Are you happy to proceed?
I am happy to proceed.

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?

Neither agree nor disagree

Please provide any comments you have:
This guidance does go some way to explaining what health and care organisations are required to do to comply with the transparency principle. In general, the guidance is clear but it doesn't always go far enough to provide practical steps on how to achieve and demonstrate compliance.

This seems to be because the guidance (by necessity) is very broad and seems focussed on large public sector organisations rather than the smaller organisations operating across health and social care. Smaller social care organisations for example will not, in general, have a data protection officer who can support with the development of transparency materials.
Some of the language used within this guidance also won't necessarily resonate with social care provider organisations and people who use services. For example, the social care sector is moving away from using "service user" as a term to describe the people we support and who use services (c.f https://www.thinklocalactpersonal.org.uk/Blog/See-me-I-am-a-person/). It's nearly always better received (and much clearer) to use "people".

The guidance also refers to the use of data for "secondary uses" which is not always well understood by non-IG professionals working in social care. This term – and other technical terms – could do with having definitions when they are first mentioned or being linked to additional information on the ICO's other guidance pages.

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

Agree

Please provide any comments you have:
The definition is clear. In the hospital trust example, this doesn't need to be specific to a hospital but is an example which would work in any health or care setting. It could be worth making it less hospitalspecific, so that the example resonates better for people using the guidance from other service types.

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

Yes

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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?

Agree

Please provide any comments you have:
This guidance is useful and goes some way in providing additional guidance specific to the healthcare sectors, particularly as it touches on Trusted Research Environments and the use of data for public health purposes.

This could however, go into much more detail on the specific ways in which data is processed in health and social care. For example, it would be helpful to recognise that many people who use the health and care system, particularly in social care, may have no or fluctuating capacity and may well not be able to engage with transparency or privacy information. References should be made on how this should be dealt with including references to the Mental Capacity Act, individuals with Lasting Power of Attorney etc. In general, there is still some confusion within the social care sector about the interactions between the Mental Capacity Act and Data Protection Act and additional guidance would be helpful.

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

Too focused on health

Please provide any comments you have:
This guidance is very focussed on health and doesn't really touch on the specific requirements of social care - even when social care is mentioned. For example, the only example which references social care ("setting up a new system that shares hospital discharge data with social care providers.") is actually an example from a hospital trust, you could replace "social care providers" with "pharmacy" or "primary care" without it making a difference.

Social care is a large sector which has a workforce of c. 1.6 million people and covers local authorities, private and not-for-profit care organisations. We cannot comment from the perspective of local authorities, but as representative bodies for adult social care providers, this guidance doesn't really provide information which our members will be able to engage with or find useful. Particularly as the majority of the sector is composed of small and medium-sized organisations without dedicated information governance staff.

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

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?

Agree

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

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?

Disagree

Please provide any comments you have:
In principle, we agree that public engagement is vital – particularly for the development of large transparency campaigns such as "Your Data Matters"; however, this guidance isn't relevant for small social care organisations. 85% of the 18,000 adult social care organisations in England have fewer than 50 employees and would not have the resources for extensive public consultation.

In terms of larger public consultation on transparency across health and social care, individuals in longterm residential care are often excluded from participating as they are not contacted or made aware that engagement is happening. This widens exclusion in patient engagement as it is only those who can participate in patient forums who are included in engagement activities. This means that those who have the time, health, energy and resources to participate can have their views heard while those who are already more vulnerable or excluded (for example due to health, access to technology, or additional support needs) do not get represented.

Quite often, front-line community care staff such as district nurses, volunteers and domiciliary carers are vital in sharing information with people who use support services and this could be mentioned here.

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?

Disagree

Please provide any comments you have:
Many people who use health and care services are likely to have additional needs in terms of how transparency information is shared with them. They may well require transparency and privacy information in accessible formats (e.g. able to be read by screen readers for those with visual impairments or in easy-read formats for people with learning disabilities.) More detail should be put into the guidance about meeting people's specific needs.

There are also specific requirements for people who are supported by a carer or loved one – both adults and children – and how transparency/privacy information should be handled in these instances.

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?

Agree

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.

Currently, there is very limited use of shared care records and digital information sharing between health and social care. We understand and support that this will be more widespread in the future. Nonetheless, these initiatives are nearly always spearheaded by the NHS nationally or at ICS level and social care organisations are rarely involved with the design or development of these projects until the implementation phase. This gives very little time for social care organisations to be transparent with individuals they support about the change in data usage and to understand any concerns of the people who use their services. More guidance could be developed on cross-system/cross-sector transparency requirements – particularly as the Federated Data Platform and Trusted Research Environments are developed.

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.

██████████████████████

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

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

No

16. Are you acting on behalf of an organisation?

Yes

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

A representative of a professional, industry or trade association

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

National Care Association, Care England and National Care Forum (joint submission)

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

10 to 249 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

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
23. Do you think the guidance set out in this document presents additional:
neither