

Survey report

Information sharing to support direct care

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Contents

1.	Introduction	3
2.	Survey aims	3
3.	Approach	4
4.	Findings	5
5.	Discussion and recommendations	.23
Арр	endix A – survey method	.27
Арр	endix B – the online survey	.28
Арр	endix C – direct care decision support tool	.33

NDG survey on information sharing to support direct (individual) care

1. Introduction

The National Data Guardian (NDG) role is to help ensure that health and care information is used securely and appropriately. The NDG Priorities Consultation¹ conducted in early 2019, found strong support for her to do more to encourage information sharing so that health and care professionals can share patient information between themselves to support a person's direct (individual) care².

Consultation respondents supported the proposal that the NDG should work with bodies leading on professional education and training to ensure that those working within the health and care system are equipped to handle and share data with confidence. Respondents called on the NDG to work with others to embed information governance training into professional training and development. This led the NDG to set one of her three priorities as: *Encouraging information sharing for individual care³*.

The NDG commissioned an online survey to help her better understand the perceived barriers to health and care professionals sharing information to support direct care and what educational initiatives she might usefully encourage to support appropriate information sharing. This survey ran from 23rd December 2019 until 2nd February 2020.

2. Survey aims

The NDG asked participants to complete this exploratory survey to help:

- Better understand the perceived barriers to information sharing between health and care professionals to support direct (individual) care
- Determine how best the NDG could encourage information sharing to support direct care
 - Through advice that the NDG might give to the health and care system
 - By encouraging and supporting professional education, training and standards bodies to develop simple, consistent advice
 - \circ $\,$ By supporting better access for patients to their health and care information

The survey was hosted on NHS Digital's online survey tool. However, the survey was undertaken for NDG purposes and the analysis of responses was performed by members of the NDG team.

Anonymised survey results will be shared with the UK Caldicott Guardian Council (to support senior clinical informaticians in their key information sharing roles within the health and care system), the Faculty of Clinical Informatics to inform its Core

¹ <u>https://www.gov.uk/government/consultations/national-data-guardian-a-consultation-on-priorities</u>

² Understanding Patient Data has produced a quick guide about how health data is used, which explains some of the terms used in this survey report. <u>https://understandingpatientdata.org.uk/sites/default/files/2019-05/Resource%20quick%20guide For%20Web 2.pdf</u>

³ NDG finalised priorities: Supporting public understanding and knowledge; encouraging information sharing for individual care; safeguarding a confidential health and care system.

Competencies Project⁴, the and the RCGP (to assist in its preparation for the next version of The Good Practice Guidelines for GP Electronic Patient Records⁵) and other key stakeholders.

3. Approach

The detailed methodology for the survey is provided as Appendix A.

The consultation was in the form of an online survey (see Appendix B), gathering participant information in the first six questions, followed by an open question, asking respondents to state what they thought were the main barriers to sharing information to support direct care.

The survey then tested seven statements by asking respondents to answer three questions on each statement. The first question asked respondents to state their level of agreement or disagreement with each statement, on a five-point Likert scale. Respondents were invited to provide any additional comments in a text box, either reflecting their views about the statement, or elaborating on the reason why they agreed/disagreed with the statement.

Respondents were then asked how they thought the NDG could best encourage education and training initiatives which support sharing for direct care, in relation to each test statement.

At the end of the survey, there were two additional questions:

- Question 21 asked respondents to indicate which single education and training initiative they thought would be most effective in enabling care professionals to share information for individual care.
- Question 22 invited respondents to add any other general comments.

⁴ <u>https://www.facultyofclinicalinformatics.org.uk/projects/core-competencies/</u>

⁵https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/215680/dh_125350.pdf

4. Findings

Overall, there were 66 responses to the consultation, 30 (45%) from individuals and 36 (55%) from organisations, that were included in the analysis after validation and removal of duplicate entries. The RCGP responded by letter. Responding individuals were generally senior executives, senior health and care professionals, IG leads or Caldicott Guardians within their respective organisations. The responding organisations are shown below in Table 4. The detailed results below are for those 65 responses that completed the online survey.

	Table 4 –	Responding	Organisations
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Accord Housing Association Ltd Age UK (Cornwall & Isles of Scilly) Avante
British Medical Association Cadbury Health Healthcare
Cambridge Housing Society Ltd Candlelight Homecare Services
Cerner
Company Chemists' Association
Devon Air Ambulance Trust Faculty of Clinical Informatics
Genetic Alliance UK
Hampshire Hospitals NHS FT
Health and Care Professions Council Hospicecare
Independent Health Group
Lincolnshire LMC
London IG Forum
Lyndhurst Park Nursing Home National Health & Social Care IG Governance Group
NHS Digital
Nourish Care
Nursing and Midwifery Council Nutricia Ltd
Person Centred Software Ltd
PHG Foundation
Registered Nursing Home Association
Rowcroft Hospice Sanctuary Care
Sentinel Healthcare South West CIC & Devon Training Hub
St George's Surgery
The Care Group
The Hadleigh Practice The Royal College of General Practitioners*
The Royal College of Nursing
The Royal College of Radiologists
The Wellspring Surgery
*Response by letter

4.1 Q7. What do you think are the main barriers to the sharing of information to support the direct care of individuals?

There were 65 (100%) detailed responses to Q7. Example quotations from the responses to this question 7 are given below.

"Substandard technical infrastructure"

"A lack of understanding about what information can be shared, by whom and when."

"There is a culture of fear since GDPR which minimises any details provided until there is a risk of poor patient care or increased likelihood of human error. 'Share for Care' is now more difficult to promote as a valid rationale."

"This is all fundamentally based on Trust - the more that Trust is undermined the more difficult it becomes"

"Different electronic systems. we use NHS.net to share with NHS colleagues but not all providers have access to an NHS.net email address"

"Our biggest challenge has been in getting information sharing agreements and secure email addresses"

"No clear commitment to push suppliers to interoperability such that there would be easy flow of information"

"The barriers to more automated and widespread sharing are concerns about who will eventually gain access to this information"

"Myths around sharing of personal data (especially since DPA 2018/GDPR)"

"GDPR is now being used as a barrier to sharing information despite it being justifiable and appropriate to do so."

"In our view, there is a lack of consistent information governance training across the health and care service."

"Lack of a standard process or guidance that is applicable across the entire health sector."

"The main barriers are more system level than person level. We should not be expecting individual practitioners to be able to overcome system level issues."

The main areas identified by respondents related to:

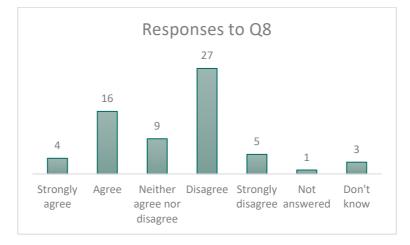
- Poor infrastructure, lack of integration and system complexity
- Legal and regulatory complexity
- Concerns about breach of confidentiality
- Professional and organisational culture
- Lack of education, training and guidance
- Concerns about onward sharing of confidential information

4.2 Q8. When thinking about sharing information to support direct care, "The distinction between direct and indirect care is clear and easy to apply".

Respondents were asked to indicate their level of agreement or disagreement with this statement. There were 64 (98%) responses to this question, with 32(49%) respondents disagreeing or strongly disagreeing with the statement and 20 (31%) agreeing or strongly agreeing. The responses to this question are particularly interesting in that it is the only question where a majority of respondents disagreed with the test statement. This was true of both organisational and individual responses.

The overall detailed responses to question 8 are shown in Chart 4.2 below.





4.3 Q8a. Please add any comments in the text box below – either reflecting your views about the statement or elaborating on the reason why you agree/disagree with the statement. Explanations of how you differentiate between direct and indirect care would be welcome.

There were 47 (72%) responses to this question. Many respondents offered their own descriptions of what constitutes direct and indirect care and there is clear evidence of uncertainty and confusion in some of the responses (see below). It seems that the phrases direct and indirect care might be part of the problem. Where respondents knew of a formal definition of the terms, they referred to either the GMC⁶ or NDG⁷ definitions. Others preferred "individual care", which is the phrase used by Understanding Patient Data (UPD)⁸. Three respondents used "secondary uses" as an alternative to indirect care. Some respondents thought new technologies such as telemedicine and genomics may further blur the boundaries between direct and indirect care, as may new ways of working, such as digital and multi-agency teams.

"Direct care would be a carer coming to someone's house to wash them. Indirect care would be offering carer support to their child so that they could do this task"

"Direct doctor to patient treatment or intervention would be direct care. Indirect care may relate to diagnostics which may assist a diagnosis and influence care."

"It is not clear whether a care manager is involved in direct care or indirect care, and these definitions may lead to delay in information flow."

"Different professions seem to view direct and indirect care differently. It would be helpful to have one agreed definition for use across all health and care settings."

"Clinicians would generally not find it difficult to make the distinction between actions that directly involve the patient and those that don't. The distinction centres on the ability of the intervention to benefit the patient in the foreseeable future."

"The same data can be used for direct care, but then aggregated to be used for indirect care, so a distinction between direct and indirect care at the point of collection/capture is hard to make.

⁶ GMC <u>https://www.gmc-uk.org/ethical-guidance/ethical-guidance-for-doctors/confidentiality/using-and-disclosing-patient-information-for-direct-care</u>

⁷ To share or not to share: The Information Governance Review. Glossary; P128: 2013. Department of Health.

⁸ <u>https://understandingpatientdata.org.uk/how</u>

Service providers would need to be more explicit about how data is processed to make this distinction."

"E.g. Population Health Management is unclear as to whether it is Risk Stratification for Direct Care or Public Health service improvement."

"The direct/indirect care distinction is blurring due to socio-technical factors. In terms of behaviours we see a shift in roles and power between citizens/patients and healthcare professionals."

"Our view is that simply using the term 'individual care' is more accurate and appropriate."

"The use of the term 'direct care' is challenging in the context of genetic diseases, since information often needs to be shared to support diagnosis, treatment and management of genetic diseases, but this may involve sharing genetic information about others who have a genetic disease which may not be perceived as being directly to support their care."

"We have ticked the 'disagree' box because whilst the above concepts are relatively clear to understand in theory, this does not always mean they can be easily translated into practice."

4.4 Q9. How do you think the NDG could best encourage education and training initiatives which support sharing for direct care?

There were 51 (78%) responses to this question. Most respondents requested guidance to clarify what constitutes direct care and others called for appropriate local and national training across health and care. Suggestions for how training might be delivered included; through the Data Security and Protection Toolkit, scenario-based training packages, e-learning, an online discussion forum and case studies, as well as accessible guidance to support front-line care, perhaps in the form of an online decision-support tool to help determine whether an activity is direct care. The need for data sharing to support new cross-boundary care models was emphasised by several respondents. The importance of education providers (e.g. Health Education England) was stressed by several respondents, as was the need to ensure that information reflected current and forthcoming challenges, such as genomics. The importance of the local Caldicott Guardian to inform and support data sharing initiatives was mentioned by several respondents. Nationally, the work of Wellcome / UPD was endorsed.

"Provide clarity as to an agreed definition of direct and indirect care."

"Tailor the needs to specific organisations"

"develop national training curriculum for information sharing that is accessible for all levels of staff."

"think across the pathway and remember the third sector (who are after all delivering mainstream health care via charitable means.)"

"As part of mandatory training for all staff."

"ensure consistent policies across different NHS bodies and trusts"

"Ensure focus on the duty to do the right thing – discourage defensive practice. Demonstrate that not sharing when you should is just as bad as inappropriate sharing."

"Realistic examples of direct and indirect care, particularly in discussions and publicity would provide clarity."

"Consistent nomenclature for different types of indirect care e.g. quality management, performance management, education, and research."

"...NHS to develop an online decision tool to help staff to determine whether an activity is considered to be direct care. This could follow a similar format to the Health Research Authority's decision tool for considering whether a project is categorised as medical research."

"The seventh Caldicott Principle (The duty to share information can be as important as the duty to protect patient confidentiality) should be emphasised."

"Using information governance as a reason for not sharing data should be discouraged, particularly when in reality, the problem has little to do with IG, but has other causes e.g. organisational problems or lack of interoperability."

"We support more nuanced discussion around the term 'care'. We also support increased public literacy around genetics, genomics and the potential impact of novel technologies on health and social care."

"Clear rules principles on information-sharing issued by the Caldicott Guardian (to improve patient care, and prevent harm to patients from misuse of their information)."

"Work with Understanding Patient Data to develop scenario-based animations/films that cover the roles of different care providers and the expectations around data sharing."

"We support the work of Wellcome in developing language that support conversations and would like to see this formally adopted by all government and associated agencies, and developed further to meet the needs of care providers working to provide care across organisational boundaries."

4.5 Q10. The NDG has heard that: "It is often the case that health and care data is not good enough, available enough, joined-up enough or shared enough to support individual care".

Respondents were asked to indicate their level of agreement or disagreement with this statement. There were 64 (98%) responses to this question and the results are shown in Chart 4.5 below. 51 (78%) of respondents agreed or strongly agreed with this statement, 6 (9%) disagreed. Organisations were slightly more likely to support this statement (31/35) than individuals (20/30) but the overall trend was clearly similar.

Responses to Q10 28 23 7 6 0 1 0 Strongly Agree Neither Disagree Strongly Not Don't agree agree nor disagree answered know disagree

Chart 4.5 – responses to Q10.

4.6 Q10a. Please add any comments in the text box below – either reflecting your views about the statement or elaborating on the reason why you agree/disagree with the statement.

There were 56 (86%) responses to this question. Many of the responses will seem familiar to the NDG from evidence that has been presented to her over the last eight years, since the IG Review. Lack of availability and accessibility to health and care data are continuing problems for care professionals and providers. This was particularly emphasised where care is being provided to patients with complex needs, end-of-life care and rare diseases. There was also a reminder that the volume of shared data can present problems in terms of finding what is needed. While structured (coded) data can facilitate interoperability, codes can be difficult to decipher when printed out as part of discharge summaries for community care providers. There were several calls for a shared electronic health record to facilitate information sharing and preserve meaning across care settings.

"It is not sufficiently joined up or shared so individuals have to repeat their story. Information from care providers is not always accepted by health care professionals which causes frustration for social care professionals and the person concerned."

"There is a real problem with data quality in health and social care organisations. Often it is impossible to share information between them because it is inaccessible/in a format that is not conducive to sharing."

"A shared electronic patient record across the NHS has the potential to improve the quality of this data and better enable information sharing to support direct care."

"Patients with genetic, rare or undiagnosed conditions often come into contact with health and social care professionals who know little or nothing about their conditions, and find themselves needing to explain complex details of their medical histories over and over again."

"Variation is huge based on individual practice, speciality or organisational culture and development and regional variation. It is only when something goes drastically wrong that information sharing comes to the fore as a root cause."

"Although discharge information may be provided, this is rarely in full and often not timely. An accessible database of discharge info, similar to the Summary Care Records held by GPs, might be useful?"

"... and our clinicians, all of whom have or still do work in other NHS organisations, report that data capture is a significant challenge."

'From a clinical point of view, it was intimated very clearly from our members that technological barriers make it difficult for primary and secondary care staff to share vital information."

"We can't even join up information in our own organisations, with data held on disparate systems behind multiple passwords and login credentials, and limited licences to a group of individuals."

"..recently having taken on Systmone within our Hospice the benefits are enormous when we can see others records."

"Further work is needed to improve communication channels between primary and secondary care and to remove the organisational barriers that exist in order to ensure a coordinated approach to patient care."

"The currents systems do not join up effectively. This is a real shame."

"To ensure that health and care data is 'good enough', information must be recorded in a structured or coded format to facilitate interoperability."

"The problem is that there is still little agreement about what a 'good' digital record looks like."

"NHS taken eye (and resource) off data quality in the last 10 years."

"Well, it definitely could be better, but in east London we do have a level 1 shared record, which is proving very helpful to clinicians and patients."

"Social care systems rarely integrate with NHS systems, making sharing difficult."

"We are now sharing our GP records with our district nursing team and our local hospice. Whilst this is helpful it can make finding the information that you need more difficult as there is so much other stuff there."

4.7 Q11. How do you think the NDG could best encourage education and training initiatives in this area?

There were 46 (71%) responses to this question. Many of the responses here are similar to those given to question 9 (see 4.4 above) in terms of suggestions for education and training initiatives to support record sharing for direct care. The need for local education and training, perhaps through Primary Care Networks, was suggested by some respondents. Others called for clarity about standards and the need for tools to share and access information. There were also calls for more funding to support interoperability across care settings and a reminder about the importance of leadership and culture as drivers of system change. Patients need to understand the implications of any decision they may make not to share their health or care information.

"Perhaps look at the Getting it right first-time initiative to see if some collaboration is possible? Perhaps communication might be a crosscutting theme?"

"Being clear in what data needs to be collected, why and in what form. This should be supported by adoption of common tools to help access and share the data."

"education and training do not replace the need for better IT/EPR systems that join up"

"...standards such as the PRSB suggested standard for digital care plans could bring significant improvement to patient experience of transfers of care and care and support received from different teams."

"The production of standards for healthcare records with follow on training for adherence."

"Encourage initiatives to ensure data interoperability is optimised"

"NDG should work with both health and care professional bodies and citizen groups to develop educational initiatives"

"Involving the PCN groups to invite the appropriate organisations for any particular PCN area. Provide training in local areas not just London!"

"I'm not sure education and training is the right approach. This is about culture of relationships and clarity of leadership; quality of technical solutions; behavioural insights; ethical understanding of professional practice."

"The development of STPs/ ICSs challenge organisational boundaries from a data sharing perspective. Some support at system leader level would be useful."

"I also think that some patients don't comprehend that when they chose for their data not to be shared that this can compromise their care."

4.8 Q12. The NDG has heard that: "There are enduring problems with sharing data across geographical and organisational boundaries, with the most problematic flow between health and social care".

Respondents were asked to indicate their level of agreement or disagreement with this statement. There were 64 (98%) responses to this question and the detailed results are shown in Chart 4.8 below. 50 (77%) of respondents agreed or strongly agreed with this statement, only 3 (5%) disagreed. There was a high level of concordance between organisational and individual responses, with (27/35) and (23/30) agreeing or strongly agreeing respectively.

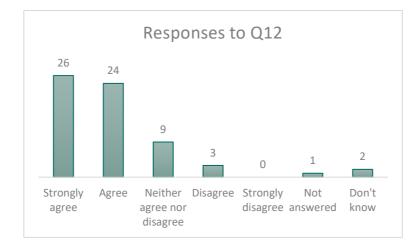


Chart 4.8 – responses to Q12.

4.9 Q12a. Please add any comments in the text box below – either reflecting your views about the statement or elaborating on the reason why you agree/disagree with the statement.

There were 53 (82%) responses to this question. Many respondents gave examples of the difficulties and frustrations they face, despite supportive professional guidance clearly being available. The problems seem to have technical, financial and cultural dimensions to them. Boundary issues and timeliness of data exchanges were also frustrations reported by several respondents. A positive note was struck by the success of the Hampshire Care and Health Information Exchange (CHIE) as a mechanism for sharing records across health and care.

"GMC and BMA guidance is clear that where a social worker is providing direct care to a patient relevant information can be accessed by the social worker on the basis of implied consent"

"...our registrants often raise queries with the HCPC asking for further guidance in this area."

"This is an issue in all areas of social care/social work"

"Health are reluctant to trust the information provided to them by social care professionals"

"Information that could be shared is not shared except verbally because people do not trust each other's emails and are unsure about whether it is "safe" for them to share the content of their assessments."

"Much of the difficulty comes from lack of technical standards actually."

"While certain NHS staff members have access to secure email (nhs.net), many still do not."

"Continual shifting sands of boundaries, providers and organisations makes sharing increasingly difficult."

"Health and social care organisational boundaries are not coterminous, often necessitating negotiation of multiple information sharing agreements."

"Systems used in Scotland and Wales are different and therefore access to records is not available."

"Sharing between devolved nations is also likely to become more problematic post-Brexit particularly because the GDPR devolves some aspects of data processing to Member States."

"The nervousness creeps in when we are talking about blanket pre-sharing of data on everyone."

"Information flow is slow and untimely, and when it does arrive it is sometimes not useful"

"It is in the timeliness of the information e.g. to multi agency meetings that problems occur. This is often cited as lack of resources in social care to provide prompt information."

"we are told we need to deliver integrated care but don't have the data sharing systems in place to do so."

The level of funding and resourcing for social care is extremely stretched and is not able to support enough work in this area."

"We have been told we will need to pay in order to share our data..., which is something we cannot afford."

"...we recognise that there is an appetite across the UK for collaboration and progress is being made in areas such as information standards (PRSB shared record standards) and shared working (Local Health and Care Record exemplars)."

"...CHIE now has >7000 unique users and >20,000 hits on data fields per day - if you make information available to clinicians, they will use it effectively."

4.10 Q13. How do you think the NDG could best encourage education and training initiatives in this area?

There were 39 (60%) responses to this question. Once again, some respondents referred to their earlier education and training responses (Q9 and Q11). Additional suggestions included; local audit of what works in terms of sharing, working with the LHCREs and

Integrated Care Systems (ICSs) and accessible guidance to support information sharing decisions. Some respondents suggested the priorities were in other areas rather than education and training.

"Support teams to look at the data flows for their organisation and identify what does/does not work well."

"Provide exemplars (here or abroad) where this has worked well"

"Work with the LHCRE network to ensure that developments maximise effective information sharing for the majority."

"Perhaps to produce guidance specifically aimed at ICSs."

"Having clear and concise information available about the requirement to share appropriate information across health and care boundaries would do wonders."

"An effective IT infrastructure and systems for the sharing of information are needed first."

"As above – the issues are structural/organisational rather than at individual clinician/practitioner level – so not sure if/how education/training could provide any meaningful difference to this unless and until the data sharing structures are in place."

4.11 Q14. The NDG has heard that: "A fear persists among health and social care staff about sharing data, despite a patient expectation that information about them will be readily available to those involved in their care".

Respondents were asked to indicate their level of agreement or disagreement with this statement. There were 65 (100%) responses to this question and the detailed results are shown in Chart 4.11 below. 50 (77%) of respondents agreed or strongly agreed with this statement, 6 (9%) disagreed or strongly disagreed. This statement was well supported by both responding organisations (26/35) and individuals (24/30).

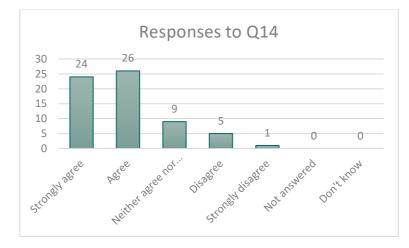


Chart 4.11 – responses to Q14.

4.12 Q14a. Please add any comments in the text box below – either reflecting your views about the statement or elaborating on the reason why you agree/disagree with the statement.

There were 54 (83%) responses to this question. Ignorance, complexity of regulations and fear of the law, particularly GDPR were frequently given as examples of why data is not shared to support direct care, though one Caldicott Guardian suggested that there was also a notable inconsistency in organisational behaviour about data sharing. Respondents did confirm that there was usually a patient expectation that data will be shared to

support their individual care, though that might not overcome professional anxieties about sharing. Fears, particularly around GDPR seem to outweigh the new 7th Caldicott Principle⁹. While fears of the law and litigation may discourage information by some care professionals, others are clearly knowledgeable and confident to share information appropriately, though some suggested that current guidance was confusing. One respondent suggested concerns over data accuracy might inhibit sharing.

"Many misinterpret/misquote legislation such as GDPR/consent as a reason to not share."

"Professionals fear of sharing data has increased with recent legislation"

"I think GDPR has made people fearful and the Trust between sectors is an issue."

"This is mainly around heavy-handed IG policies and procedures,"

"On the one hand I think many clinicians may lack confidence about data sharing but on the other hand some organisations appear to have a quite cavalier attitude towards data sharing."

"...there can be a fear amongst staff that disclosure of information could lead to disciplinary action or worse, even when common sense indicates that such a disclosure is clearly beneficial to an individual's care."

"Most patients seem surprised when we tell them how little info is shared."

"...the "need to know" principle is difficult to implement, particularly in multidisciplinary teams and environments."

"Despite the adoption of an additional data sharing principle which encourages a default of data sharing to support patient care, there is a widespread anxiety amongst health care professionals about inappropriately sharing patient information."

"We would amend the statement to read that a fear persists among 'some' healthcare professionals about data sharing...'. There are a number of doctors who are confident and have considerable expertise in this area."

"We do not see this as a fear about sharing as much as confusion as a result of guidance focused on abstract data concepts rather than purposes for good"

"...the main reasons for these fears is a general lack of guidance, support and processes for information to be shared efficiently."

""Multiple sources of guidance exist which adds to the complexity of the picture for professionals."

"Legal guided clarification for the whole of the NHS and private sector so that all HCPs know what they can record and with whom they can share that data could be invaluable."

"Many professionals have concerns about the accuracy of the information held hence a reluctance to be the person responsible for sharing potentially inaccurate information."

4.13 Q15. How do you think the NDG could best encourage education and training initiatives in this area?

There were 43 (66%) responses to this question. Accessible education, training and guidance about the law and the Caldicott Principles was suggested by several respondents. Other respondents proposed that training should be mandatory. Other suggestions included myth busting initiatives, and perhaps an NDG blog along the lines of that posted regularly on the ICO website to deal with misconceptions about data protection law. Exemplars and case studies of good practice could be helpful in promoting information sharing, perhaps "kite-marking" the best. Others emphasised the need for locally accessible IG expertise, advice and a supportive organisational culture. What emerged clearly, was a heartfelt call for accessible, authoritative guidance applicable across health and care.

"Education regarding the law and how this is applied, also the Caldicott principles, especially no.7."

⁹ <u>https://www.igt.hscic.gov.uk/Caldicott2Principles.aspx</u>

"Emphasise seventh Caldicott principle - importance of not impeding information flows that are important to individual care"

"There needs to be top level clear advice - we are all running scared of the ICO fines for a data breach."

"Simple, clear guidance which is applicable across both the NHS and social care."

"Working with other organisations, professional bodies and regulators to produce guidance aimed at front line health and social care staff tailored to direct care data sharing in common healthcare settings."

"Mandatory training to equip practitioners with effective information governance knowledge that facilitates culture change and acceptance that patient access and sharing of data is permitted and encouraged wherever appropriate"

"The ICO provides regular 'blogs' about misconceptions and actual requirements, which are excellent resources for sharing. Perhaps a similar set of 'stories' posted from the NDG office could be provided."

"myth busting and some clear simple messaging."

"give examples of where good cross organisational working has produced good results"

"Again - 'kite-marking' a range of implementations"

"Ensure staff are confident to raise and discuss issues with local IG teams, and that those teams are consistent in their response"

4.14 Q16. The NDG has heard that: "There needs to be more clarity about the legal and ethical framework for health and care professionals to share information for direct care".

Respondents were asked to indicate their level of agreement or disagreement with this statement. There were 65 (100%) responses to this question and the detailed results are shown in Chart 4.14 below. 45 (69%) of respondents agreed or strongly agreed with this statement and 7 (11%) disagreed or strongly disagreed with the statement. Of individuals responding, 21/30 agreed or strongly agreed and 24/35 organisational respondents agreed or strongly agreed with the statement.

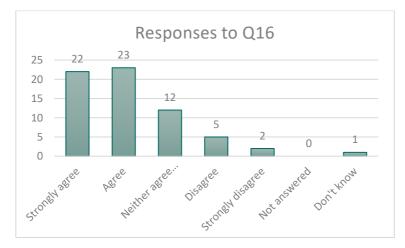


Chart 4.14 – responses to Q16.

4.15 Q16a. Please add any comments in the text box below – either reflecting your views about the statement or elaborating on the reason why you agree/disagree with the statement.

There were 51 (78%) responses to this question. Many respondents complained about the complexity of the law and guidance, particularly around implementing the GDPR and reconciling it with the common law duty of confidence. This very clearly echoes the responses given earlier to question 14a (see 4.12 above). Once again there is a clear call for authoritative, accessible guidance for the health and care sector that is available at the front-line and not requiring local interpretation. One organisation mentioned how useful they find the Caldicott 2 guidance on direct care and they use that when advising their own members. The complexities of new organisations (e.g. PCNs) reiterates the cross-boundary issues raised in responses to questions 12 and 12a (see 4.8 and 4.9 above).

"Professionals often have little experience of using the legislation and of the scope of legislation that may help information sharing."

"Clarity would be good but is not easy to achieve because context is so variable."

"The framework is there. The understanding is not, except within specialised IG teams who don't help by making things too technical and complex for clinical staff."

"...this is not about new rules/laws but is about "clarity" of how data can be utilised."

"Having read as much material about my role as CG as I can find, it is still difficult to be clear about where to draw the line"

"Often the common law duty of confidentiality is not considered when data sharing is considered."

"We had a far too long and technical talk by our information officer for GPDR recently, which served to make us more anxious."

"...it's madness that each organisation is producing its own interpretation here - we should have national good resources for this."

"The RCN are building two online learning modules about the digital agenda and the role of data. We think that more needs to be done to provide citizens and staff with a coherent narrative about the themes raised by the learning. However, while this is necessary it is not sufficient. There needs to be ongoing access to an evolving programme of content and communities to support learning in this area..."

"Staff often feel they are working without clear guidance particularly as the "integration agenda" pushes health and social care more closely together but without clear information sharing protocols"

"In particular there is very poor understanding of the legal bases for data sharing and which rules apply"

"But in plain English - with real world examples from complex care challenges."

"Nursing Home sometimes as regarded as a second level of professional care and thus by some are left out of the loop..."

"There needs to be absolute clarity as to which organisation is offering advice in this area."

"Caldicott 2 Report definition of Direct Care is difficult for social care."

"Clear guidelines need to be put in place re disparity between GDPR and CLDC."

"Yes, there needs to be strong messages that undoes some of the damage created by overzealous application and misunderstanding of GDPR"

"I think the framework is reasonably clear, but the understanding is inconsistent across health and social care."

"Yes - just yes."

"...we are concerned that well-established principles are under strain through pressures for access to medical records."

"Chapter 3 of 'Caldicott 2' set three tests for establishing the conditions under which consent can be implied for sharing for direct care and listed the criteria which indicate when a legitimate relationship with a patient is created. We agree with this approach..."

"In the context of sharing information, our Standards of Conduct, Performance and Ethics require registrants to 'share relevant information, where appropriate with colleagues involved in the care, treatment or other services provided to a service user" *"If HCPs had more education about when they would face legal issues, there would be far less reluctance to share information. As previously mentioned, GDPR requirements would also need to be clarified."*

"Currently most PCNs are setting up data-sharing agreements. However, if you have not signed-up to these then data will not be shared. This does not help patients who may be on holiday and outof-area as record sharing is limited or non-existent under these provisions."

4.16 Q17. How do you think the NDG could best encourage education and training initiatives in this area?

There were 37 (57%) responses to this question. The very strong message from respondents was a call for clear, consistent, accessible and authoritative guidance, perhaps accompanied by mandatory training. NHSX were encouraged to take a leading role. But there is more to this than guidance, organisational culture needs to change to support appropriate sharing of health and care information to support direct care. Some of this will be about familiarity with other organisations, reflected in the call for nurse training to include community care settings.

"Working with other organisations, including professional bodies and regulators to raise awareness of appropriate sharing and the consequences of both sharing and not sharing to help ground professionals in the concepts surrounding the legal and ethical frameworks."

"Comprehensive and accessible guidance about what can legitimately be shared for the whole of the NHS and private sector should be issued"

"NDG to work with Policy leaders on clear and unambiguous statements and commitments."

"Again, some clear guidance applicable across the system."

"Work with NHSX in an IG harmonisation programme"

"We suggest the encouragement of training initiatives which focus on, and affirm, the existing concepts which enable appropriate sharing of records: implied consent based on legitimate relationships and sharing on a 'need to know' basis'."

"Avoid conflicting statements / guidance and support existing programmes, ensuring that there is one version of the "true" guidance reflected in national mandatory training"

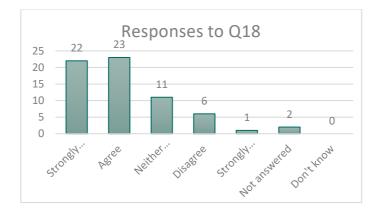
"My general view particularly in relation to safeguarding is that the legislative framework is in place and is not the barrier. This is about culture of practice"

"Nurses during their training do a small placement in good nursing homes giving them a better understanding of our role and competences"

4.17 Q18. Patient access to records is another priority for the NDG. She has heard that: "Easier access by patients to their own data may help improve data quality and drive down barriers to wider information sharing".

Respondents were asked to indicate their level of agreement or disagreement with this statement. There were 63 (97%) responses to this question and the detailed results are shown in Chart 4.17 below. 45 (69%) of respondents agreed or strongly agreed with this statement, 7 (11%) disagreed or strongly disagreed. Of individuals responding, 24/30 agreed or strongly agreed with the statement. Organisational responses showed a slightly lower level of support for the statement with 21/35 agreeing or strongly agreeing (11 neither agreed nor disagreed and 2 did not answer).

Chart 4.17 – responses to Q18.



4.18 Q18a. Please add any comments in the text box below – either reflecting your views about the proposal or elaborating on the reason why you agree/disagree with the proposal.

There were 51 (78%) responses to this question. While this statement was well supported in responses to question 18, the complexities of giving access are highlighted by the respondents quoted below. One respondent reminds us that to talk of patients' "own" data is not strictly correct. The issue is not about ownership, but access to health and care records *about* the individual. We are reminded that patients do not have a right to change information in their records unless it is incorrect, that the content may be complex, sensitive and require expert interpretation. Also access arrangements for shared records need to be coordinated across a health and care community so practice is consistent and sensitive to issues such as third-party information. Information provided by or about third parties presents a problem in terms of patient access and may require health professional input to make decisions about redaction and sharing. So, patients / service users may be better informed, able to improve data quality and more trusting if they have records access, but the process of giving access may not be straightforward and could be associated with risks to patients and extra burden for health and care professionals.

"… we query the use of the term 'own' data. From a legal perspective, an individual cannot 'own' individual data or their records"

"Patients should have easier access to their records and to go further and give the ability to correct inaccuracies or missing information."

"...developing the public's understanding of the way their health information can be used to improve their direct care is essential in building their trust in the NHS and enabling better information sharing overall. "

"It is absolutely vital that people have the right to see the data held about them"

"We have seen how greater patient involvement in their care can result in more "safety captures" <u>https://qualitysafety.bmj.com/content/27/9/673</u>. However, while the hypothesis of greater access = reduction of factual errors in the record appears sound we have yet to see this enter routine practice."

"When patients are able to access their own data, this enables them to gain a full overview of the care they are receiving, as well as all their test results and other medical information, empowering them to more effectively advocate for the care and support they need. It also allows them check whether their medical record is accurate and up to date, and too share the information in it with whoever they consider appropriate."

"Yes - the willingness of activist patients to review their own information and point out problems will help to drive up data quality and possibly encourage data sharing."

"For shared (NHS/social care), this should include their social care record."

"Well informed / chronic disease patients tend to be very good at bringing recent letters and their recent repeat prescriptions with them. This makes clinical decision making so much easier"

"...with the caveat that the vulnerable will need robust protection, patients controlling their own data access will facilitate patient decisions and improved trust."

"Agree and it is helpful for health and care staff that directly treating patients to also have access to the same info"

"The process to access data will also need to be logical and secure and there may need to be a degree of technical control over how interactive patients can be with their own records."

"We support easier access to records by patients, and we also support the concept of patients making contributions to their records. To avoid misunderstanding, however, it must be clear that patients cannot remove or change clinicians' entries in the record – unless there are factually inaccuracies."

"I think this needs careful consideration. A lot of health data is complex and needs careful interpretation. it is also not often written in a way that is designed for patients' consumption, as is often is a tool for health professionals to communicate with each other"

"If one party (GP practice / Trust / etc.) shares information with patients, but another does not, then it may create a barrier for information sharing to avoid risks of data "leaking" and liability for unintended release of sensitive / third party information"

"There is obviously a need to remove third party references, there are difficulties with domestic violence, and the transition between childhood to adulthood"

"Software to help with redaction and 'tidying' of notes may make it easier for GPs to release the whole record to patients, but there are financial and resource costs of doing this."

"Although this may be true, there are some caveats that should be borne in mind:

- in relation to genetic information, learning of a prediction about future genetic disease may require counselling and support and may be psychologically burdensome

- disclosing information about psychiatric illness, mental health issues need to be done sensitively and compassionately. Sources of support need to be available..."

4.19 Q19. How do you think the NDG could best encourage education and training initiatives in this area?

There were 28 (43%) responses to this question. There were suggestions for education and training for professionals and patients but there were very few responses that specifically addressed question 18 (4.17 above). One important point was to be able to present record access to patients / service users in ways that help them understand the content. The importance of system / cultural change was mentioned by several respondents. There was a suggestion that patients' representatives could provide leadership in this area.

"Training around these difficult areas would help "

"Clinicians may require additional education and training in conducting consultations that strike the appropriate balance between professional, patient and computer i.e. ensuring that the patient's voice is heard and that 'the computer' does not dominate both patient and professional."

"Training initiatives required to deliver information to patients in an understandable format. "

"This needs systematic change and investment in order to be safe- I'm not sure how education/training will facilitate it."

"Provide the cultural leadership to enable the change."

"It is suggested that patient participation groups could assist to understand more about what patients want access to and how."

"A joint approach with Human Factors experts might help break down assumptions as to what "easier access" may mean or how it could be implemented in practice."

4.20 Q20. The NDG has heard that: "There should be a presumption that patients have access to their care records. Where patients have not been given such access, their care professionals should be able to provide clear reasons why not."

Respondents were asked to indicate their level of agreement or disagreement with this statement. There were 64 (98%) responses to this question and the detailed results are shown in Chart 4.20 below. 54 (83%) of respondents agreed or strongly agreed with this statement, only 2 (3%) respondents disagreed or strongly disagreed. Of organisations responding, 29/35 agreed or strongly agreed with the statement and the results for individual respondents showed a similar level of support with 25/30 agreeing or strongly agreeing. This level of agreement was slightly higher and the level of disagreement lower than for any of the other statements tested.

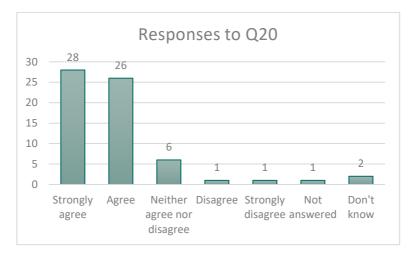


Chart 4.20 – responses to Q20.

4.21 Q20a. Please add any comments in the text box below – either reflecting your views about the proposal or elaborating on the reason why you agree/disagree with the proposal.

There were 38 (58%) responses to this question. Most respondents supported the statement and agreed that patient / service-user access should be the default (in keeping with their rights under the Data Protection Act 2018). However, respondents also highlighted the technical, legal, organisational and workload barriers that will need to be addressed if patient access to their health and care records is to become a system-wide reality.

"The presumption must be on accessibility"

"Every patient should have access to information about their own health to ensure their information is accurate and help manage their own conditions."

"I think patients should have access to their own personal data and be part of the clinical decisions, with capacity. Some patients with complicated histories will sometimes know more as they live with it etc."

"There will always be clinicians who are able to cite cases where it would not be safe to give a patient a reason for not giving them access but it is important that a solution is found so that this does not inhibit the expectation for the majority."

"We agree with the statement because this approach promotes transparency, trust, and patients" ability to check the accuracy of the records"

"We expect our registrants to provide full and clear explanations to service users about matters relating to their care and other services including access to their records."

"Slightly concerned this only talks about patients, not including service users."

"Where should the 'burden' lie?"

"Data controllers need to check the suitability of content in the record prior to sharing with the patient, especially regarding data that may cause harm to patients."

"Need to be careful about information within the record given in confidence by a third party. Also need to ensure that someone is on hand to explain any elements of the record that come as a surprise or may upset or mislead the patient"

"What is not so clear is that family / carers may not always have the same access rights."

"Where do we find the time to read through patient notes and check that there is nothing detrimental to their mental health, for example? Some notes go back many decades and contain 3rd party info too."

"One of the problems here is the disastrous legacy of records we have – e.g. our trust has >150 separate electronic applications which are not linked and multiple reservoirs of information here there and everywhere."

"Care Records rarely constructed primarily for the purpose of patient access - much work to do to evolve them!"

"Concerns remain over patients accessing 'bad news' without access to direct support"

"Care may be needed in providing access to medical records if disclosures in one person's record could imply that another family member carries a genetic disease"

"Also, we have subject access request teams under-resourced and, on their knees, because having free access to this information has resulted in exponential growth in requests (as well as FOIs) - many requests being commercially motivated rather than about direct patient care."

"...there are issues for children which might need to be considered...."

4.22 Q21. Which single education and training initiative, do you think, would be most effective in enabling care professionals to share information for individual care?

There were 58 (89%) responses to this question. Suggestions included education on sharing starting at undergraduate level and subsequently being regularly updated, mandatory and multi-disciplinary. GDPR was raised again as an area where professionals felt the need for additional guidance. Education, training, guidance and support needs to be available locally, evidence-based and consistent with national guidance across health and care. Specific technical solutions are becoming available that may facilitate health and care record sharing.

"We believe that education and training initiatives that are effective in demystifying relevant requirements of the GDPR would be particularly helpful for healthcare professionals. Providing interagency guidance for employers and healthcare professionals would also help information sharing to support direct care."

"Consistent messages are needed throughout all stages of education - particularly around communication with patients, emphasising the importance of listening to the patient and judging their level of understanding and of communicating information. "

"Something like a 'Share for Care' initiative to empower health and care professionals to share information with confidence and let patients / service users know what to expect."

"Clear, unambiguous guidance on what isn't and is allowed to be shared"

"Yearly training. Mandatory for all staff - clear national message. Simply delivered."

"Clear guidance to doctors, nurses and allied health professionals from the Caldicott Guardian about what patient information can be shared without breaching patient confidentiality"

"Promoting trust and confidence is key in encouraging care professionals to share information for individual care. Staff need to feel supported in their work, and by their employer." "Specific training on when to share or not to share, including specifics re internal sharing between e.g. social care and housing, and / or between organisations. Also across boundaries such as the third sector that is providing care."

"We still do not know what the most effective training initiatives are. However there has been some success with models like Action Learning Sets in primary care..."

"We do not have interprofessional learning across health and social care. Professions still learn, on the whole, uniprofessionally. This has implications for many things, including patient safety and data quality."

"Probably ongoing statutory mandatory training. This could be multi-disciplinary."

"I think that this is about a culture of conversation even if the conversation is through digital systems."

"Information on suitable technical solutions, e.g. HealtheRecord, would be helpful"

4.23 Q22. Is there anything else you would like to add?

There were 29 (45%) responses to this final, open question. Respondents indicated that wider data sharing to support direct care has no quick or easy solutions. The problems are system-wide at every level of the health and care system. Those problems have many dimensions, including legal, technical, organisational and cultural. Education and training initiatives by themselves are unlikely to shift the balance towards wider record sharing.

"Remember hospices please and include and involve them"

"There is a huge amount to clarify"

"NDG has a major role to encourage BUT be pragmatic about the journey not the destination. Support honest conversations and decisions to do better when perfection undefinable or unattainable. Data sharing for direct care is a 'wicked question' - therefore no right answer, only better or worse options"

"Many misconceptions and frustrations around data sharing - sharing facts with all involved regarding benefits as well as real facts and figures re risks"

"To reiterate - most important principle for me would be to avoid complicating the landscape with NDG guidance that differs from other guidance - this just creates the need for further work to align / interpret things for staff"

"The RCN is addressing nursing digital skills and confidence through our Every Nurse an eNurse initiative."

"While the regulatory framework is clear, actually achieving the desired outcome is very difficult. there are a range of factors that will affect how quickly and effectively these issues are addressed. Some factors relate to individuals and their education and training, some are cultural, some are organisational and some are down to system suppliers/design, usability, and interoperability."

"To sum up, the current NHS IG system is complex, and needs to be harmonised to produce a single framework and guidance that is adopted throughout the NHS and is clear to all levels of staff."

"The NDG could support education and training initiatives by working directly with education providers and with employers to provide information to healthcare professionals about best practice in sharing of information to support and improve care in line with respective professional codes of practice and behaviour. We would also support the development of accessible toolkits and resources to explain how and why data sharing can be accessed and brought to life to support student learning. Interprofessional learning approaches would also be of great benefit here to support effective multi-disciplinary learning. These efforts would promote greater student confidence in this area, for when they register and join professional practice."

"Given the opportunities that technology is offering in secure, ethical, and effective sharing of data between care providers to improve patient safety, care quality, experience of care. The NDG could usefully explore how her work can support this, rather than on more conceptual approaches."

5. Discussion and recommendations

This consultation was in the form of an online survey. The survey method is described in detail in Appendix A. There were 65 responses to the survey, 30 from individuals and 35 from organisations. There was very little difference between the responses of individuals and organisations in terms of the test statement questions, though organisations did tend to provide more detailed responses to the free text questions. Many respondents provided detailed, thoughtful and constructive responses, but others showed clear errors of fact, misunderstandings and lack of awareness of the law and existing guidance. It is worth noting the strong levels of agreement with all the test statements, apart from the first (question 8) on the distinction between direct and indirect care.

5.1 General

Modern health and care provision increasingly depends upon effective communication between professionals, patients, service-users and carers across different organisations and at multiple points in a person's interaction with the system. While the UK legal framework governing the sharing of data does allow health and care data to be used and shared for these purposes, the responses provided to this survey indicate that those working in the system feel that the law is so complex, poorly understood and difficult to navigate that they do not have confidence to do so.

In this survey, we have heard clearly that patients may be suffering as a result. Relevant information about them is not being shared appropriately and not being made available at the point of care. Respondents to this survey also highlighted how, with the further blurring of boundaries between clinical and non-clinical elements of teams supporting people (through activity such as population health management), this environment is becoming ever more complex and the need for clear guidance and support in this area will only grow.

5.2 Barriers

Question 7 asked respondents what they thought were the main barriers to the sharing of information for direct care. While much of the focus of the survey was on education on training, respondents identified a wider range of barriers to good information sharing. The themes to emerge from the responses are shown below:

- Poor infrastructure, lack of integration and system complexity
- Anxiety about legal and regulatory complexity
- Concerns about breach of confidentiality
- Professional and organisational culture
- Lack of education, training and guidance
- Concerns about onward sharing of confidential information

These themes recur regularly in the responses to the rest of the survey.

5.3 The test statements

A majority of respondents disagreed that the distinction between direct and indirect care is clear and easy to apply, which was further evidenced in some of the detailed text responses. While the terms themselves may be a problem, the boundaries between direct and indirect care may be blurred by new technologies and new ways of working. Lack of access to health and care data are causing continuing problems for care professionals, providers and patients, particularly for those with complex needs. Patients end up having to repeat their stories across care settings. Data quality may be affected with a consequent impact on clinical safety. Interoperability was identified as a priority and there were calls for a shared electronic health record to facilitate joined-up care.

Boundary issues have technical, financial, organisational and cultural dimensions to them, and respondents reported difficulties and frustrations with cross-boundary information flows at national, regional, local and even intra-organisational levels.

Ignorance, perceived complexity of regulations and fear of the law, particularly GDPR were frequently given as examples of why data is not shared to support direct care, despite patients expecting that their records will be available at the point of care. Many respondents complained about the complexity of the law and guidance. Concerns about data quality may also reinforce reluctance to share.

There was strong support both for patient access to information about their health and care and the presumption that patients should have such access. This was framed more in terms of information about their health and care than records access per se, as it is important that information is presented to patients / service-users in ways that help them understand the content and context. Respondents highlighted the technical, legal, organisational and workload barriers that will need to be addressed if patient access to information about their health and care is to become a system-wide reality. Records access may help support data accuracy and patient trust, but the process of giving access may not be straightforward and could be associated with risks to patients and extra burden for health and care professionals, particularly around third party data.

5.4 Education and training

In relation to each of the test statements, respondents were asked what education and training initiatives the NDG might encourage to support sharing for direct care. The responses to these questions consistently identified a number of themes and suggestions. Not all of these were solely suggestions for education and training initiatives; there was also a strong appetite for clearer guidance and desire for better technology.

- The law around data protection and confidentiality is complicated and guidance at national and local levels is not perceived as accessible, clear or consistent. There is evident misunderstanding of commonly used terms such as "direct" and "indirect" care and the combination of fear and ignorance of the legal framework leads some organisations and individuals to take an overly cautious approach to sharing information to support individual care.
- A need for clear authoritative, accessible national guidance to support information sharing across the whole of health and care supported by key stakeholders that is compatible with new models of care, including cross-boundary flows of information, and new technology challenges.
- National guidance should particularly address anxieties about GDPR and how to reconcile privacy law with the common law duty of confidence.
- Leadership at all levels must foster and promote a culture of appropriate information sharing between care professionals, patients and service-users.
- Accessible local education, training and support about the law and Caldicott Principles that is consistent with national guidance.
- Exemplars and case studies of good practice could be helpful in promoting information sharing, perhaps "kite-marking" the best. People want real-world

examples, recognisably similar to their own experience and that provides help on the specific context they face.

- Local education and training could be organised and delivered through Caldicott Guardians, Primary Care Networks and LHCREs.
- Consider mandatory, on-going professional training on data and information sharing.
- Technology solutions including inter-operability, shared records and secure email to facilitate appropriate, secure information sharing alongside any education and training initiatives.

5.5 Draft recommendations

The evidence presented here is clear and overwhelming that the NDG is correct to set as one of her priorities¹⁰; *Encouraging information sharing for individual care,* by working with bodies leading on professional education and training to ensure that those working within the health and care system are equipped to handle and share data with confidence. The findings from this report are also relevant to the NDG's consultation response and published work priorities¹¹. This report should inform the NDG's priority workstreams.

- **Recommendation 1:** The findings from this report are used to develop an education and training strategy to encourage information sharing for individual care. The key elements of this approach should include the following dimensions:
 - o Accessible and authoritative sector-wide guidance
 - Clear, consistent and accessible use of language
 - \circ $\,$ Measures to promote a culture of safe sharing to support personal care $\,$
 - Exemplars of good practice
 - o Consistency with new models of care and emerging technology challenges
- **Recommendation 2:** There needs to be clarity about what falls within direct care and what does not. Any new guidance needs to use clear language and be consistent with a changing health and care landscape.

To fill the gap until such time as this recommendation can be met in full, we have developed a draft decision-support algorithm¹² which may help frontline health and care professionals. If validated and assured, such a decision-support tool could be incorporated into an app or clinical / care record system.

- **Recommendation 3:** An approach should be developed to ensure patients, carers and service users can access important information about their health and care in ways that help them understand the content and context of that information.
- **Recommendation 4:** A better understanding should be developed of what specific data and information is required by the health and care system to meet the different demands of care provision, research and planning. This should be combined with an increased focus on data quality, structure and access hierarchies. This would enable the relevant data (and only the relevant data) to be accessed by the appropriate teams and the appropriate points, without the issues that could be caused by the sharing of the entire patient record.

5.6 Conclusion

¹⁰ NDG published priorities: Supporting public understanding and knowledge; encouraging information sharing for individual care; safeguarding a confidential health and care system.

¹¹ https://www.gov.uk/government/consultations/national-data-guardian-a-consultation-on-priorities

¹²https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/906534/Direct_care_deci_sion_support_tool.xlsx

Respondents stated that wider data sharing to support direct care has no quick or easy solutions. The problems are system-wide at every level of the health and care system and any solution requires a multi-faceted approach across the legal, technical, organisational and cultural dimensions of the health and care system. Education and training initiatives would be welcomed, but by themselves are unlikely to be sufficient to shift the balance towards wider data sharing.

Dame Fiona Caldicott National Data Guardian for Health and Social Care (July 2020)

Appendix A – survey method

The NDG launched this consultation on 23rd December on the NHS Digital *Citizenspace* website, which ran until 2nd February. The consultation was publicised through the NDG networks and key stakeholder organisations were contacted by email to notify them of the consultation and invited to participate. The survey was also open to individuals and organisations not specifically invited. Responses were limited to one per individual and one per organisation. We aimed for between 60-100 responses to ensure breadth of response and allow enough information for key themes to emerge. We repeated the recruitment process two weeks and one week before the survey closed to ensure we had at least 60 responses.

The consultation was in the form of an online survey (see Appendix B), gathering participant information in the first six questions, followed by an open question, asking respondents to state what they thought were the main barriers to sharing information to support direct care.

The survey then tested seven statements by asking respondents to answer three questions on each statement. The first question asked respondents to state their level of agreement or disagreement with each statement, on a five-point Likert scale (from strongly disagree through disagree, neither agree nor disagree, agree to strongly agree). Respondents were invited to provide any additional comments in a text box, either reflecting their views about the statement, or elaborating on the reason why they agreed/disagreed with the statement.

Respondents were then asked how they thought the NDG could best encourage education and training initiatives which support sharing for direct care, in relation to each test statement. The statement question triplets were numbered Qn (statement), Qna(additional comments), Qn+1 (education and training) – e.g. Q8, Q8a and Q9.

At the end of the survey, there were two additional questions. Question 21 asked respondents to indicate which single education and training initiative, they thought, would be most effective in enabling care professionals to share information for individual care. Question 22 invited respondents to add any other general comments.

Responses were downloaded by the NDG team as an *Excel* file for subsequent analysis at the end of the consultation period. No members of the NDG team or Panel participated in the survey. All responses to the statements tested in the Likert scales are presented as simple counts and percentages with supporting charts, with results split by individual and organisational response, where any differences were apparent. The detailed text responses were analysed by question and by respondent to identify commonalities and differences in the responses. The aim was to be able to gain additional insights from the detailed text responses to supplement the findings from the simple level of agreement with each of the statements provided by the Likert scale responses. Simple content analysis was used to identify commonly occurring words and phrases as a prelude to identifying themes.

Appendix B – the online survey

Consultation – your responses

Q1. Your Name:

- Q2. Your Role/Title:
- Q3. Your clinical speciality (if applicable):
- Q4. Your email address:
- Q5. What is the name of your organisation??

Q6.	Are you responding on behalf of an organisation?	Y/N
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Q7. What do you think are the main barriers to the sharing of information to support the direct care of individuals?

Q7. Please add your comments in the text box below.

Q8. When thinking about sharing information to support direct care, "*The distinction between direct and indirect care is clear and easy to apply*".

Please indicate below the degree to which you agree or disagree with the statement above.

Q8.

Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	Don't know

Q8a. Please add any comments in the text box below – either reflecting your views about the statement or elaborating on the reason why you agree/disagree with the statement. Explanations of how you differentiate between direct and indirect care would be welcome.

Q9. How do you think the NDG could best encourage education and training initiatives which support sharing for direct care? Please add your comments in the text box below.

Thinking about this broad category of data quality and availability, please indicate below the degree to which you agree or disagree with the statement above.

Q10.

Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	Don't know
agree	Agree	disagree	Disagree	disagree	Don't know

Q10a. Please add any comments in the text box below – either reflecting your views about the statement or elaborating on the reason why you agree/disagree with the statement.

Q11. How do you think the NDG could best encourage education and training initiatives in this area? Please add your comments in the text box below.

Q12. The NDG has heard that: "*There are enduring problems with sharing data across geographical and organisational boundaries, with the most problematic flow between health and social care*".

Thinking about this broad category of data flows around the health and care system, please indicate below the degree to which you agree or disagree with the statement above.

Q12.

Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	Don't know

Q12a. Please add any comments in the text box below – either reflecting your views about the statement or elaborating on the reason why you agree/disagree with the statement.

Q13. How do you think the NDG could best encourage education and training initiatives in this area? Please add your comments in the text box below.

(14. The NDG has heard that. A rear persists among health and social care start about sharing data, despite a patient expectation that information about them will be readily available to those involved in their care". Please indicate below the degree to which you agree or disagree with the statement above.

Q14.

2					
Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	Don't know

Q14a. Please add any comments in the text box below – either reflecting your views about the statement or elaborating on the reason why you agree/disagree with the statement.

Q15. How do you think the NDG could best encourage education and training initiatives in this area? Please add your comments in the text box below.

Q16. The NDG has heard that: "There needs to be more clarity about the legal and ethical framework for health and care professionals to share information for direct care".

Please indicate below the degree to which you agree or disagree with the statement above.

Q16.

Strongly agree Agree	Neither agree nor disagree	Disagree	Strongly disagree	Don't know
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Q16a. Please add any comments in the text box below – either reflecting your views about the statement or elaborating on the reason why you agree/disagree with the statement.

Q17. How do you think the NDG could best encourage education and training initiatives in this area? Please add your comments in the text box below.

Please indicate below the degree to which you agree or disagree with the proposal above.

Q18.

Q10.					
		Neither			
Strongly		agree nor		Strongly	
agree	Agree	disagree	Disagree	disagree	Don't know

Q18a. Please add any comments in the text box below – either reflecting your views about the proposal or elaborating on the reason why you agree/disagree with the proposal.

Q19. How do you think the NDG could best encourage education and training initiatives in this area? Please add your comments in the text box below.

Q20. The NDG has heard that: "There should be a presumption that patients have access to their care records. Where patients have not been given such access, their care professionals should be able to provide clear reasons why not."

Please indicate below the degree to which you agree or disagree with the proposal above.

Q20.

Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	Don't know

Q20a. Please add any comments in the text box below – either reflecting your views about the proposal or elaborating on the reason why you agree/disagree with the proposal.

Q21. Which single education and training initiative, do you think, would be most effective in enabling care professionals to share information for individual care?

Q21. Please add your comments in the text box below.

Q22. Is there anything else you would like to add?

Thank you, Dame Fiona Caldicott, National Data Guardian for Health and Social Care

Appendix C – direct care decision support tool

In the second Caldicott Report¹³, direct care is defined as: *a clinical, social or public health activity concerned with the prevention, investigation and treatment of illness and the alleviation of suffering of individuals. It includes supporting individuals' ability to function and improve their participation in life and society. It includes the assurance of safe and high-quality care and treatment through local audit, the management of untoward or adverse incidents, person satisfaction including measurement of outcomes undertaken by one or more registered and regulated health or social care professionals and their team with whom the individual has a legitimate relationship for their care.*

If you are unsure whether what you are doing comes under this definition, we present below an example of a simple decision-support algorithm designed to help front-line health and care clinicians. If validated and assured, such a decision-support tool could easily be incorporated into an app or clinical / care record system.

The algorithm is shown as an image below and is provided as an Excel spreadsheet download on our associated GOV.UK webpage¹⁴.

Question	Answer	Action	Help / links				
1 Could this be research?	Yes	Goto HRA	Present user with link to Health Research Authority (HRA) tools				
			http://www.hra-decisiontools.org.uk/research/				
			For both research and non-research, if your project involves the use of patient data				
			without consent, you may still need a recommendation from the Confidentiality Advisory Group (CAG)				
			https://www.hra.nhs.uk/approvals-amendments/what-approvals-do-i-need/confidentiality-advisory-group/				
	No	Go to 2					
2 Could this be audit?	Yes	Go to 3	Present user with clinical audit support centre info-graphic and formal NHSE definition				
			https://www.england.nhs.uk/clinaudit/				
			https://www.clinicalauditsupport.com/what-is-clinical-audit.html				
			https://www.clinicalauditsupport.com/clinical-audit-resources.html				
			https://www.clinicalauditsupport.com/download/ca/DocB.pdf				
	No	Goto 4					
3 Could this be local audit?	Yes	>>>	The audit and its data involve one or several organisations in a local area where a care pathway involving				
			multiple providers is being commissioned as a whole and each clinical team are participating in				
			the audit and taking full responsibility for their component part.				
			This may be direct care subject to meeting the condition set out in GMC guidance below:				
			If an audit is to be carried out by the team that provided or are providing care, or those working to support them				
			nudit is to be carried out by the team that provided or are providing care, or those working to support them linical audit staff, doctors may disclose personal information about patients on the basis of their implied consent led that they have ready access to information explaining how their information will be used				
			clinical audit staff, doctors may disclose personal information about patients on the basis of their implied consent vided that they have ready access to information explaining how their information will be used that they have a right to object and have not objected.				
			and that they have a right to object and have not objected.				
			https://www.gmc-uk.org/ethical-guidance/learning-materials/disclosure-for-local-clinical-audit				
	No	STOP!	This is NOT direct care:				
			This is a national or regional audit and requires a different basis to meet the common law duty of confidentiality				
4 Could this be national	Yes	>>>	The UK national population screening programmes are listed on gov.uk below (e.g. bowel, breast, cervical screening)				
screening?			https://www.gov.uk/topic/population-screening-programmes				
			If an activity is classed as national screening, it will have been approved by the UK National Screening Committee				
			https://www.gov.uk/government/groups/uk-national-screening-committee-uk-nsc				
	No	Goto 5					
5 Is this personal care of	Yes	>>>	Direct care is defined* as "a clinical, social or public health activity concerned with the prevention, investigation and treatm				
a named individual (s)?			of illness and the alleviation of suffering of individuals.				
			It includes supporting individuals' ability to function and improve their participation in life and society.				
			It includes the assurance of safe and high-quality care and treeatment through local audit, the management of untoward or				
			adverse incidents, person satisfaction including measurement of outcomes undertaken by one or more registered and				
			regulated health or social care professionals and their team with whom the individual has a legitimate relationship for care.				
			* See To Share or Not to Share: The Information Governance Review. 2013. Ch3 p35-48 & Glossary p128				
			https://www.gov.uk/government/publications/the-information-governance-review				
			You have a reasonable basis for having satisfied the common law duty of confidence > you can PROCEED				
	No	STOP!	You are NOT providing direct care				

https://www.gov.uk/government/publications/the-information-governance-review

¹³ To Share or not to Share: The Information Governance Review. 2013.

¹⁴https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/906534/Direct_care_dec ision_support_tool.xlsx