

Annex: A summary of the Transparency in Health and Social Care guidance impact assessment

1. Impact assessment context

Following best practice and the guidance in our '[Impact Assessment Framework](#)', we deem it appropriate to conduct a proportionate impact assessment of our proposed guidance intervention to increase regulatory certainty around the ICO's expectations on standards of transparency for health and social care.

We have produced a draft initial assessment, as summarised in Table 1 below. We are seeking feedback on our identified impacts, as well as any other insights stakeholders can provide on impacts, via the consultation on the draft guidance.

It is important to note that we do not intend for this summary to provide an exhaustive assessment of impacts. It is just an initial overview of our considerations. Post consultation we will consider the proportionality of further assessment of the impacts as we move towards final publication of the guidance.

2. A summary of the draft impact assessment

Table 1 provides a summary of our draft impact assessment.

Table 1: Impact assessment summary

1: Problem definition	<p>The responsible sharing of patient data has the potential to transform health and social care delivery, and contribute to developments in:</p> <ul style="list-style-type: none">• Advancing medical research in areas such as understanding the cause and prevention of disease.• Improving diagnosis, though linking datasets to offer better and earlier support to patients.• Supporting the planning and delivery of health and social care services. <p>A 2019 report by EY estimated that data held by the NHS could be worth nearly £10bn a year, through operational savings, improved patient outcomes and benefits to the wider economy.</p> <p>Public attitudes research demonstrates that patients and service users are supportive of health and care data being used if certain expectations are met, including that it delivers a public benefit. However, if individuals do not understand the</p>
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	<p>intended use of their health and social care information, this can weaken public trust and lead to individuals opting out of sharing their data. The latest NHS figures¹ show that around 3.3m patients in England have opted out of sharing their health information beyond the purposes of their own care. This diminishes the potential value of initiatives which depend on the processing of patient data.</p> <p>A lack of public understanding can be the result of by poor transparency practices. A report on the GP data for planning and research programme (GPDPR) found shortcomings in scheme’s transparency and communications programme, which contributed to the delay of programme. As highlighted by the National Data Guardian, it is important that organisations are transparent with the public around how their information is processed in order to sustain public trust.</p> <p>For data subjects, a lack of transparency can also result in data protection harms, such as a loss of personal control. These are discussed in more detail in the next section.</p>
<p>2: Rationale for intervention</p>	<p>The ICO is of the view that the existing guidance is high level and does not provide sufficient insight into our expectations on standards of transparency for the health and social care sectors. Stakeholder feedback highlights that further clarity on areas such as the exercising of Data Protection (DP) rights in practice and third-party access to data, is needed to improve regulatory certainty.</p> <p>A lack of transparency and public understanding over how organisations process their health data can lead to a number of DP harms and have the potential to undermine public trust. If public information on how an organisation processes personal data is extremely complex, this can deter individuals from accessing and reviewing it, leading to a loss of control of personal data. Where people do not understand the intended use of their health and social care information it may also result in psychological harms such as embarrassment, anxiety or fear. These harms can be exacerbated by the sensitivity and volume of data processed by organisations in the health and social care sectors</p>

¹ Data accessed 11th October 2023

<p>3: Options appraisal</p>	<p>There are a range of intervention options available to increase regulatory certainty. In this case, it was considered that updating the existing guidance on ICO expectations around transparency was the most appropriate policy tool.</p> <p>Options considered include:</p> <ol style="list-style-type: none"> 1: Do nothing. 2: Guidance explaining ICO expectations around transparency in the health and social care sector. 3. Other regulatory tools (e.g. engagement, outreach, etc). <p>Option 2, alongside a programme of targeted engagement, was identified as the preferred option.</p>						
<p>4: Detail of proposed intervention</p>	<p>The ICO will provide updated guidance to assist health and social care organisations in understanding our expectations around transparency. This will supplement existing guidance on the principle of transparency and the right to be informed.</p> <p>Whilst some of the issues highlighted in the problem statement are specific to England (such as the application of opt-outs), we are of the view that the guidance can be developed to be generally applicable across the UK regions.</p>						
<p>5: Cost-benefit analysis</p>	<p>The costs and benefits of the intervention have been identified, as far as is possible and proportionate.</p> <p>The legal requirements around transparency are set out in UK GDPR. This guidance seeks to support organisations in the health and social care sector to better understand their obligations under this legislation. Only costs and benefits of the guidance are considered here.</p> <table border="1" data-bbox="424 1487 1370 1998"> <thead> <tr> <th data-bbox="424 1487 687 1563"></th> <th data-bbox="687 1487 1038 1563">Benefits</th> <th data-bbox="1038 1487 1370 1563">Costs</th> </tr> </thead> <tbody> <tr> <td data-bbox="424 1563 687 1998"> <p>The ICO</p> </td> <td data-bbox="687 1563 1038 1998"> <ul style="list-style-type: none"> • Efficiency savings on advice and support to organisations in health and social care relating to transparency expectations. • Potential reduction in supervision costs from improved understanding of transparency requirements. </td> <td data-bbox="1038 1563 1370 1998"> <ul style="list-style-type: none"> • Resource cost of updating guidance to clarify ICO expectations on transparency. </td> </tr> </tbody> </table>		Benefits	Costs	<p>The ICO</p>	<ul style="list-style-type: none"> • Efficiency savings on advice and support to organisations in health and social care relating to transparency expectations. • Potential reduction in supervision costs from improved understanding of transparency requirements. 	<ul style="list-style-type: none"> • Resource cost of updating guidance to clarify ICO expectations on transparency.
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	<p>Data Subjects</p>	<ul style="list-style-type: none"> • Reduction in potential DP harms from better understanding over how organisations process sensitive information. • Enhanced understanding of and ability to exercise DP rights. • Improved trust and confidence in data processing by health and social care organisations. 	<ul style="list-style-type: none"> • Potential time costs of engaging with public transparency materials produced by health and social care organisations.
	<p>Health and Social Care Sectors</p>	<ul style="list-style-type: none"> • Improved regulatory certainty over the transparency expectations for organisations in the health and social care sector. • Greater confidence and certainty over what is compliant processing of personal data. • Potential time and cost savings from more efficient resource planning and service delivery. 	<ul style="list-style-type: none"> • Familiarisation costs of reading the updated guidance. • Time costs associated with a potential rise in data subjects exercising their DP rights. • Cost of developing and updating transparency materials explaining how data subjects' information is processed.
	<p>Wider Society</p>	<ul style="list-style-type: none"> • Potential for improved public trust and confidence in the processing of personal data. • Potential for wider benefits such as improved data for research purposes as a result of individuals being better informed, and potentially more willing to consent to their personal data being processed. • Potential for improved health outcomes, and more efficient public services, from individuals being better informed, and potentially more willing to consent to their data being processed. 	

	Overall our assessment suggests that the benefits of producing this guidance outweigh the costs.
6: Monitoring and evaluation	In line with best practice and organisational standards, when the proposed guidance is finalised we will put in place an appropriate and proportionate review mechanism.