.

Q1.6.3 To what extent do you agree with the proposal to confirm that the reidentification test under the general anonymisation test is a relative one (as described in the proposal)?

o Somewhat agree

If the reidentification test were a relative one, it would need to be clear in the legislation what criteria is used to assess what is 'reasonably likely' and the process for doing this. The importance of the mandatory Data Protection Impact Assessment as a vehicle to include this assessment is key, along with retaining the mandatory function of the Data Protection Officer role. The relative test and outcomes need to be transparent to the public to build trust in anonymous data. It also needs to include ongoing due diligence. And any such test must be kept under review as new technologies become available.

Q1.6.4. Please share your views on whether the government should be promoting privacy-enhancing technology, and if so, whether there is more it could do to promote its responsible use.

There should be more promotion of privacy enhancing technology, along with the funding required for the health sector to implement. Open safety was a good example of a very secure, trusted and transparent solution for analysing health records without the records leaving the environment they reside in. More funding is needed for analysts to undertake this work, train, and create knowledge sharing networks. There also needs to be strong and clear public facing communications and engagement campaigns to improve understanding of how privacy enhancing technology works and its benefits, in order to build public trust.

Q1.7.1. Do you think the government should have a role enabling the activity of responsible data intermediaries?

○ **No**

Please explain your answer, with reference to the barriers and risks associated with the activities of different types of data intermediaries, and where there might be a case to provide cross-cutting support).Consider referring to the styles of government intervention identified by Policy Lab - e.g. the government's role as collaborator, steward, customer, provider, funder, regulator and legislator - to frame your answer.

In order to build public trust an independent organisation such as the ICO should have the role of considering, assessing and assuring this activity, as long as the independence of the ICO from the government is maintained. Processes that include public involvement and scrutiny of the activity are key to building trust.

Q.1.7.2. What lawful grounds other than consent might be applicable to data intermediary activities, as well as the conferring of data processing rights and responsibilities to those data intermediaries, whereby organisations share personal data without it being requested by the data subject?

Please explain your answer, and provide supporting evidence where possible, including on:

- **If Article 6(1)(f) is relevant, i) what types of data intermediary activities might constitute a legitimate interest and how is the balancing test met and ii) what types of intermediary activity would not constitute a legitimate interest**
- **What role the government should take in codifying this activity, including any additional conditions that might be placed on certain kinds of data intermediaries to bring them within scope of legitimate interest**

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- **Whether you consider a government approved accreditation scheme for intermediaries would be useful?**

This question is difficult to answer as there is not enough information on how data processing rights and responsibilities could be transferred to data intermediaries; or how these would be accountable and ensure protections for data subjects when exercising their rights. Until there is further clarity around this and the nature of the controller and processor relationship, we do not support the introduction of such legislative changes.

Whilst Article 6(1)(f) may be able to be used as long as the balancing test is met and it is not added to an exhaustive list of legitimate interests that do not require a balancing test, there is not enough evidence presented in the consultation to answer the question.

Q1.8.1. In your view, which, if any, of the proposals in 'Reducing barriers to responsible innovation' would impact on people who identify with the protected characteristics under the Equality Act 2010 (i.e. age, disability, gender reassignment, marriage and civil partnership, pregnancy and maternity, race, religion or belief, sex and sexual orientation)?

There are a number of proposals in this section that would impact on people who identify with the protected characteristics under the Equality Act 2010, including the proposals on anonymisation and reidentification, proposed changes to the legitimate interests lawful basis, the proposals on how sensitive personal data can be lawfully processed for the purpose of ensuring bias monitoring, detection and correction in relation to AI systems. It is important that if there is a substantive concept of outcome fairness that this has regard to the concept of fairness enshrined across legislation, including the duties and rights covered by the Equality Act 2010. Data Protection Impact Assessments must be retained to ensure that risks to the rights and freedoms of all data subjects are addressed.

Q1.8.2. In addition to any of the reforms already proposed in 'Reducing barriers to responsible innovation' (or elsewhere in the consultation), what reforms do you think would be helpful to reduce barriers to responsible innovation?

The current data protection regime already provides a framework for responsible innovation. Further measures could reduce the protection of data subjects and put at risk the UK's world-leading data protection standards, which the consultation aims to maintain.

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Chapter 2: Reducing burdens on businesses and delivering better outcomes for people

Q2.2.1. To what extent do you agree with the following statement: 'The accountability framework as set out in current legislation should i) feature fewer prescriptive requirements, ii) be more flexible, and iii) be more risk-based'

○ Neither agree nor disagree

We disagree with i) and ii) but agree with increased regard to risk in iii). Any such framework should also consider ethical considerations. However, the consultation proposes removing Data Protection Impact Assessments, which assess the risk to the rights and freedoms of data subjects, which would mean that such a future framework wouldn't be risk based. The consultation states [paragraph 139] that "the current model, in practice, tends towards a 'box-ticking' compliance regime" but doesn't provide any evidence for this assertion or evidence to demonstrate that the current accountability framework is a burden and doesn't deliver better outcomes for people. A case for the need to change is not made. Health and care organisations are required to complete a Data Security and Protection toolkit submission each year which complements the accountability framework in UK GDPR.

Q2.2.2. To what extent do you agree with the following statement: 'Organisations will benefit from being required to develop and implement a risk-based privacy management programme'?

○ Strongly disagree

Please explain your answer, and provide supporting evidence where possible and in particular:

- **Please share your views on whether a privacy management programme would help organisations to implement better, and more effective, privacy management processes.**

The consultation states [paragraph 144] "[t]hese rules ***may*** be generating a significant and disproportionate administrative burden, and leading organisations to misdirect time and energy away from the activities that ensure the responsible use of personal data in a specific context. This approach to compliance may also be putting a particularly disproportionate burden on SMEs and organisations that undertake low risk processing, despite some current requirements being risk-based and limited exemptions applying." It emphasises 'may', but there is no supporting evidence provided in the consultation about the need for the change to a risk-based privacy management programme. There are no examples of where there is a disproportionate burden

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Implementing a privacy management programme wouldn't necessarily help organisations to implement better, and more-effective, privacy management processes, as the consultation allows for each controller to decide their own privacy management process which will lead to inconsistencies. This would not allow the principle of accountability to be at the heart of the UK's data protection regime and enable high standards to be met. The consultation itself recognises [paragraph 150] that clear guidance from the ICO would need to be available to "organisations lacking capacity or expertise to design their own accountability practices without support." However, it doesn't mention the ICO's accountability framework which is already available to support organisations in assessing their accountability under the current legislation and covers the areas outlined for a privacy management programme [paragraph 152]. The consultation also asserts [paragraph 158] that "a strong privacy management programme is likely, in practice, to exhibit many of the same features as the current legislation." Given the lack of evidence provided in the consultation for the need to change and the fact that a privacy management programme would require many of the same features as the current legislation, it is not clear how this would enable better implementation and more effective processes. For the health and care sector which already has the Data Security and Protection toolkit, to put in place a new risk-based privacy management measure would be an unnecessary workload burden.

Please share your views on whether the privacy management programme requirement would risk creating additional burdens on organisations and, if so, how.

All previous Data Protection legislation has also created necessary 'burdens' for organisations as these data protection barriers protect data subjects. Reducing these reduces the protections for data subjects. In the health and care sector, changing the current framework to a new privacy management programme risks creating additional burdens on organisations, particularly on smaller health organisations like GP practices who have processes in place and for whom such changes could prove an unnecessary workload burden.

Q2.2.3. To what extent do you agree with the following statement: 'Individuals (i.e. data subjects) will benefit from organisations being required to implement a risk-based privacy management programme'?

○ Somewhat disagree

Please explain your choice, and provide supporting evidence where possible.

- **Please share your views on which, if any, elements of a privacy management programme should be published in order to aid transparency.**
- **What incentives or sanctions, if any, you consider would be necessary to ensure that privacy management programmes work effectively in practice.**

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Current legislation already provides an accountability framework for organisations. The proposal to require organisations to implement a risk-based privacy programme would not benefit data subjects as it would allow each controller to decide their own privacy management process, which would lead to inconsistencies. This would not allow the principle of accountability to be at the heart of the UK's data protection regime and enable high standards to be met, benefiting data subjects.

Q2.2.4. To what extent do you agree with the following statement: 'Under the current legislation, organisations are able to appoint a suitably independent data protection officer'?

○ Somewhat agree

Under the current legislation organisations are given the power to appoint a suitably independent Data Protection Officer. However, whether they are 'able' to – ie whether there are enough suitably qualified independent data protection officers available to appoint - is a different question. Concerns do not lie with the legislation, but around implementation, availability, and funding, and ensuring independence is possible. Appointing a DPO in each practice is not often practical for individual GP practices, but the legislation has the flexibility in the UK GDPR in Article 37 (3) for a Data Protection Officer to be designated for several public authorities or bodies. The challenge is therefore one of funding and availability.

Q2.2.5. To what extent do you agree with the proposal to remove the existing requirement to designate a data protection officer?

○ Strongly disagree

If there are not enough suitable qualified independent Data Protection Officers available, the answer to this skills shortage is not to remove the mandatory requirement to have one from the legislation. It will be extremely difficult to ensure organisations comply with the law if the existing requirement to designate a Data Protection Officer is removed and organisations are not obliged to have an expert who understands it. The removal of the DPO runs the risk of regressing progress on data protection compliance to pre-GDPR implementation, when DPO roles were often not taken seriously by the wider organisation and the board. It is important that the public are reassured that there is an individual ensuring compliance who they can contact directly to discuss any concerns or exercise their rights. In implementing the proposed PMP responsible person there will be issues because the status of the individual may be reduced, if the functions of the role are delegated to different people this could lead to conflicting advice and that the important safeguard that the dedicated role of the Data Protection Officer provides to ensure that data subject's data is properly protected will be lost.

Q.2.2.6. Please share your views on whether organisations are likely to maintain a similar data protection officer role, if not mandated.

Organisations are unlikely to maintain a Data Protection Officer role if it is not mandated and this would be a retrograde step as data protection is unlikely to remain one of the top priorities for organisations and organisations could lose the current level of expertise held by a Data Protection Officer if they are able to appoint a less qualified person.

Q2.2.7. To what extent do you agree with the following statement: 'Under the current legislation, data protection impact assessment requirements are helpful in the identification and minimisation of data protection risks to a project'?

○ Strongly agree

Data Protection Impact Assessments are helpful in the identification and minimisation of data protection risks but this question is incorrectly worded as a data protection impact assessment assess the identification and minimisation of data protection risks to the rights and freedoms of the data subjects not to the project. Without a Data Protection Impact Assessment it would be really difficult to uncover the risks to the data subjects and to assess the likelihood of the impacts of development and deployment of AI, to assess the re-identification risks in anonymous data. Data Protection Impact Assessment can also be used to increase public trust when available transparently.

Q.2.2.8. To what extent do you agree with the proposal to remove the requirement for organisations to undertake data protection impact assessments?

○ Strongly disagree

Please explain your answer, and provide supporting evidence where possible, and in particular describe what alternative risk assessment tools would achieve the intended outcome of minimising data protection risks.

Data Protection Impact Assessments (DPIAs) remain the best option to identify and minimise data protection risks to the data subjects and to enable organisations to consider risks early and adopt a privacy by design approach. DPIAs could be revised to include ethical considerations and focus on cyber/ digital aspects. Guidance by the ICO on how to undertake DPIAs needs to be continually updated to remain relevant to future developments. Previous data protection legislation prior to GDPR had Privacy Impact Assessments (PIAs) but these, were not always completed and/ or were not done well when they were completed. Removing DPIAs would be a retrograde step in protecting data subjects' rights and freedoms and undermine the UK's world-leading data protection standards which the consultation is keen to maintain. The proposed privacy management programme would still require organisations to have "Risk assessment tools for the

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identification, assessment and mitigation of privacy risks across the organisation" [paragraph 156 (a)(iii)], but these could be decided by organisations and it would lead to an inconsistent approach to risk management and an undermining of the current protections to the rights of data subjects.

Q. 2.2.9 Please share your views on why few organisations approach the ICO for 'prior consultation' under Article 36 (1)-(3). As a reminder Article 36 (1)-(3) requires that, where an organisation has identified a high risk that cannot be mitigated, it must consult the ICO before starting the processing. Please explain your answer, and provide supporting evidence where possible.

Organisations are often worried about being judged unfavourably and scrutinised if they approach the ICO. They also worry that there might be a delay in receiving a response. It is the role of the ICO to make itself approachable and assistive, and this must remain a priority for ICO mission and funding going forward. A clear communications campaign to encourage organisations to seek prior consultation and alleviate concerns about consulting the ICO would improve uptake. Retaining Data Protection Impact Assessments would ensure that an organisation can identify that they are required to consult with the ICO.

Q.2.2.10. To what extent do you agree with the following statement: 'Organisations are likely to approach the ICO before commencing high risk processing activities on a voluntary basis if this is taken into account as a mitigating factor during any future investigation or enforcement action'?

○ Neither agree nor disagree

Please explain your answer, and provide supporting evidence where possible, and in particular: what else could incentivise organisations to approach the ICO for advice regarding high-risk processing?

This would depend on the risk appetite of the organisation and its IG maturity. Retaining Data Protection Impact Assessments and the mandatory role of the Data Protection Officer would support organisations being encouraged to contact the ICO on a voluntary basis.

Q.2.2.11. To what extent do you agree with the proposal to reduce the burden on organisations by removing the record keeping requirements under Article 30?

○ Strongly disagree

The removal of the record keeping requirements under Article 30 is considered high risk. If organisations are not required to know what information they have, they will not be able to manage risks effectively or ensure that the processing of data is lawful. It is also unclear

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why it is proposed to remove the requirements under Article 30 but then reimpose them under the consultation proposals for the privacy management programme [paragraph 156 (III)(i)] which states that organisations must have "Personal data inventories which describe and explain what data is held, where it is held, why it has been collected and how sensitive it is". It is not clear why the consultation proposes removing one mandatory requirement to replace it with another mandatory requirement on record keeping requirements.

Q.2.2.12. To what extent do you agree with the proposal to reduce burdens on organisations by adjusting the threshold for notifying personal data breaches to the ICO under Article 33?

○ Somewhat agree

Please explain your answer, and provide supporting evidence where possible and in particular:

- **Would the adjustment provide a clear structure on when to report a breach?**
- **Would the adjustment reduce burdens on organisations?**
- **What impact would adjusting the threshold for breach reporting under Article 33 have on the rights and freedoms of data subjects?**

The current threshold is high, which means that organisations can often over-report. However, if the threshold is lowered too much there is a risk that significant breaches could go unreported. It is important to clarify the threshold for reporting data breaches in legislation and support organisations in understanding when to report and how to assess if the breach will have an impact on the rights and freedoms of data subjects. Even data breaches that may not meet the thresholds for reporting can identify trends or concerns particularly with cyber security and this needs to be considered within any adjustment of the threshold. For the health and care sector, the incident reporting tool within the Data Protection and Security toolkit allows for sector intelligence to be gathered on data breaches and for local solutions to groups of incidents to be implemented. It includes a risk matrix to decide if the breach needs to be reported to the ICO, providing consistency across the sector. A similar tool in other sectors could assist in reducing the burden on organisations whilst ensuring that the rights and freedoms of data subjects are protected.

Q.2.2.13. To what extent do you agree with the proposal to introduce a voluntary undertakings process? As a reminder, in the event of an infringement, the proposed voluntary undertakings process would allow accountable organisations to provide the ICO with a remedial action plan and, provided that the plan meets certain criteria, the ICO could authorise the plan without taking any further action.

○ Somewhat agree

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It is agreed that this could be a good move forward where organisations have a good understanding of their own data security, but the criteria would need to be well thought out and articulated and the ICO would need to retain inspection powers to check compliance has been achieved and the power to take regulatory action later on if it hasn't.

Q.2.2.14. Please share your views on whether any other areas of the existing regime should be amended or repealed in order to support organisations implementing privacy management requirements.

Amending or repealing other areas of the existing regime would undermine the accountability principle and could threaten the UK adequacy agreement, which was agreed on the assumption that GDPR accountability standards would be maintained in the UK.

Q.2.2.15. What, if any, safeguards should be put in place to mitigate any possible risks to data protection standards as a result of implementing a more flexible and risk-based approach to accountability through a privacy management programme?

Retaining Data Protection Impact Assessments at the heart of a risk-based approach, with the incorporation of ethical considerations. Retaining the mandatory role of the Data Protection Officer.

Q2.2.16. To what extent do you agree that some elements of Article 30 are duplicative (for example, with Articles 13 and 14) or are disproportionately burdensome for organisations without clear benefits?

○ Strongly disagree

Please explain your answer, and provide supporting evidence where possible, and in particular address which elements of Article 30 could be amended or repealed because they are duplicative and/or disproportionately burdensome for organisations without clear benefits.

There is some necessary duplication in the articles. Removing this duplication will cause an increased risk to data subject rights. The UK GPDR Article30 requires all processing to be recorded whereas there are exemptions in Articles13 and 14 on what needs to be recorded so this is not a duplication. Clear accountability is crucial for transparency.

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Q.2.2.17. To what extent do you agree that the proposal to amend the breach reporting requirement could be implemented without the implementation of the privacy management programme?

○ Strongly agree

The proposal to amend the breach reporting threshold requirement is a separate issue to the suggested implementation of the privacy management programme and its' requirement for a procedure for handling breaches, and they should be considered separately to avoid confusion. Under the current legislation, organisations already have to demonstrate their effective management of breaches. If a privacy management programme was implemented, they would still need to have a procedure for handling breaches.

Q.2.2.18. To what extent do you agree with the proposal to remove the requirement for all public authorities to appoint a data protection officer?

○ Strongly disagree

The proposal to remove the requirement for public authorities to appoint a Data Protection Officer doesn't consider the large quantities of personal data that public authorities have the power to demand, or the imbalance of power for data subjects who have to provide personal data in order to access services from a public authority. The consultation states [paragraph 184 (d)(I)] that it is a 'one-size-fits-all' model that applies to all public authorities, regardless of how much personal data is processed and the specific risks to individuals' rights and freedoms. However, the current data protection regime in Section 7(3) of the DPA18 already allows for flexibility; it is not a one size fits all model, as some public authorities eg parish councils are on the list that are not included in the definition of a public authority for the purpose of the data protection legislation.

The role of the DPO has provided a very positive change in the approach to IG in public sector organisations, raising the profile of data security and allowing organisations to take a thorough, risk-based approach to data sharing. The removal of this function will severely weaken the data security/IG of the organisations, making it more difficult to implement a risk-based approach without the independence that the Data Protection Officer role provides. This proposed change feels like a substantial backwards step.

Q.2.2.19. If you agree, please provide your view which of the two options presented at paragraph 184d(V) would best tackle the problem.

Please provide supporting evidence where possible, and in particular:

- **What risks and benefits you envisage**

- **What should be the criteria for determining which authorities should be required to appoint a data protection officer.**

Neither of these options are required as the current legislation already has the flexibility to designate public authorities as not being included in the definition of a public authority in Section 7(3) of DPA18.

Q2.2.20 If the privacy management programme requirement is not introduced, what other aspects of the current legislation would benefit from amendments, alongside the proposed reforms to record keeping, breach reporting requirements and data protection officers?

This question is misleading as it suggests an agreement to the reforms of record keeping, breach reporting requirements and data protection officers as a package. There is scope to amend the breach reporting requirements, but separate to the other reforms. The current data protection regime provides a strong, transparent, risk-based approach to data protection.

Q2.3.1. Please share your views on the extent to which organisations find subject access requests time-consuming or costly to process.

Please provide supporting evidence where possible, including:

- **What characteristics of the subject access requests might generate or elevate costs**
- **Whether vexatious subject access requests and/or repeat subject access requests from the same requester play a role**
- **Whether it is clear what kind of information does and does not fall within scope when responding to a subject access request**

For GP practices, as small organisations with large amounts of special category data, Subject Access Requests (SARs) can be both time-consuming and costly to process, particularly where the volume is high and where both redaction and clinical review is required.

SARs are an important vehicle to uphold the rights and freedoms of data subjects and introducing a nominal fee to allow organisations to charge where it may be necessary and to challenge complex repeated SARs more effectively would provide some balance to the time and costs involved. However, the nominal fee would need to be straightforward to apply and not occur additional workload in working out what to charge.

Organisations would benefit from additional legislation to assist with vexatious complainants.

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Q2.3.2. To what extent do you agree with the following statement: 'The 'manifestly unfounded' threshold to refuse a subject access request is too high'?

○ Somewhat agree

Please explain your answer, providing supporting evidence where possible, including on what, if any, measures would make it easier to assess an appropriate threshold.

The current definition of 'manifestly unfounded' is not detailed enough. Guidance with examples and use cases to help identify when a Subject Access Request (SAR) is manifestly unfounded.

Q2.3.3. To what extent do you agree that introducing a cost limit and amending the threshold for response, akin to the Freedom of Information regime (detailed in the section on subject access requests), would help to alleviate potential costs (time and resource) in responding to these requests

○ Somewhat agree

Please explain your answer, and provide supporting evidence where possible, including on:

- **Which safeguards should apply (such as mirroring Section 16 of the Freedom of Information Act (for public bodies) to help data subjects by providing advice and assistance to avoid discrimination)**
- **What a reasonable cost limit would look like, and whether a different (ie. sliding scale) threshold depending on the size (based on number of employees and/or turnover, for example) would be advantageous**

It could be advantageous to have a cost limit or nominal fee as long as the costs did not become too burdensome for the requestor, leading to an inability to request and reducing their ability to be able to exercise their rights. The workload involve in managing a sliding scale of costs would be great and burdensome for small organisations, such as GP practices.

There also needs to be a provision for the Data Protection Officer to waive costs where necessary and appropriate to ensure the rights and freedoms of the data subject are upheld.

Q2.3.4. To what extent do you agree with the following statement: 'There is a case for re-introducing a small nominal fee for processing subject access requests (akin to the approach in the Data Protection Act 1998)'?

○ Somewhat agree

Please explain your answer, and provide supporting evidence where possible, including what a reasonable level of the fee would be, and which safeguards should apply.

Subject Access Requests (SARs) are an important vehicle to uphold the rights and freedoms of data subjects and introducing a nominal fee to allow organisations to charge where it may be necessary and to challenge complex repeated SARs more effectively would provide some balance to the time and costs involved. The nominal fee would need to be straightforward to apply and not occur additional workload in working out what to charge. The fee must be reasonable to ensure that it does not lead to an inability for a data subject to exercise this right. A provision for the Data Protection Officer to waive costs where necessary and appropriate to ensure the rights and freedoms of the data subject are upheld would be a safeguard.

Small organisations who process large amounts of special category data, such as GP practices, should receive funding to support the processing of SARs until nationally provided appropriate software with appropriate safeguarding and redaction processes is implemented to support safe electronic access to records for data subjects.

Q2.3.5. Are there any alternative options you would consider to reduce the costs and time taken to respond to subject access requests.

Yes

Introduction of national Subject Access Requests (SAR) software to support all organisations.

Redaction software for GP practices, as stated in Regulation 71AZ(2) of the General Medical Services Contract Regulations, to support the electronic access to records for data subjects. This needs to ensure that it supports GP practices in complying with SARs, has appropriate safeguarding and does not add additional time burdens.

Q2.4.1. What types of data collection or other processing activities by cookies and other similar technologies should fall under the definition of 'analytics'?

Any use of cookies should be transparent to the user. Analytical cookies should not track users and only collect anonymous data this is particularly important for health websites and apps. Any change to the definition of analytics needs to be carefully considered as many analytical cookies also collect identifiable data and track users across sites. For users visiting health websites and apps, if there are cookies tracking them this presents a risk to their rights and freedoms.

Q2.4.2 To what extent do you agree with the proposal to remove the consent requirement for analytics cookies and other similar technologies covered by Regulation 6 of PECR?

○ Somewhat disagree

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Any use of cookies should be transparent to the user. If the consent requirement was removed for analytical cookies, then there need to be appropriate safeguards in place to protect the rights and freedoms of data subjects. A safeguard could be that the requirement for consent is only removed for analytical cookies which do not track users and only collect anonymous data. This would present a low risk to the data subject and a low risk of harm.

Q2.4.3. To what extent do you agree with what the government is considering in relation to removing consent requirements in a wider range of circumstances? Such circumstances might include, for example, those in which the controller can demonstrate a legitimate interest for processing the data, such as for the purposes of detecting technical faults or enabling use of video or other enhanced functionality on websites.

○ Somewhat disagree

There needs to be further evidence gathered on how this could work, what safeguards would be appropriate and work effectively, along with an assessment of potential risks and harms to data subjects before a decision could be made on whether it would be appropriate to remove consent requirements. If legitimate interests were the lawful basis used for processing identifiable data from cookies, this would need to have the balancing test applied and shouldn't be put onto an exemption list for legitimate interests. A separate assessment of the risks and potential harms should be conducted for children's data.

Q2.4.4. To what extent do you agree that the requirement for prior consent should be removed for all types of cookies?

○ Somewhat disagree

Please explain your answer, and provide supporting evidence where possible, including how organisations could comply with the UK GDPR principles on lawfulness, fairness and transparency if PECR requirements for consent to all cookies were removed.

There needs to be further evidence gathered on what safeguards would be appropriate and work effectively, along with an assessment of potential risks and harms to data subjects before a decision could be made on whether it would be appropriate to remove consent requirements for all cookies. A separate assessment of the risks and potential harms should be conducted for children's data.

Q2.4.6. What are the benefits and risks of requiring websites or services to respect preferences with respect to consent set by individuals through their browser, software applications, or device settings?

There could be benefits to requiring websites and services to respect preferences with respect to consent set by individuals through their browser, as this would protect the rights and freedoms of the data subject without the burden of lots of consent cookie tools. It would need to be clear in privacy notices what cookies are set on the website and what tracking is occurring, what is being blocked by browsers, and how different browsers are respecting the consent set by an individual.

However, there are also a number of risks; not all data subjects are aware that there is ability to set browsers and there is a risk that in the absence of a setting in the browser it will be taken as user consent; different browsers work in differently ways and not all browsers will block tracking if consent is only provided for necessary cookies; technology keeps changing and the browser settings would need to stay updated, and; different users may use the same browser or device but want to have different consent settings.

Q2.4.7. How could technological solutions, such as browser technology, help to reduce the volume of cookie banners in the future?

Browser technology could help reduce the volume of cookie banners once the risks are addressed and users are aware that this is an option. There are other options which organisations could consider, including only using cookies which collect anonymous data.

Q2.4.8. What, if any, other measures would help solve the issues outlined in this section?

Organisations could consider only using cookies which collect anonymous data.

Q2.4.14. What are the benefits and risks of mandating communications providers to do more to block calls and text messages at source?

There is a benefit that this upholds the rights and freedoms of the data subjects, however there is a risk that legitimate calls and text messages might be blocked at source. A number of organisations, including GP practices, contact patients from a withheld private number and there needs to be consideration about how such contacts would be managed as patients would not have the ability/ know the numbers to add them to any allowed list. Similar consideration should be applied to text messages sent to patients by GP practices containing key practice information and details of appointments and online consultations to ensure that these are not blocked at source.

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Q2.4.15 What are the benefits and risks of providing free of charge services that block, where technically feasible, incoming calls from numbers not on an 'allow list'?

An 'allow list' is a list of approved numbers that a phone will only accept incoming calls from.

Whilst this can be framed as a benefit upholding the rights and freedoms of the data subjects, there is a risk that a blunt 'allow list' might block legitimate incoming calls.

A number of organisations, including GP practices, contact patients from a withheld private number and there needs to be consideration about how such contacts would be managed as patients would not have the ability/ know the numbers to add them to any allowed list. Similar consideration should be applied to text messages sent to patients by GP practices containing key practice information and details of appointments and online consultations to ensure that these are not blocked at source.

Q2.6.1. In your view, which, if any, of the proposals in 'Reducing burdens on business and delivering better outcomes for people', would impact on people who identify with the protected characteristics under the Equality Act 2010 (i.e. age, disability, gender reassignment, marriage and civil partnership, pregnancy and maternity, race, religion or belief, sex and sexual orientation)?

Removal of the mandatory requirement for a Data Protection Officer and/ or removal of the requirement for a Data Protection Impact Assessment would impact on people who identity with the protected characteristics under the Equality Act 2010.

Chapter 4 - Delivering better public services

Q4.3.1. To what extent do you agree with the following statement: 'Private companies, organisations and individuals who have been asked to process personal data on behalf of a public body should be permitted to rely on that body's lawful ground for processing the data under Article 6(1)(e) of the UK GDPR'?

○ Somewhat disagree

The consultation states that this proposal is in response to difficulties encountered by private companies using the legitimate interest lawful basis Article 6(1)(f). It is important to note that there are already alternatives in the current data protection regime that could be used. Eg a government could impose legal obligations on controllers to process data and therefore the lawful basis of legal obligation Article 6(1)(c) could be used, or public body controllers could contract a private company to act as a processor to undertake the processing under a public task.

The ICO in their response to the consultation have stated "The implication of this proposal is that the public authority, rather than the private sector organisation, would be accountable for determining that all relevant aspects of the public task lawful ground are satisfied." There needs to be further clarity on how the checks and balances that apply to public bodies would be apply to private companies and where health data is processed an assessment of potential harms and risks to patient confidentiality

Q4.3.2. What, if any, additional safeguards should be considered if this proposal were pursued?

If this proposal was pursued, there would need to be consideration as to whether the private company needs to be a controller or if the public task could be fulfilled with the private company contracted as a processor for the public body. Additional safeguards to be considered are clarity on how the checks and balances for public bodies would apply to private companies, including consideration of the private companies being subject to the Freedom of Information requests in relation to the processing, that the legislation states that the private companies cannot reuse the data for a different purpose, that data protection impact assessments remain a mandatory requirement, and where heath data is processed that risks to confidentiality are addressed and the Caldicott Principles are met. It would be important to be transparent on the processing by a private company to ensure public trust, that the data subject's right to object could be exercised, and to be clear whether the public body or the private company would respond to requests under that right and others.

Q4.3.3. To what extent do you agree with the proposal to clarify that public and private bodies may lawfully process health data when necessary for reasons of substantial public interest in relation to public health or other emergencies?

○ Somewhat disagree

It is high risk to allow the processing of health data by public and private bodies for reasons of substantial public interest without applying the current safeguard for processing health data for reasons of substantial public interest. Allowing such processing without the current safeguard of requiring it is overseen by healthcare professionals or undertaken under a duty of confidentiality could result in a loss of public trust.

The National Data Guardian clearly explains in "Data-driven innovation: why confidentiality and transparency must underpin the nation's bright vision for the future of health and care" of the importance of a consideration of the potential harms and risks to patient confidentiality and public trust with data use. She stated that "People need to trust that they can share information in confidence with those responsible for their care without worrying how it will be used, by the police or others. And health professionals need to trust

that that confidential information they routinely collect as part of care will not be used in ways that could negatively impact care, or which may be at odds with their professional and ethical duties and obligations to their patients."

Q4.3.4. What, if any, additional safeguards should be considered if this proposal were pursued?

A duty of confidentiality is a minimum safeguarding requirement in order to retain public trust. Such processing would still need to be time-limited and subject to appropriate safeguards that reflect the sensitivity of the data. Processors should also be required to retain the requirement for Data Protection Impact Assessments with an additional consideration of ethical considerations to assess risks and harms to the rights and freedoms of data subjects.

Q4.4.1. To what extent do you agree that compulsory transparency reporting on the use of algorithms in decision-making for public authorities, government departments and government contractors using public data will improve public trust in government use of data?

○ Somewhat agree

Public trust and understanding in decision-making where public data is used can be built via compulsory transparency reporting on the use of algorithms, if it is in clear and accessible language explaining the processes used, how data protection and ethical risks were addressed, and the role of human intervention in the process.

Q4.4.2. Please share your views on the key contents of mandatory transparency reporting.

Transparency reporting should be in a clear and accessible language explaining the processes used, how data protection and ethical risks were addressed, and the role of human intervention in the process. If any exemptions have been applied, it should be clear what the exemption was. Undertaking a Data Protection Impact Assessment (DPIA) should be a mandatory requirement. There can be commercial sensitivities to publishing technical details/specifications of algorithms and where this is the case, then the DPIA can provide reassurance that the risks have been identified and addressed.

Q4.4.5. To what extent do you agree with the following statement: 'It may be difficult to distinguish processing that is in the substantial public interest from processing in the public interest'?

○ Somewhat agree

Clarity would be beneficial to distinguish between what constitutes 'public interest' and what constitutes 'substantial public interest'. Where health data is processed, if it is not identified in Part 2 of Schedule 1 to the Data Protection Act 2018, then a test must be applied as to whether it is in the substantial public interest, and a Data Protection Impact Assessment completed to assess the risks and harms to the rights and freedoms of data subjects in connection with the processing.

Q4.4.6. To what extent do you agree that it may be helpful to create a definition of the term 'substantial public interest'?

○ Somewhat agree

Please explain your answer, and provide supporting evidence where possible, including on:

- **What the risks and benefits of a definition would be**
- **What such a definition might look like**
- **What, if any, safeguards may be needed**

It may be helpful to create a definition of the term 'substantial public interest' but there would need to be consideration of how this would be tested. Further consultation with stakeholders on substantial public interest should be sought before any decisions are made.

Q4.4.7. To what extent do you agree that there may be a need to add to, or amend, the list of specific situations in Schedule 1 to the Data Protection Act 2018 that are deemed to always be in the substantial public interest?

○ Somewhat agree

Please explain your answer, and provide supporting evidence where possible, including on:

- **What such situations may be**
- **What the risks and benefits of listing those situations would be**
- **What, if any, safeguards may be needed.**

It may be helpful to add to or amend the list of specific situations in Schedule 1 to the Data Protection Act 2018 but there would need to be consideration of how this would be tested and that appropriate safeguards are in place. For any additional situations involving health data that might be added to the list, the duty of confidence must be met. Further consultation with stakeholders on 'substantial public interest' should be sought before any decisions are made.

Q4.6.1. In your view, which, if any, of the proposals in 'Delivering Better Public Services' would impact on people who identify with the protected characteristics under the Equality Act 2010 (i.e. age, disability, gender reassignment, marriage and civil partnership, pregnancy and maternity, race, religion or belief, sex and sexual orientation)?

The proposals on changes to processing under 'substantial public interest' would impact on people who identify with the protected characteristics under the Equality Act 2010.

Chapter 5 - Reform of the Information Commissioner's Office

Q5.5.2. To what extent do you agree with the proposal to give the Secretary of State the power to require the ICO to set up a panel of persons with expertise when developing codes of practice and complex or novel guidance?

○ Somewhat agree

Using panels of people with expertise when developing codes of practice and complex or novel guidance would help to ensure that all viewpoints are considered. The ICO needs to retain the right to decide who is on a panel as part of their independent role.

Q5.6.1. To what extent do you agree that the ICO would benefit from a more proportionate regulatory approach to data protection complaints?

○ Somewhat agree

Any changes to the ICO's regulatory approach needs to enshrine the right of data subjects to complain to the Commissioner.

Q5.6.2. To what extent do you agree with the proposal to introduce a requirement for the complainant to attempt to resolve their complaint directly with the relevant data controller prior to lodging a complaint with the ICO?

○ Somewhat agree

This would bring the ICO into line with other domestic ombudsmen and regulatory bodies, which require a complaint to be lodged first with the organisation before a formal complaint is made to the regulator or ombudsman. This change would need to be accompanied with clear guidance for organisations and data subjects on any exemptions that would allow a direct complaint to the ICO. It would also require a change to privacy notices to explain the complaints process before the ICO could be contacted.

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It would be helpful to clarify if the proposed changes to the complaint process will only be in reference to complaints under the Data Protection Act, or would apply to complaints under PECR and the Freedom of Information Act 2000 in the future.

Q5.7.1. To what extent do you agree that current enforcement provisions are broadly fit for purpose and that the ICO has the appropriate tools to both promote compliance and to impose robust, proportionate and dissuasive sanctions where necessary?

○ Somewhat agree

Consideration of a new power to allow the ICO to commission technical reports would provide an additional tool, where appropriate.

Q5.7.2. To what extent do you agree with the proposal to introduce a new power to allow the ICO to commission technical reports to inform investigations?

○ Somewhat agree

Please explain your answer, and provide supporting evidence where possible, including:

- **Whether there are any other risks or benefits you can see in this proposal**
- **If you foresee any risks, what safeguards should be put in place**

Providing the ICO with the power to commission technical report to inform investigations would strengthen their investigative powers, enabling them to make an assessment of the risks within a data breach, particularly with the rapid development of technology and AI. The ICO needs to ensure that they have right skillsets within their caseworkers to interpret and understand the technical reports. There also needs to be guidance on when these would be commissioned, including an assessment on a case-by-case basis.

Q5.7.5. To what extent do you agree with what the government is considering in relation to introducing a power which explicitly allows the ICO to be able to compel witnesses to attend an interview in the course of an investigation?

○ Neither agree nor disagree

Please explain your answer, and provide supporting evidence where possible. In particular, please give your views on any benefits or risks you envisage and what measures could mitigate these risks.

There needs to be a fuller discussion on this power, which is potentially a wide-ranging power, with a clear assessment on the risks to the rights and freedoms of individuals.

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Q5.7.6. To what extent do you agree with extending the proposed power to compel a witness to attend an interview to explicitly allow the ICO to be able to compel witnesses to answer questions in the course of an investigation?

○ Neither agree nor disagree

Please explain your answer, and provide supporting evidence where possible. In particular, please give your views on:

- **Any benefits or risks you envisage**
- **What, if any, additional safeguards should be considered**

There needs to be a fuller discussion on this power, which is potentially a wide-ranging power, with a clear assessment on the risks to the rights and freedoms of individuals.

Q5.7.7. To what extent do you agree with the proposal to amend the statutory deadline for the ICO to issue a penalty following a Notice of Intent in order to remove unnecessary deadlines on the investigations process?

○ Somewhat agree

This would provide organisations with more time to comply with the ICO's enquiries.

Q5.7.8. To what extent do you agree with the proposal to include a 'stop-the-clock' mechanism if the requested information is not provided on time?

○ Somewhat agree

Q5.7.9. To what extent do you agree with the proposal to require the ICO to set out to the relevant data controller(s) at the beginning of an investigation the anticipated timelines for phases of its investigation?

○ Somewhat agree

This would support organisations with responding to the ICO enquiries. Consideration should be given to allowing mutually agreed flexibility in extending those deadlines.

- END -

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