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Submitted to **National Data Guardian - Survey on information sharing to support direct care**

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Please tell us something about you and your organisation

1 Please provide your name:

Name:

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2 Please provide your role/job title:

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Policy & Academic Research Manager

3 Please provide your clinical specialty (if applicable):

Clinical specialty:

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5 Please provide your organisation name:

Organisation:

The Royal College of Radiologists

6 Are you responding on behalf of an organisation?

Yes

Barriers to sharing information

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

Please add your comments here::

Main barrier one: Technology

Digital technologies, in health and in the NHS, result in data silos. Previously, paper records were integrated, and once accessed all the information is available to support front-line patient care. This is not the case with electronic records. IT departments in the NHS often withhold access to vital digital systems from frontline clinical users. The justification being that they are preventing inappropriate access to confidential patient information. Any doctor involved in clinical management decisions for individual patients, should have access to blood results, pathology reports, clinical letters, discharge summaries, medication history and so on. All systems housing these data should be enabled with single sign-on technology with ready access for frontline doctors and other Allied health professionals as appropriate.

Sharing of clinical information across NHS organisations also remains a challenge. For example, multiple hospital IDs can be generated for patients who attend multiple times in different places, with different software used even within departments in the same hospital. Use of the NHS number should be mandated as a priority. Too many IT systems are unable to communicate without this being used. Multiple usernames and passwords are frustrating to front line clinical users. Forgotten usernames and passwords create barriers to access to vital clinical information to enable safe patient care.

Unnecessary technical barriers are also unwittingly created by IT departments and technology vendors. Often, staff members do not understand how to procure IT systems which support global interoperability standards and how these standards enable safe patient care. The IT Industry can take advantage by not supplying IT systems that communicate with other vendor systems. The Royal College of Radiologist Informatics Committee has published a report highlighting these issues called Who Shares Wins. However, the frustration remains that front line users and professional representative bodies are not involved in IT system procurement in the NHS.

Main barrier two: Culture & interpretation of the legal framework

The sharing culture of the NHS needs to change to enable safe patient care. As patients occasionally, some members have reported it disheartening to see how many times health care professionals (HCPs) start afresh with a blank information form rather than simply adding information onto an existing record. The main impediment is felt to be due to clinicians being wary of breaching Information Governance rules. If hospitals and HCPs are so scared of falling foul to breaching GDPR, they will naturally err on the side of caution rather than capturing patient data that would be of beneficial use for long term treatment. Indeed, many Trusts have complicated information governance procedures, often implemented in a 'knee jerk' punitive fashion at management level.

Additionally, there are grey areas with respect to: patient communication and informed consent for access outside of direct care teams; lack of information regarding legalities; and a lack of trusted reporting templates. For example, in radiology, big lack of consistency of outside scans and reports available for MDTs. To mitigate this, succinct legal guided clarification for the whole of the NHS and private sector should be issued so that all HCPs know what they can record and with whom they can share that data.

What do we mean by direct (individual) care?

8 Please indicate the degree to which you agree or disagree with the statement above:

Disagree

Please add any comments to support your selection::

There was no real consensus among RCR members on the distinction/definition of direct vs indirect care, and an internet search shows that there is also confusion among the public. Suggested definitions offered:

- Direct care – activities related to active medical management of a patient (procedures/examinations)
- Indirect care – supporting activities associated with the care of a patient

Even with these definitions, the distinction between direct care and indirect care can be subject to ambiguity. For example, images used for educational purposes are not considered direct care, but essential for the delivery of future direct care. Please see the guidance document (https://www.rcr.ac.uk/system/files/publication/field_publication_files/bfcr177_use_of_pateint_images.pdf) for the RCR position on this. It was also felt that there should be facilitation of information sharing, using Hospital or NHS numbers, to encourage audit and research within Trusts and research organisations (which is crucial for implementing innovative practice and service improvements) in addition to direct care of individual patients.

9 Please tell us how you think the NDG could best encourage education and training initiatives in this area:

Tell us how you think the NDG could best encourage education and training initiatives in this area::

RCR members have suggested the following:

- Clear nationally recognised definitions for all stakeholders - education and training should enforce and enhance this clarification.
- 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).
- Facilitation of patient consent for use of information for purposes of teaching and research as standard, with option for opt out. Anonymisation, where practical, for teaching purposes and anonymization/pseudo anonymisation of data for research and artificial intelligence
- On line training or best practice module within Trust mandatory training
- Promote the understanding that other trusts need vital information to deliver optimal patient care
- Provide a mechanism for highlighting the significance of direct care data at induction
- Have a named departmental information governance lead

Data quality and availability

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

Strongly agree

Please add any comments to support your selection::

Among respondent members, deep frustration was expressed at the unnecessary obstacles to patient data flow. It was noted that the NHS National Programme for IT (<https://www.parliament.uk/business/committees/committees-a-z/commons-select/public-accounts-committee/news/npfit-report/>) failed the population of this country, with one member venturing that, "had this been designed as a 20 year programme broken down into manageable projects, we would have been some way down that pathway by now. Industry was trying to guide the leaders of that programme at that time, but nobody was listening – too political and not being driven for the right reasons". We would urge the National Data Guardian and NHS bodies to learn from this experience.

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. Many of the IT systems are completely separate with inconsistent availability of secure messaging or email systems. As already stressed in the opening section, multiple datasets for individual patients are a perpetual hindrance as this often requires multiple log-ins and re-entry of patient identification details to gain access. In addition, limited or no access to data from primary care or adjacent healthcare providers can result in unnecessary repeat imaging and lack of continuity of care. Ultimately, it is the patient who loses out.

Sharing of information is even more prohibitive with organisations outside the NHS, which can exacerbate poorer patient outcomes further, as they do not receive appropriate transfers to social care or aftercare, such as rehabilitation. The reaction to GDPR and management-led information governance protocols could again play a part here – with hospitals and care professionals exerting spurious over-caution when sharing patient data.

A suggestion to ameliorate this was a system with exception handling that has a free-flowing electronic patient record (EPR) with the NHS number as a core identifier and capabilities to selectively distribute the findings and secondary care results to patients, GP's and other parties on a need to know basis.

For diagnostics, it was suggested that: standardised digital reporting (pathology & imaging) with a proforma and free text options be offered – standard text for specific investigations/findings – SNOWMED (<https://www.england.nhs.uk/digitaltechnology/digital-primary-care/snomed-ct/>) as standard. All will assist audit and tracking patient outcomes in relation to specific diagnoses.

11 Please tell us how you think the NDG could best encourage education and training initiatives in this area:

Tell us how you think the NDG could best encourage education and training initiatives in this area::

RCR members have suggested the following:

- The production of standards for healthcare records with follow on training for adherence
- With increased patient access to their data, clinicians may require specific education and training in structuring of reports for patient readability, personalised with insertion of images (where appropriate) and relevant data as to what results actually mean for the individual patient.

Sharing data across geographical and organisational boundaries

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

Agree

Please add any comments to support your selection::

While certain NHS staff members have access to secure email (nhs.net), many still do not. This prohibits sharing of information, even between individual NHS hospital sites. There can be holdups in the patient pathway while essential information is awaited from neighbouring sites and even departments. We know that this is even more difficult for social care, due to their lack of shared systems.

For radiologists, sharing image files or reports can also be problematic. Image sharing requires "request & push" – only feasible if the requester knows where and when the imaging was performed. This can result in unnecessary repeat or further imaging which has been previously undertaken elsewhere. These delays in acquiring previous imaging can impact on patient care/radiation burden.

Robust IT systems based on nationally-agreed and interoperable standards would easily permit the necessary flow of data. To illustrate, members working in Scotland report that overcoming data sharing barriers has made a huge difference in oncology where cancer centres often serve multiple Trusts and hospitals. There is no technical reason this cannot be achieved across the rest of the NHS, but there unfortunately seems to be many political and organisational drivers that serve as a blockage.

13 Please tell us how you think the NDG could best encourage education and training initiatives in this area:

Tell us how you think the NDG could best encourage education and training initiatives in this area::

None offered.

Anxiety about data sharing

14 Please indicate the degree to which you agree or disagree with the statement above:

Agree

Please add any comments to support your selection::

Frustrations and fear exist as data sharing for patient care is complex and often difficult to achieve. Fear can be heightened due to an NHS blame culture, both from an internal whistle-blowing perspective and from the press, coupled with an overstretched workforce showing high levels of stress and burnout (<https://www.bma.org.uk/news/2019/october/stress-undermining-retention-says-gmc>). As we have already stated, an oft perceived barrier to sharing information appropriately can be pressure exerted from managers, coupled with persistence of a hierarchical NHS culture, where perceived Information Governance breaches are heavily penalised. This can all permeate into daily practices around sharing of patient information.

The general consensus from our respondents was that the fear around sharing data within the healthcare IT systems is more pronounced when there is a public patient/medical interface. 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.

15 Please tell us how you think the NDG could best encourage education and training initiatives in this area:

Tell us how you think the NDG could best encourage education and training initiatives in this area::

RCR members have suggested the following:

- 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

Legal and ethical framework

16 Please indicate the degree to which you agree or disagree with the statement above:

Agree

Please add any comments to support your selection::

Currently, the general assumption that sharing is not permitted has negative impact on patient care. A lack of understanding among many clinicians was highlighted – as an example, we have heard that radiologists are often reluctant to share images for teaching when requested via certain tangible mediums, such as a flash drive, which invites clarity on nuances around the line of ethical duty of confidentiality and the legal duty to protect data. 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.

17 Please tell us how you think the NDG could best encourage education and training initiatives in this area:

Tell us how you think the NDG could best encourage education and training initiatives in this area::

RCR members have suggested the following to encourage education and training initiatives:

- Comprehensive and accessible guidance about what can legitimately be shared for the whole of the NHS and private sector should be issued, with podcasts/bite sized examples to support and enable change

Patient access to records

18 Please indicate the degree to which you agree or disagree with the statement above:

Agree

Please add any comments to support your selection::

There will be a requirement for health professionals to access patient data in order to support patients when they access their own data. When patients are convinced that data is being held securely and with good cause they would undoubtedly be happy for all data about them to be stored. Many patients would embrace the opportunity to "own" their data – this could improve efficiency and safety. However, it was suggested that there may be unintended consequences of such ready access with issues around patient expectation, deeper explanation of results requiring more clinician time, and increased costs to provide the information (which would be passed onto the data controller).

From a slightly more challenging perspective, some respondents felt that patients can often overestimate their own medical understanding - often not realising that while the internet is a good source of information, it can be highly misleading. Increasing blanket access to patient's own notes could just lead to doctors practising more defensively, or ordering unnecessary investigations to satisfy a patient's demands, for example.

Some IT systems already allow patients to access some of their data, but as stated previously, hospitals and other care providers are unnecessarily nervous about allowing patient access. Additionally, the issue of "sensitive" data that may be held about certain patients was noted as a potential hindrance to sharing. Timing of release of data to patients needs to be considered in this context, (e.g. cancer diagnosis). In short, the healthcare environment must have the governance support to keep the information organised, with access points and levels of information kept up to date.

19 Please tell us how you think the NDG could best encourage education and training initiatives in this area:

Tell us how you think the NDG could best encourage education and training initiatives in this area::

RCR members have suggested the following:

- Training initiatives required to deliver information to patients in an understandable format. Research undertaken shows that the optimum format harbours a required reading age, with insertion of pictures and what the results mean for the individual patient. This is new for many healthcare professionals and will require support.
- Working with stakeholder groups – there are many enthusiastic and skilled health care workers, social care staff and patient/carer groups
- There continues to be an underpinning role for public health education e.g. to encourage uptake of vaccinations, and to combat epidemics such as obesity and smoking. This would lead to a healthier population and reduce demand on the NHS

Patients not having access to records

20 Please indicate the degree to which you agree or disagree with the statement above:

Neither agree nor disagree

Please add any comments to support your selection::

This statement comes with the strong caveat that information may confuse some patients and add to their stress and worries. Concerns remain over patients accessing 'bad news' without access to direct support e.g. at night/weekends/remotely. In addition, there needs to be clear information about the next steps/appointments/who and how to access the right information and necessary support. There will need to be a way of ensuring that sensitive information is not shared inadvertently or lost.

With this in mind, there needs to be safeguarding mechanisms in place for patients to access their records. Equally, there must be safeguards for professionals treating patients against inappropriate use of any patient's medical records by external agencies e.g. lawyers, insurance firms etc.

Education; Final comments

21 Which single education and training initiative do you think would be most effective to encourage care professionals to share information for individual care?

provide one example of an education initiative to promote sharing:

1. Clear guidance to doctors, nurses and allied health professionals (e.g. radiographers) from the Caldicott guardian about what patient information can be shared without breaching patient confidentiality
 - a. within a Trust
 - b. between trusts
 - c. with the wider medical/ scientific community (e.g. for audit/ research)

22 Is there anything else you would like to add?

Please provide any final comments you may have::

We feel that everything has been covered above.