Consultation on the draft Transparency in Health and Social Care guidance

The Information Commissioner's Office (ICO) is producing guidance on transparency in the health and social care sector.

The draft of this guidance is now published for public consultation.

The draft transparency in health and social care guidance has been developed to help health and social care organisations understand our expectations about transparency.

We are also seeking views on a draft summary impact assessment for this guidance. Your responses will help us understand the code's practical impact on organisations and individuals.

This survey is split into four sections. This covers:

- Section 1: Your views on the draft guidance
- Section 2: Your views on our summary impact assessment
- Section 3: About you and your organisation
- Section 4: Any other comments

The consultation will remain open until 7th January 2024. Please submit responses by 5pm on the 7 January 2024. We may not consider responses received after the deadline.

Please send completed form to PolicyProjects@ico.org.uk or print off this document and post to:

Regulatory Policy Projects Team
Information Commissioner's Office
Wycliffe House
Water Lane
Wilmslow
Cheshire
SK9 5AF

Privacy statement

For this consultation we may publish the responses received from organisations or a summary of the responses. We will not publish responses from individuals acting in a private capacity. If we do publish any responses, we will remove email addresses and telephone numbers from these responses but apart from this we will publish them in full.

Please be mindful not to share any information in your response which you would not be happy for us to make publicly available.

Should we receive an FOI request for your response we will always seek to consult with you for your views on the disclosure of this information before any decision is made.

For more information about what we do with personal data please see our privacy notice.

Are you happy to proceed? *

✓ I am happy to proceed.

Section 1: Your views on the draft guidance

Answers to the following questions will be helpful in shaping our guidance. Please use the comments boxes to provide further detailed information as far as possible. Some of the questions may not be relevant to you or your organisation, so please skip these as necessary.

1. Do you agree that this guidance clearly sets out what is required of health and care organisations to comply with the data protection transparency principle?

Strongly agree

✓ Agree

Neither agree nor disagree

Disagree

Strongly disagree

Please provide any comments you have (max. 500 characters):

In general, having ICO guidance reiterates the importance for organisations to engage with the users of their services to demonstrate they are not only complying the law but being ethically and morally responsible with highly sensitive data.

There are some areas that could be clearer, for example defining what 'meaningful engagement' should include (or aspire toward).

Engagement with the public on complex topics often needs to ensure:

- hard to reach groups are adequately represented and consulted
- engagement is inclusive of the diverse nature of the people living in Wales.
- enough time is given to explain why we should be sharing data
- there is opportunity for the public to explore the benefits and risks before they can fairly offer their views

The quality of the engagement is just as important than demonstrating a wide reach.

Our experience suggests that much of the public have only a cursory understanding of how their data is used and this understanding is often guided by stories in the media and elsewhere that fuel public mistrust in organisations' handling of data.

There is also a risk of pushback from organisations who might view the requirements as box-ticking and deflecting away from the purpose of their interaction with an individual.

2(a). Do you agree that this guidance provides a clear definition of transparency and privacy information?

Strongly agree

✓ Agree

Neither agree nor disagree

Disagree

Strongly disagree

Please provide any comments you have (max. 500 characters):

It would be useful if the ICO could provide a wide range of ready-made resources that could be used by organisations to explain such distinctions with individuals who may require a support service.

2(b). Does the distinction between transparency information and privacy information make sense to you?

✓ Yes

No

Unsure

Please provide any comments you have (max. 500 characters):

Nothing additional to add.

3. Do you agree that this guidance provides useful additional information to the Health & Social Care sector that is not part of our existing guidance on the principle of transparency and the right to be informed?

Strongly agree

✓ Agree

Neither agree nor disagree

Disagree

Strongly disagree

Please provide any comments you have (max. 500 characters):

We welcome the emphasis on working together

Perhaps the example could look at existing good practice such as OneLondon Citizen Summit or other citizen-jury based engagement models?

The draft guidance might be seen by some as evidence that data-sharing for safeguarding purposes is already routinely happening without issue. We know from recent research that this is not always the case and hope that the ICO take account of work that examines the lessons learned on the use of data in a social care (and safeguarding) context, particularly in relation to the necessity for sharing of data across organisational boundaries. Issues with data sharing are a consistent theme in Child Practice Reviews as seen in the thematic analysis of child practice reviews in Wales published last year: https://safeguardingboard.wales/wp-content/uploads/sites/8/2023/11/Briefing-Report-Risk-Response-Review-CPRs-Wales-2023.pdf Professionals **must** be able to feel more confident, not less confident in understanding how data is able to be used. Good, easy to use guidance and resources to use with the public is therefore critical.

Work on sharing data will also be relevant when considering advances in technology that improve the ability to share data in real-time between data systems, (such as the planned National Data Resource)

4. Do you agree that this guidance is balanced between the separate areas of health and social care?

✓ Too focused on health

Too focused on social care

About right

Not enough information on either

Unsure / don't know

Please provide any comments you have (max. 500 characters):

Our view is that the language used in the guidance is far too health focused. Where the inclusion of social care is more carefully considered, the language and terminology that is used is often out-of-date and too generalised. We have given some examples of this below:

'Service user' - is used throughout the guidance. This is an increasingly outdated means of expressing individuals who require social care in Wales. The Social Services and Wellbeing (Wales) Act 2014 uses the term 'citizens' but we most often use 'people' or 'individuals' who require care and support, or support as a carer.

Informed choices - This is not always possible where people may lack capacity and where a course of action must be taken to protect life and limb (in the case of a safeguarding decision). Explicit recognition of this would be useful.

It might also serve as a signpost to the need to be mindful of considering this as part of good practice. Linked to this, should there be something about consideration of different formats and mediums of information as part of good practice?

'Secondary care' - This might be interpreted as being aligned to health models of primary, secondary and tertiary service provision. Could there be examples of how circumstances apply in social care provision?

What are the most effective ways of **communicating with your audience?** - See earlier comments about 'informed choice' above. More emphasis or examples that are not just 'website' or 'paper'.

Safeguarding - Would a reminder that data sharing for safeguarding purposes is both important and allowed, and should be considered/built-in to guidance etc.?

5. Do you agree that the use of the terms must, should and could in this guidance clearly defines the ICO's expectations in the legislative requirements section and that the terms are applied consistently throughout the guidance?

Strongly agree

✓ Agree

Neither agree nor disagree

Disagree

Strongly disagree

Please provide any comments you have (max. 500 characters):

We find these distinctions useful.

6. Do you agree with the definitions we have provided on openness and honesty? Are the examples of how you can demonstrate that you are being open and honest useful and accurate in the context of health and care?

Strongly agree

✓ Agree

Neither agree nor disagree

Disagree

Strongly disagree

Please provide any comments you have (max. 500 characters):

Generally, the examples given in this section are appropriate and helpful.

However, the challenge in practice is no longer the technology and systems architecture but the ethical and moral position. Far too often the focus is still 'can we do it?' where we should be asking 'should we do it?'

Organisations aren't being intentionally dishonest or vague when developing platforms that can house, link and share data. These massive, federated data platforms house significant data with layer upon layer of complexity. The ability for an organisation to be able to describe *all* of the complexity of these systems to the public would be an arduous, if not impossible task.

The goal of openness and honesty must be explored pragmatically, with the public being able to openly define what they are comfortable with and where their red lines are with the use of their data. Systems architects, data engineers and leaders need to be able to understand and recognise where they are most likely to encounter push-back from the public and these are the areas that should be prioritised during engagement for discussion and potential redesign.

There may also be a reluctance for organisations to ask the public difficult questions about using their data in case they get the 'wrong' answer. This is a logical fallacy because if they don't ask the hard questions and go through the

work of creating alternative and workaround solutions with the public, then confidence from the public will be low and so will trust which is crucial for data to be collected, used and shared.

7. Do you agree with that the section on harms is useful for organisations when considering the risks of failing to provide sufficient transparency material?

Strongly agree

Agree

✓ Neither agree nor disagree

Disagree

Strongly disagree

Please provide any comments you have (max. 500 characters):

Societal harm example only refers to damage to public health, but the definition of societal harm is much broader. Could we also identify social care in terms of wider determinants such as inadequate housing, impact of poverty, substance abuse, domestic violence and risk of exploitation and discrimination?

Examples of bad practice (and the subsequent consequences) here may also serve a purpose.

8. Do you agree that the section on patient engagement provides useful information to help organisations develop transparency information that responds to people's needs and priorities?

Strongly agree

Agree

Neither agree nor disagree

✓ Disagree

Strongly disagree

Please provide any comments you have (max. 500 characters):

There is a tendency at various points to default to 'patients' as a catch-all. We suggest the whole text is reviewed to ensure inclusivity and create more balance with social care and those who require care and support, and for unpaid carers.

9. Do you agree that the section on providing transparency information sets out clearly how organisations should approach the delivery of transparency and privacy information?

Strongly agree

Agree

✓ Neither agree nor disagree

Disagree

Strongly disagree

Please provide any comments you have (max. 500 characters):

There may be some reluctance to implement some of the measures as these may be seen to detract from the reason for the person coming to a social care service in the first place.

There is already a great deal of research on the burden of collecting and processing data for case recording and fulfilling 'performance monitoring' obligations. Frontline workers may feel their role has changed to a focus on managing data instead of supporting people. This can make people disillusioned and leave the profession.

These feelings need to be accounted for and mitigated by supporting staff to feel more confident in working with personal data by creating tools and resources that allow professionals to easily explain principles around transparency and privacy with the people they are working with that do not direct the focus away from the reason for people seeking their help in the first place.

There is also a small risk that some people may stop engaging with services altogether if they feel the interactions relate to collecting more and more data as opposed to offering support.

The collection of data **must** be balanced in favour of the primary purpose of the interaction – the delivery of care and support, or support for a carer.

10. Do you agree that the transparency checklist provides a useful summary of the guidance and a mechanism to assess an organisation's transparency level?

Strongly agree

✓ Agree

Neither agree nor disagree

Disagree

Strongly disagree

Please provide any comments you have (max. 500 characters):

Under should – add *we have involved our service manager and frontline workers in the development of our transparency material* (similar to involving DPO)

The DPO will know the legal compliance. Frontline workers and service managers know the data subjects they provide support to and as such know what will work in practice.

11. Have you identified any aspects of the guidance that you feel are inaccurate or any areas we have missed or not covered sufficiently?

If so, please provide further details.

The guidance makes reference to policies agreed for England e.g. Opt out however no such policies have been agreed yet in Wales. This should be reflected if the guidance is to be a UK document.

Will the guidance also be available in Welsh? Some terminology cannot be easily translated and this should be considered when drafting/ publishing (i.e. it may be pragmatic in some areas to change the English term to something more accessible)

12. We have provided placeholders for case studies and examples in the guidance to further illustrate certain issues relating to: Public trust in use or sharing of health and social care information; Harms associated with transparency and the impacts on patients and service users; Providing easily understandable information to patients and service users on complex forms of data processing; and Organisations working together to develop a 'joined-up' approach to the delivery of transparency information. Do you have any examples of good practice relating to these topics? Would you like to provide these to the ICO to

be summarised and included in the guidance?

If so, please provide your name and email address below and we may contact you to discuss further.

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Section 2: Your views on our summary impact assessment

The following questions are about our impact assessment. Some of the questions may not be relevant to you or your organisation so please skip these as necessary, or as indicated in the descriptions.

We are seeking views on our impact assessment summary table, which was provided as supporting evidence for the consultation. This sets out a high-level overview of the types of impacts that we have considered.

We will consider the proportionality of further assessment of the impacts as we move towards final publication of the guidance.

13. To what extent do you agree that the impact assessment summary table adequately scopes the main affected groups and associated impacts of the guidance?

Strongly agree

Agree

✓ Neither agree nor disagree

Disagree

Strongly disagree

If you answered disagree, strongly disagree or unsure/don't know, please provide further examples of affected groups or impacts we may have missed or require further consideration. (max. 500 characters)

Social care is made up of a diverse range of services provided by over 1,200 providers in Wales. Organisations will need to consider the costs in educating their own staff as well as public engagement costs, which if to be done well can be very high. Care also needs to be taken to ensure that people do not become overwhelmed by information issued by the range of providers (who may each be separate data processors/controllers) involved in the delivery of care and support.

14. Can you provide us with any further evidence for us to consider in our impact assessment?

Yes

✔ No

If you answered Yes, please could you provide the impact evidence or a link to it in the box below, or contact details where we can reach you to discuss further. (max. 500 characters)

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15. Please provide any further comments or suggestions you may have about the impact assessment summary table.

Nothing additional to add

16. Are you acting on behalf of an organisation?

✔ Yes

No

Section 3: About you and your organisation

To further assist our consultation process, it would be useful to know some details about you. Your information will be processed in accordance with our privacy notice.

17. Are you answering as: (tick all that apply)

An organisation or person processing health data

A representative of a professional, industry or trade association

An organisation representing the interests of patients in health settings (eg GP practice, hospital trust)

An organisation representing the interests of patients in social care settings (eg care home)

A trade union

An academic

✔ Other (please specify):

Regulator of the Social Care Workforce in Wales with remit for service improvement and development including Research, Data and Innovation

18. Please specify the name of your organisation (optional):

Social Care Wales

19. How would you describe your organisation's size?

0 to 9 members of staff

✓ 10 to 249 members of staff

250 to 499 members of staff

500 or more members of staff

20. If you work in a health or social care providing organisation, how many patients or care users is your organisation responsible for (approximately)?

N/A

21. Who in your organisation needs to read the guidance? Please provide job titles or roles, rather than names.

Our Executive Management Team, Research Data and Intelligence Team, Data Protection Team and those involved in developing national policy and improvement for social care in Wales.

22. To what extent (if at all) do data protection issues affect strategic or business decisions within your organisation?

Data protection is a major feature in most of our decision making

✓ Data protection is a major feature but only in specific circumstances

Data protection is a relatively minor feature in decision making

Data protection does not feature in decision making

Unsure / don't know

23. Do you think the guidance set out in this document presents additional:

cost(s) or burden(s) to your organisation

✓ benefit(s) to your organisation

both

neither

unsure / don't know

24. Could you please describe the types of additional costs or benefits your organisation might incur?

As an organisation we agree the uses for health and social care data along with the potential benefits and risks should be clear and articulated to the public. To do this well, adequate resources will required to engage with stakeholders, adequately train social care practitioners and engage with the users of health and social care services.

25. Can you provide an estimate of the costs or benefits your organisation is likely to incur and briefly how you have calculated these?

N/A

26. Please provide any further comments or suggestions you may have about how the guidance might impact your organisation?

N/A

Section 4: Any other comments

This section is for any other comments on our guidance or impact assessment that have not been covered elsewhere.

Do you have any other comments you would like to make?

We welcome the ICO taking an interest in this area.

When responding to this consultation, Social Care Wales have considered how the guidance fits with our function, but also how we expect the whole of social care to be able to use this guidance in day-to-day practice.

We are currently working closely with Welsh Government and DHCW on developing processes for engaging with the public about the use of their health and case data. Our research and experience to date suggests that whilst a transparent approach is critical in building the trust required from the public to allow better use of their data, a range of mechanisms for engagement and deliberation are required to do this effectively.

All resources that can be co-produced and made readily available to professionals in health and care to be able to explain how data is collected and used would be readily welcomed – the more straightforward it is to understand the better.