MedConfidential submission to the Caldicott Consultation

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About medConfidential

medConfidential is an independent non-partisan organisation campaigning for confidentiality and consent in health and social care, which seeks to ensure that every flow of data into, across and out of the NHS and care system is *consensual, safe and transparent*.

Founded in January 2013, medConfidential works with patients and medics, service users and care professionals; draws advice from a network of experts in the fields of health informatics, computer security, law/ethics and privacy; and believes there need be no conflict between good research, good ethics and good medical care.

Question 3 - Further Engagement.

“The NHS has not yet won the public’s trust in an area that is vital for the future of patient care” — Secretary of State Jeremy Hunt quoted in paragraph 1.5 of the Review.

MedConfidential is happy to engage further to help restore that trust.

We are happy to engage on many issues, and have explicitly sought out engagement with current active efforts on invoice reconciliation, only to discover there doesn’t appear to be any.

We can be contacted via coordinator@medconfidential.org

Executive Summary

The opt out language on page 41 of the Review is clear, understandable and capable of being delivered with public confidence - it will be able to win the public's trust in an area that is vital for the future of patient care. The alternate on page 40 is the opposite.

We would comment on the evidence for an override of dissent for invoice reconciliation, GP extraction, and the disease registries, but no case for override was provided. Absent evidence, those overrides should be treated very skeptically and approved by Parliament when the opt out is placed on a statutory basis.

The Review was focussed on solving the consent questions outstanding from care.data's failure in 2014 - the response from the Department will need to take a forward looking view. By the time the iterative steps proposed in the Review have been implemented, the patient experience and expectation will have changed, the NHS will have continued to innovate, new projects will have emerged to undermine the good work of the National Data Guardian, and watered down steps will be seen in retrospect as insufficient half-measures.

The quality of the Review is clear from the fact that to cope with problems from outside the remit, none of the numbered recommendations of the Review need to be reduced.[1] They simply need to be extended further to cope with other issues. The terms "apps" or "smartphone" do not appear in the Review or the Consultation.

Healthy, successful, and particularly male protagonists commonly have no understanding or insight of the type of sensitive information that they will one day have to divulge to their doctor, and the consequences of confidentiality not being respected.

We do not know what innovations genomics data, for example, will bring in the next decade - change is iterative and compounding. However, how genomics data is used in 98 months time will look very similar to how it is used in 100 months time. In that gap, providing patients an account of how their data has been used will also provide the knowledge that can reassure the nervous, while allowing the NHS to innovate extensively.

With genomics and AI, and whatever comes after genomics and AI, there must be a mechanism for those technologies to have the data they need, safely, while they develop the process. It may require some innovation in process, but that does not necessarily involve risk to patients. The NHS's governance processes are capable of delivering on that challenge, but public transparency and understanding will be fundamental to confidence.

Care.data exemplified the data trust deficit[2], and the Wellcome Trust identified the underlying "Context Collapse" that prevents an easy fix. With the rush of new technologies and innovations across the NHS, if Confidence Collapse is to be avoided, not only must every data flow in the NHS be consensual, safe, and transparent, they must also be seen to be consensual, safe, and transparent.

[1] The suggestion that the GP opt out is discontinued is not a numbered recommendation of the Review.
[2] https://www.statslife.org.uk/news/1672-new-rss-research-finds-data-trust-deficit-with-lessons

Recommendations

1. There must be a clear, unambiguous, implementable, statement of policy on consent, both by the Secretary of State and the top of NHS England, to deliver the patient dissent choice outlined on page 41 of the Caldicott Review:
   "Information about me can only be used by the people directly providing my care."

2. To demonstrate progress on delivery, offer a summary to each patient of how data about them has been used, and why. This should cover organisations providing direct care and projects for secondary uses, to be as comprehensive as and where possible.[3]

3. For patients who have not expressed dissent, or opted back in, linked data for secondary uses should only be used within a "safe setting":[4]
   a. Any data held by HSCIC may be linked.[5]
   b. Review/enhance the ONS Vital Statistics[6] to resolve discrepancies that have evolved over time between the data published as Official/National Statistics, and the required denominators for population statistics.
   c. Disease registries should become a top flight NHS-facilitated data product, by drawing on the expertise of the current registries, and the breadth of data from the NHS. This is necessary for high quality research.

4. Based on an understanding of their data has been used, and how is being used following full implementation of measures, then each patient should be able to choose whether to end their existing GP opt out, in light of reality not promises.

These steps allow confidence to underpin all data projects into the long term: not just the secondary uses for running the NHS or research, but also facilitating improvements in Direct Care from apps, machine learning / artificial intelligence, and genomics, and also whatever innovation comes next after apps, AI or genomics.

The department has been here before. The Accredited Safe Havens consultation in 2014 was similarly compromised by half-measures of implementation and bureaucratic timidity. As such, it would have done very little to solve actual problems. In assessing responses, the Department took the view that half-measures would be ineffective, would simply prolong problems, and a move to the "end state" would be more efficient and worthwhile. The same should happen again here.

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[3] https://medconfidential.org/2014/what-is-a-data-usage-report/
[4] https://medconfidential.org/wp-content/uploads/2015/08/2015-08-20riskstratification.pdf
[5] It is likely that certain areas of sensitive data, e.g. HIV, may require additional approvals processes for access.
[6] See http://digital.nhs.uk/vital or https://www.gov.uk/government/statistics/vital-statistics-population-and-health-reference-tables-summer-2015-update

Tests for the Government's Response

1. Is the opt-out offer clear and without jargon?

2. Is the opt out available and accessible to everyone?

3. Does the small print undermine the headline promise?

4. Are the disease registries a first class data product of the health system, equal to others (or better) in terms of governance, transparency, consent and accountability?

5. Does DH/HSCIC have a scenario and response in place for the unrestricted publication of the complete HES dataset, that was disseminated to a requestor who then had an accident?

6. Do the arrangements for Invoice Reconciliation encourage (or hinder) the rollout of accountable EHR and electronic records transfers along care pathways?

7. Given the lack of justification in the Review and Consultation, is a compelling case made for overriding:
    a. Existing dissent from patient data leaving the GP?
    b. For purposes of invoice reconciliation?
    c. For the disease registries?

The Consultation suggests a belief in the Department that it is easier to force patients to surrender their data to the Government against, their own wishes, than it is to change its own bureaucracy in ways it has already told the public it will.

"Healthcare is going digital in the 21st Century with huge benefits to patients," says UK life sciences minister George Freeman. "But NHS patients need to know their data will be secure and not be sold or used inappropriately".[7]

8. Will they know how their data was used in line with their wishes, or will they have to trust?

9. Is the new opt-out statutory? What is the process by which it can be changed?

[7] https://www.newscientist.com/article/2086454-revealed-google-ai-has-access-to-huge-haul-of-nhs-patient-data/

Consultation part 2: Data Security

The consultation discusses data security only within the remit of Direct Care, which seems to be an omission. Here, we cover both Direct Care and then Secondary Uses.

Part 2a: Direct care

Overview

There is little technically innovative in this part of the Review and the Consultation proposals - the innovation comes solely from the enforcement and implementation measures, due to the lack of previous systemic enforcements.

That data handling is safe, and believed to be safe, is necessary for the rest of the NHS innovation agenda. The furore around the Royal Free Hospital sharing data with Google Deepmind shows what happens when this is not the case - and the extent of coverage shows the interest.

Care.data was destructive primarily in trust, but secondarily in the opportunity cost of pausing other work that would have improved the health of the nation. That was not a “luxury” the NHS should have had to endure. It is unlikely to be possible to repeat that 2 year pause the next time a project implodes.

While this was outside the remit of the Caldicott Review, it must be in scope for the Department’s response, and the approach of the Department, NHS England, HSCIC, and beyond, in improving the health of the nation.

Be seen to recognise good practice

The Martha Lane Fox Review of digital in the NHS suggested that NHS Choices include an icon for free wifi, which may be extended to cover quality of digital services. The higher standards of that metric should have various cyber/digital requirements or prohibitions.

This item should be considered the highest priority. Just as patients’ wishes must be seen to be honoured, there has to be cultural recognition for meeting the required digital standards - which absent a catastrophe, may otherwise be invisible.

The Review focusses on what should be done; but for confidence, it must both be done and be seen to be done. As with a surgery checklist, that an action has to be seen to be taken increases the confidence that it has been taken.

Outdated OS and browsers

Using technical means to identify the Operating System fingerprints,[8] no traffic from Windows XP (and other prohibited operating systems) should be permitted to enter the successor to N3, and this prohibition be enforced by inviolable technical means.

Consideration should be given to the optimum places to enforce browser warnings, and prohibit certain systems access.

Language

The term “data breach” should only be used in it’s Data Protection Act definition.

The concept of missing data or withheld data should not be conflated with “lost” data. While a narrow reading of the Data Protection Act could imply that it is unlawful not to share data where it is in a patient’s interest, it is contrary to the normally expected understanding of the term. An alternative formulation should be used.

The optimal terminology, is at present, unclear.

Comments on Proposed Data Security Standards - Direct Care

1 - “Lawful and appropriate purposes”.

While it acknowledges that data should not be used for unlawful or inappropriate purposes, extra detail is needed, with a direct reference in the text that is currently absent.

This item, especially as the first item, is at risk of reading like an irregular verb:

> “My purposes are lawful and appropriate;
> Yours follow the letter of the Data Protection Act;
> He should be prosecuted.”

Care.data was lawful and appropriate, right up until the point where it wasn’t, which was what led the NHS to discover that it was in this mess in the first place.

The only way that “lawful and appropriate” will be enforced is with transparency of whether standards have been met. This should be designed to avoid adverse consequences from honesty, but also to provide reassurance to patients. The rules should not just be followed, but should be seen to be followed.

[8] https://en.wikipedia.org/wiki/TCP/IP_stack_fingerprinting

For example, Google DeepMind and the Royal Free Hospital believe their use of 5 years of SUS data was lawful and appropriate, although investigations are ongoing. It is unreasonable to expect every choice to be made correctly, immediately. But accountability to patients of how data about them has been used allows the patient to know what decisions have happened. This will allow the NHS to, transparently, get to where the Review says it should be, and start from where it is. It is that transition that can happen with both transparency, integrity, and compassion. Patients are generally forgiving of errors, if lessons are seen to be learnt.

3 - Education

Education should be the primary focus, reflecting the 7th Caldicott Principle. Clarity on what is direct care and what are secondary uses has caused a variety of problems.

If patients are given a comprehensive accounting of how data is used, that will allow for a small and iterative feedback loop, at the level of patient to provider, of whether wishes were followed or why. This will allow organisations to resolve the issues locally and transparently to patients. There should be a recognition that referring a question to the Caldicott Guardian for clarity is a welcome step.

Proper education should not undermine secondary uses.

Direct care can be described as “an Identified Patient receiving Individual Care from an Identified Clinical Professional”. Many other people are necessary to support Direct Care by providing tools, but they do not provide it themselves.

Providing a working computer system, or electricity, or cleaning services is a necessary task, it *is* improving the health of the nation, **but it is not providing direct care**. To summarise our presentation on the topic - not everyone gets to be an astronaut.

Other clinical professionals in an organisation, while they *are* doctors, are not *your* doctor. Someone can be *a* father and doing childcare, but that’s not the same as being *your child’s* father. That they provide care to some, does not necessarily mean they provide care to you. The only reason to others argue that there is “gray area” here, is to justify the ignorance behind decisions already made.

Everyone in the NHS is committed to improving the health of the nation - not everyone does direct care.[9]

[9] https://medconfidential.org/wp-content/uploads/2016/07/2015-09-NDG-presentation-shortenedforweb.pdf

4 - “Personal Confidential data” / Information

The term “Personal Confidential data” and “Personal Confidential Information” should be removed from all documents that a patient may ever read. It is NHS jargon than is not meaningful to patients.

The use of this term was what allowed NHS England to claim that the opt out for care.data would do one thing, while justifying their continued grab of a patient’s medical history buried in the Privacy Impact Assessment.

The replacement for this term should be “patient level data” - data that relates to an individual patient, but language testing is required.

Part 2b: Data Security beyond Direct Care

There aren’t adequate standards; and there isn’t any security.

Secondary uses data security is not covered in the Review. It is, in some ways, more problematic than data held for purposes of direct care. For one hospital to lose all their digital records may be regarded as misfortune, for a commercial user to lose all of them looks like carelessness. Primarily only the part of the decision to continue supplying them on an ongoing basis.

The HSCIC continues to routinely disseminate over 1.5 *b*illion hospital events, trusting that the recipients will not get hacked or lose them.

Does DH/HSCIC have a contingency plan for responding to the uncontrolled publication on the internet of the complete 1.5 bn record collection of HES, should any one of the 1500 recipients[10] lose the data?[11]

CareCERT does not cover the secondary uses of data by HSCIC recipients. This may be worthy of some consideration, as part of a notification process if nothing else.

Penalties for mishandling data in secondary uses should not be lower than those for identical data in direct care. The penalty for a commercial company mishandling millions of patients’ data[12] is far lower than that for an NHS body mishandling a single patient record. This is unsustainable.

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[10] The 1500 figures is from a Google DeepMind press briefing. We have an FOI request into HSCIC for their figure, but it has not been answered at the time of writing.
[11] No.
[12] E.g http://digital.nhs.uk/media/21985/Data-Sharing-Agreement-Audit---Health-IQpdf-196-KB/pdf/Data_Sharing_Agreement_Audit_-_Health_IQ.pdf

The sustainable solution to this risk is to dramatically reduce the number of copies that HSCIC disseminate, which means a safe setting system as recommended by the Health Select Committee at evidence sessions looking into the care.data failure in 2014. This work should be scaled up and accelerated to cope with truly remote arrangements.

Many of the recipients already operate their own form of “disconnected from the internet” arrangements (which often means only a firewall rule), and it would reduce the burden and load of compliance for the companies, increase actual compliance with the rules, and increase public confidence in data use.

See also our response to Part 4 of the Consultation.

Consultation part 3: Importance of Data Sharing

We note that there are no questions in this part of the Consultation. It appears as a statement of policy, rather than a topic for comment. It mirrors the thinking that went into care.data, which, while not necessarily fundamentally flawed, the key questions continue to come down to implementation.

Healthy, successful, and particularly male protagonists commonly have no understanding or insight of the type of sensitive information that they will one day have to divulge to their doctor, and the consequences of confidentiality not being respected.

Ending the “good chaps” theory of data dissemination

The policy intent of this work is to create a process that the public may have confidence in into the future. Unfortunately, the Terms of Reference for the Caldicott Review were limited to issues surrounding care.data, which was suspended in early 2014. It is worth remembering that care.data began active implementation in 2012, and follows a model of the commercial “use” of the Hospital Episode Statistics from the late 1990s, which follow a design of the late 1980s[13].

The pre-2014 HSCIC model was entirely based on the long standing assumption that all those who got hold of data were “good chaps” and no one would do anything wrong. That was the first impact when the end of the patrician model of care started to end - as we saw with Pharmacy2U and the NHS Apps Library. The first people in the queue may not be the people who have the NHS goals and ideals or delivery on patient expectations.

With Pharmacy2U, the first people in the queue were lottery fraudsters targeting those with cognitive impairments, and those promoting fake medicines trying to convince patients to pay more for a fake substitute, and disregard the legitimate medicines they had just received via the NHS.[14] The Apps Library contained a similar laundry list of digital predators using the NHS to appear legitimate to victims - which is why it was shut down. In both cases, the underlying assumption of good faith was fatally flawed.

While the Review was not able to consider such issues, the Department’s response to this consultation will not have such a luxury. The framework put in place by the Department must be resilient into the future, and should improve on the status quo. Such improvements should not be particularly difficult given the current state, and are also necessary to deliver the other priorities of the Department.

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[13] See the Hospital Episode Statistics Privacy Impact Assessment’s discussion of the (lack of a) legal basis for the HES going back through time.

[14] https://ico.org.uk/media/action-weve-taken/mpns/1433030/pharmacy2u-ltd-monetary-penalty-notice.pdf

Public Perceptions: A tower built on sand?

The public perception of the success of the Caldicott Review is dependent entirely upon the response that the Department of Health makes. The Review delivered upon its primary goal, which was to deliver new, acceptable, correct wording for patients - listed on page 41 of the Review (the flaws in the model on page 40 are covered elsewhere).

There is the opportunity to have data flows across the NHS that are consensual, safe and transparent, which have public trust and confidence, and which provide the right information to those who need it, in a way where there are no secrets from patients on how data about them has been used.

Not all flows can respect opt outs, but those that do not must have a clear legislative basis, tight legislative constraints, and reporting (digitally first[15]) to each patient that the opt out did not apply in that case, and why.

We strongly oppose any suggestion that the type-1, GP opt outs (9Nu0), is changed in any way. The issues that this causes in current processes for NHS digital can be mitigated as part of new systems being designed, along similar lines to the GPES system.

We strongly support the transformation of the “type-2” (9Nu4) opt out into a spine based NHS-wide opt out for patients. Mirroring the name change from HSCIC to NHS Digital, this simplifies the system significantly, since an opt out that applies only to “NHS Digital” makes absolutely no sense to those who don’t follow the minutiae of NHS reorganisations.

Patients who wish privacy should not be punished for DH, NHS, or supplier failures in the past.

If patients do not have confidence in the system, that fear will be compounded in genomics, in AI, or whatever is next. If the future of the NHS is technology and innovation, as (former) DH minister George Freeman repeatedly pointed out, that has to be grounded in a basis of public confidence. The review recommendations around CQC and inspections are hence fundamental, however, it is unclear whether the system policing itself will rebuild confidence, or simply report on a steady drip of one-off failures, undermining confidence.

The consent system must not only work, it must be seen to work. The public have a great deal of forgiveness for failures, if they are seen to be learnt from. But a lack of systematic confidence requires a systematic solution.

[15] https://medconfidential.org/2014/what-is-a-data-usage-report/

Direct Care vs Secondary Uses

The Royal Free Hospital's agreement with Google Deepmind

Investigations into what happened are ongoing; although the publication of the Privacy Impact Assessment is likely to be a primary document describing the root cause of the failure.[16] We do not propose to reopen that debate here, but simply look at wider lessons of the firestorm, whatever the trigger.

Innovation around data has been stymied since at least the collapse of care.data in 2014. With NHS England's original assertion that the programme would continue, then its cancellation, and the presumed restart of the same policy intent under a new name at some point in the future.

However, the RFH/DeepMind fiasco shows that the world, and the NHS, will continue to change and innovate whatever the processes of DH would prefer. As such, innovation should be facilitated. It is unlikely that the next innovations that cause a collapse in public confidence will be as easy to pause.

Therefore, the desire for transparency comes from all sides - those doing innovative work that may freak the public or press out need an infrastructure within the NHS that allows them to be transparent, without everyone having to reinvent the wheel.

"A Doctor" vs "My Doctor"

The suggestion that "Direct care" and "secondary uses" are insufficient to handle such innovations are also flawed - there is no grey area between the two. Such confusion was necessary for the flaws of the DeepMind/RFH project.

The distinction between "a doctor" and "my doctor" is a central tenet of the NHS, of clinical regulation, and of patient consent. While the DeepMind algorithms may at some point pass the exams required for GMC regulation to be seen as "a doctor", that is still one step short of being "my doctor". However, understanding that those are separate steps is necessary.

We cover this elsewhere under education, but the final slide in the presentation is especially relevant here.[17]

[16] Note no reference to the SUS datasets: https://www.whatdotheyknow.com/request/331981/response/819841/attach/3/Privacy%20Impact%20Assessment%20for%20Waking%20Project%2027%20Jan%202016%20V0%201%20redacted.pdf

[17] https://medconfidential.org/wp-content/uploads/2016/07/2015-09-NDG-presentation-shortenedforweb.pdf

Coding of data

Changes in the data environment may have unintended consequences on data that is stored. As integrated care environments become more common, the differences in the intent of recording data will be exacerbated. A GP may record a stroke as the date it happened, but will be surprised when they look at their patient's medical history and find their patient subsequently has a stroke every Tuesday morning. As the physio records not that they had a physio appointment, but the reason why they needed it in the first place: a stroke. Such misinterpretations of data are only going to grow.

Maintain the existing GP opt out ("9Nu0" / "type-1")

An attempt by the Department to withdraw the existing opt out from patients, that is in place and working, would have a devastating effect on public confidence in NHS/DH Data handling, both in the past and into the future. It would be unclear, if the old consent model could simply disappear at the swish of a Ministerial pen, on what basis the new consent model will be resilient against a repeat.

The public effects of removing the GP opt out would be to undermine all other work that any organisation, across Government or civil society, to try and improve patient trust.
When civil servants from the Department remind NHS bodies that a single misstep can undermine all other good work, the Department are entirely right. The attempt to remove the GP opt out is one such step. Whether it is substantially correct or not is an entirely separate issue, but the legacy of care.data is toxic in this aspect especially. Any decision to remove 9Nu0 must be via primary legislation, and even if that is passed, it must not be the first item in the trust building process, but the last. But in that context, it should be entirely unnecessary, as if such legislative force is required to be used, it is a statement of failure by the Department that attempts to rebuild public trust have failed, and a Kelsey-esque scorched earth strategy is now to be employed.

Such an action will undermine everything else. If measures are put in place to satisfy the needs with 98% of patient data, then that will reassure those whose fears are current exacerbated.

The best way to restore trust is to accept the decision of the public, not to try and override it. We have seen no evidence of compelling need, but understand that there is an overarching desire on the part of some organisations to have an absolutely complete dataset, not a 98% complete dataset. Nothing is likely to exacerbate the fears of the public more than saying "2% of people opting out is too many". It is penny wise and pound foolish, and the Secretary of State should clearly state that, patients who do not want their data used for purposes beyond their direct care will not have their data used. That is a political decision.

CCGs and other data vampires will want it all, and will likely complain loudly. But the demand, expectation, or assumption, of being able to receive everything for all data, which will still be insufficient, is what causes public concern in the first place.

The current opt out rate is 2%. BBC research showed that, at the height of the controversy, only a third of people knew what care.data was. Mishandling this project yet again may make the opt out rate go up.

The department has been here before. The Accredited Safe Havens consultation in 2014 was similarly compromised by half-measures of implementation and bureaucratic timidity. As such, it would have done very little to solve actual problems. In assessing responses, the Department took the view that half-measures would be ineffective, would simply prolong problems, and a move to the “end state” would be more efficient and worthwhile.

The same should happen again here.

Invoice Reconciliation

MedConfidential has previously published a numbered of detailed papers on how to deliver on Invoice Reconciliation,[18] including the particular problem of A&E.

This process has a broad s251 approval, which has been endlessly and “temporarily” renewed for years. Yet, despite this, it appears there is yet another extension to be given.

Is the Department going to insist that this question is resolved, or is the problem going to infect a modern consent world? The Department can not credibly claim to wish to improve data handling if it ignores problems within its remit to resolve, and which patients do not wish to consider.

We have written to the Department to request involvement in any work to remove the need for the Invoice Reconciliation exception. While the response said “we are keen to continue engaging”, it did not include a commitment to actually work to resolve this problem, beyond past measures that have been shown to be ineffective.

The continuing problem of invoice reconciliation shows the fundamental problem of all 3 Caldicott Reports: good information governance is undermined by ineptitude or bureaucratic neglect in the absence of leadership and commitment. That is what led to care.data, and we hope the lessons have been learnt. If not, they can be taught again, with the consequent recognition by patients that their trust is misplaced, degrading from the low base that care.data’s mismanagement left the system in.

[18] https://medconfidential.org/2015/towards-protecting-data-in-secondary-uses/

Invoice Validation and Consent in a world of Electronic Health Records[19]

"By 2018, clinicians in primary care, urgent and emergency care and other key transitions of care contexts will be operating without the use of paper records" says the Department of Health. MedConfidential agrees that Electronic Health Records to pass information electronically along a patient's care pathway will lead to better care and better patient outcomes, but that's not all they do.

To ensure the uptake of flows along care pathways, there should be transparency of process. As part of a Data Usage Report, patients should be able to see where their EHRs have gone and why. That data could go anywhere is mitigated by telling patients exactly where it did go, so patients can have confidence it didn't go elsewhere. The requirement for all care providers to use the NHS number makes this feasible.

There will also be published statistics on the adoption of EHRs. Those statistics should also include what percentage of patients arrive at an organisation with an EHR, or how many need to have an NHS number lookup to create a record (organisations with walk-in patients, including A&E, should be excluded). By institution, they don't tell us very much, but when you look at pairs of institutions, you can see patterns. How many EHRs did hospital A send to care provide B? How many B receive from A? Where does this process go wrong, and is there anyone chasing up why and fixing it?

The answer, of course, is no.

The place that the chasing up does happen, predictably, is when money becomes involved. The NHS has a balance of accountants whose job it is to make sure that one bit of the NHS bills the other bits the right amounts for the care provided. Given NHS bodies don't trust each other, those other bits of the NHS then have a different balance of accountants to check all the invoices.

In a world with Electronic Health Records that flow along care pathways with patients, that doesn't have to happen - the constraint on the Review should not apply to the Department. The reporting on those flows can include a summary of care provided at the previous stage from that provider, which provides a separately accountable (to CCG via HSCIC) reporting streams which the accounts can rely on. As it derived from clinical data, any fraud by commercial actors in the system would require clinical fraud, as well as accounting fraud, with it's far higher penalties. If the counts of care provided from one side are very different to another, that is examined as a clinical issue as well as a financial one.

"Should we pay this invoice?" becomes a simple question based on audited information from multiple automated sources. The counts will show whether all care provided along pathways has yet been paid for by the relevant CCG. Where there are queries, it means there was an

[19] This is an adaptation of a version posted online: https://medconfidential.org/2016/how-much-confidence-does-the-department-of-health-actually-have-in-electronic-health-records/

EHR flaw which should be addressed, not just for financial reasons, but to improve care. (This is in need of refinement, but the likely question for adoption is “What percentage of new records have an NHS number entered manually, rather than via an electronic records transfer?”. Care per provider per CCG is derivable from EHR flows by third parties).

Invoice reconciliation has been a thorn in the side of privacy and good governance since the inception of the internal market in the NHS - the Department of Health has *never* bothered to fix it. As EHRs roll out on the same timescale as the Caldicott Review, there is the opportunity to do so. Besides legislative changes in the consent model, when the CAG regulations are finally laid, they should prevent the approval of s251 for invoice reconciliation “by 2018”. If the organisations of the NHS care about high quality EHRs because Treasury cares about accounting, incentives will be aligned to resolve problems along care pathways, which will improve direct care at the same time.

There is the opportunity for a change that aligns with many of the DH and care provider priorities, and solves a long standing problem. As care providers move to EHRs, the need for invoice validation should change radically, and reduce costs and administration all round. This should be the desired end state.

Disease Registries[20]

If they were to be created today, no one would expect the disease registers to look like they currently do.

The disease registers often get undeservedly forgotten. They are an important, if underutilised, resource to allow legitimate research from the perspective of the condition, not the hospital. The contain data on (almost) everyone who has had a particular disease (e.g. cancer, or diabetes, or many other conditions). There is a good overview as it was in 2002 from SEPHO.[21]

All too often, they are a backwater of the data culture because of the way they have evolved to help a condition, or a temporary priority, rather than part of a designed whole. They have good intent, but it is far from clear whether every disease register is fulfilling their legal obligations around fair processing and consent any better than the NHS was before care.data. The luxury of inconspicuity is unlikely to last.

Having the disease registers under the broad NHS opt out brings them fully into the NHS family. They are each a type of deep expertise in their chosen fields, covering data for a condition. The disease registers deserve to be a first class data pool for research, not silos of subsets of data copied into corners and barely acknowledged.

[20] This has more context https://medconfidential.org/wp-content/uploads/2016/09/diseaseregisters.pdf
[21] http://www.sepho.org.uk/download/Public/5445/1/disease_registers_in_england.pdf

What should a modern Disease Register look like?

A modern disease register should be a centre of knowledge and data for the relevant topic. It should have access to all data within the NHS that has not been dissented from linkage and sharing, with a commitment to transparency on projects and outputs, be they academic publications, new treatments, or cures.

Broader research access to linked data will require the use of safe settings for the analysis,[2] as there should be no expectation that the data is "safe" to release, or anonymised in any way, beyond basic pseudonymisation.

The need for accurate denominators

For some conditions, there is a legitimate need for accurate denominators to establish prevalence and calculate confidence intervals (including the effect of dissent) in short, to calculate accurate population pyramids for the broad subpopulations, which was a primary reason for exclusion from the Caldicott Consent model.

While this may be a superficial argument in favour of a "collect it all" strategy, it is flawed by the fact that such data is already collected by other means to produce official statistics. As an example, data on tumours is collected by ONS for the Vital Statistics, and such data should be the basis for the subpopulations (which also simplifies analysis by ensuring all population bases are synchronised). This may require harmonisation of definitions, or the production of additional entries in the Vital Statistics, rather than simply entirely ignoring their existence.

A mandatory notification of a description of the tumour, but not the medical history of the patient, via the existing tight ONS legislative framework mandating publication, does not raise novel privacy concerns.[22] Requiring non-consented data for the Vital Statistics only also resolves the issue of the HSCIC mixing consented and non-consented purposes within the same flows the separation is robust, standard, and used across Government for a variety of reasons.

A high quality culture of disease registers is possible with consented data, if there is a willingness to deliver it for the research community.

Disease Registers: A test of Research Confidence in NHS Consent

In a fully Caldicott Compliant world, all data used for research would be consented, and it should all be linked and available to the disease registries. Doing anything else would be a failure of vision at this opportunity for change the NHS has to upgrade its consent model,

[22] There will need to be a discussion of the content of the mandatory notification, however the principle already stands for notifiable diseases and food poisoning, etc.

and the disease registries can take their rightful place at the same time. Whether they wish to take this opportunity or not is up to them.

Consultation part 4: Consent and Opt outs

Comments on the Principles

1 - You are protected by law

Regarding the specific language of “It will never be used for marketing or insurance purposes, without your consent”, it is unclear whether the proliferation of companies providing “market access”[23] services would be covered under “marketing” or not. This language should be implemented broadly.

4 - Personal Confidential Data/Information

Our comments above re this piece of NHS jargon apply here equally. It is not a term that the public will understand to mean the same thing that the NHS may use it to mean.

The term “patient level records” or similar should be used. Patients do not know what this jargon means and, as was seen with the confusion in care.data, the use of a narrow definition means that identifiable patient data may flow[24] even when patients have objected. This will undermine patient expectations of the consent model, and now is the time to resolve that properly.

The examples given in this text should line up to the examples given on pages 40/41 for the opt out model. These should include accurate examples of commercial use that will be permitted under those categories (see our comments on that elsewhere).

The opt out language on page 40 of the Review is confusing between the categories, whereas the opt out language on page 41 is clear and unambiguous.

5 - Scope

We agree with this item; although what patients are told has to be true. There are other areas of the review, particularly around exclusions, where this may not be the case.

[23] http://www.harveywalsh.co.uk/what-we-do.aspx
[24] Specifically unique and dated events.

7 - Anonymisation[25]

We agree with this principle that properly anonymised data should not be subject to the opt out, however, the definition of anonymisation used in the Review is flawed. Most health data, including the Hospital Episode Statistics, is incapable of being anonymised to an effective standard, while also being usable for high quality research. Alternate methods, such as safe settings, are necessary for the data to be used safely, even if the data itself is unsafe without those steps.

The definition of whether data are anonymous is covered by the UK Anonymisation Network, which says quite clearly on page 16:[26]

> *"Anonymisation – refers to a process of ensuring that the risk of somebody being identified in the data is negligible. This invariably involves doing more than simply de-identifying the data, and often requires that data be further altered or masked in some way in order to prevent statistical linkage.27*
>
> *We can highlight further* ***the difference between anonymisation and de-identification (including pseudonymisation)*** *by considering how re-identification might occur:*
>
> 1. *Directly from those data.*
> 2. *Indirectly from those data and other information which is in the possession, or is likely to come into the possession, of someone who has access to the data.28*
>
> ***The process of de-identification addresses no more than the first, i.e. the risk of identification arising directly from data. The process of anonymisation, on the other hand, should address both 1 and 2.*** *Thus the purpose of anonymisation is to make re-identification difficult both directly and indirectly. In de-identification – because one is only removing direct identifiers – the process is unlikely to affect the risk of indirect re-identification from data in combination with other data."*

Additionally, the forthcoming General Data Protection Regulation is quite clear:

> "Personal data which have undergone pseudonymisation, which could be attributed to a natural person by the use of additional information should be considered to be information on an identifiable natural person."

According to the Hospital Episode Statistics Privacy Impact Assessment from HSCIC, this is the risk to patients of re-identification: "This may happen in future" (risk 7)[27].

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[25] A broader variant of this summary is available at https://medconfidential.org/wp-content/uploads/2016/09/anonymisation-2016-briefing.pdf

[26] http://ukanon.net/wp-content/uploads/2015/05/The-Anonymisation-Decision-making-Framework.pdf

[27] http://digital.nhs.uk/media/21216/HES-PIA-Report/doc/HES_PIA_Report.docx

None of that is to say that the opt out should apply to properly anonymised statistics - those that meet the ONS definition - it undoubtedly should apply. However, putting “statistics” in a dataset name does not make mean they are statistics.

The Hospital Episode “Statistics” are not statistics in any normal form, they are a longitudinally linked, administratively collected, census of all treatments in all hospitals going back around 25 years. It is as close to a panopticon as is possible to get - which is entirely the point of collecting data on patients for their care, and the legitimate fear of hte public.

8 - Statutory Exceptions

Where there is a claimed mandatory legal requirement or statutory exception to the opt out, the Legislation section/clause providing such a specific power must be cited. This should include new legislation where existing legislation is insufficient. It is likely that the legislation that will place the National Data Guardian on a statutory footing would be a suitable place for any such amendments.

The first bulleted list (page 13 of the Consultation) is, on the whole, unproblematic. However, all such exceptions should have a clear statutory basis for the override which is cited for each exception. We would suggest that the list is split into two categories.

The first, a “notifications” category, where a named body must be notified of defined information in the case of a particular event (and would cover the items in the list where the word “*must*” appears).

The second, is an “access” category, where a named organisation may access records under a particular power. With the exception of “fraud”,[28] we would expect that any patient whose record was accessed should be able to be notified that their record had been accessed and why as part of their Data Usage Report.[29]

Uniquely in relation to the GP data, data provision to the HSCIC is not an “exceptional circumstance” - **the exception for the HSCIC should be removed.** Although data provided under another exception may be provided to the HSCIC for processing.

Regarding National Disease Registers and Invoice Validation, see our comments in part 3 of this response. Neither of these are treated appropriately in the Review or Consultation, partially due to work that has happened since the Review and consultation were published.

The basis for the opt out should be statutory itself.

[28] Our proposal for the “Fraud” category is that every data usage report contains a standard line “Your data may have been used to help reduce fraud against the NHS”, without more details. This would meet the requirement, without raising concerns of identifiability.
[29] https://medconfidential.org/2014/what-is-a-data-usage-report/

Questions 14 - Locations of advice

The lessons of care.data should be heeded, and the precedent of the Summary Care Record followed. When an opt out form is posted to each patient, that should be accompanied by a clear booklet which is designed to inform, and which is entirely accurate. A great deal of work was done by the Care.Data Advisory Group reviewing such a booklet. As the opt out is now extended, some of that work will need to be extended to cover the new areas.

Wellcome Trust research has discussed a “Context Collapse” when patient data is used in a context that patients did not understand, even if there was a bureaucratic justification. Should that be ignored, “Confidence Collapse” will surely follow.

If process has confidence, we would expect all areas of the health and social care system to wish to be included, including the disease registers if they are covered by the opt out. All data that is a primary output of the NHS should be included in that booklet.

It may prove helpful for the Taskforce being run out of the Wellcome Trust to establish some ground rules over which the charities wish to follow, and to act as a coordinating function. Care.data demonstrated that a misstatement by any group impacts upon all.

The Role of Clinicians

The call for data sharing explanations to be clinician led is helpful, if properly implemented, to the satisfaction of the relevant professional bodies.

However, if the expectation is that the opt out promise will by made by a clinician to their patient, it can not be the case that doctors make promises which are then broken at the whim of NHS England or the Secretary of State. The understanding has to be clearly written down in law, in a manner which can not trivially be changed.

If the Secretary of State believes he can undo his past promises, then what confidence do the junior doctors have that he will not undo the promise they have just made to their patients?

Similarly, “the system” has to demonstrate confidence to each doctor who is expected to explain to their patients what has happened and why. The vast majority of the workload for this ongoing communications process must be taken up by the system itself, in a manner that firstly commands Professional confidence.

In doing so, transparency to patients of which organisations have accessed data, and when, should also help provide a feedback loop for identifying problems, and reducing the risk and fears of themselves making a mistake. Honest mistakes can be transparently accounted for,

but more importantly, the clear feedback loop reduces the fear of making a mistake and can increase clinician confidence in making a decision as a judgement call - remembering that professional judgement in difficult circumstances is a large part of their professional training.

The fundamental need here is Education. If the direction of travel is improvement, and there is confidence and reassurance around the system, this will work. We have covered this from a different perspective in this presentation[30]

[30] https://medconfidential.org/wp-content/uploads/2016/07/2015-09-NDG-presentation-shortenedforweb.pdf

Question 15 - The transition

In short:[31]

Currently “Anonymised data”, “arguably” isn’t

We understand that, for there to be an official admission that the Hospital Episode Statistics are not anonymised, would be to require the admission of a de facto breach of the Data Protection Act since the very first day the Act came into force. We appreciate that may be cognitively difficult for the HSCIC and Department to accept, even if it breaches the existing NHS standard for anonymisation.[32]

The forthcoming General Data Protection Regulation is explicit that pseudonymised data is identifiable. That will give a hard legal deadline of May 2018 for a change, which is conveniently similar to the timetable for the implementation of the Caldicott Review. The world has moved on from the ad hoc creation of the data in the late 1980s, but the data protection applied to JES has not. Denial only lasts so long before there is an uncontrolled change - there will be a change of some form, the mechanism is partially within the Department’s control if it chooses to exert it.[33]

Data that is properly anonymised in line with the Anonymisation Code of Practice would not be subject to the opt out, as it had been properly anonymised, and have had some measure of statistical disclosure control applied.

Telling patients you will protect data about them, and then not doing so, is going to end badly.

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[31] https://twitter.com/bengoldacre/status/656577067698356224
[32] http://digital.nhs.uk/media/18876/1523202010spec/pdf/1523202010spec.pdf
[33] https://medconfidential.org/wp-content/uploads/2016/09/anonymisation-2016-briefing.pdf

The offer to patients

The offer to patients must be clear, it must be comprehensible, and it must be true. We have made comments above about certain parts of NHS jargon that should be clarified in the longer version.

The Wellcome Trust has detailed the "Context Collapse"[34] where data is copied from one scenario to another causing public concern. The creation of an artificial boundary "within NHS Digital" to simply replace "within HSCIC" is likely to exacerbate such a collapse. Without steps being taken, after context collapse comes Confidence Collapse.

We strongly support the transformation of the "type-2" (9Nu4) opt out into a spine based NHS-wide opt out for patients. Mirroring the name change from HSCIC to NHS Digital, this simplifies the system significantly, since an opt out that applies only to "NHS Digital" makes absolutely no sense to those who don't follow or care about the minutiae of NHS reorganisations.

Such a transformation allows the NHS to begin to rebuild confidence, by not "resetting" consent, and is a clear reason to write to all patients about the new arrangements.

Onward dissemination

The ability to chain loopholes will cause public concern when the practice is exposed - there should be no expectation of eternal secrecy.

If data flowing from the HSCIC is unprotected, and data flowing to HSCIC is unprotected, the constant demand for more data will lead to all data eventually shared and flowing out of NHS Digital. While the name change for the arms length body of the Department of Health may slightly reassure the public, it is still clear that the Department does as Directed, and is not subservient to the wishes of NHS England. While this has clear advantages when it acted as a brake on the excesses of care.data, it does not prevent actors acquiring data in their own interest, "within the rules" but outside their spirit. The continued flow of data for "market access" purposes being the new face of "marketing".[35]

[34] https://wellcome.ac.uk/what-we-do/our-work/public-engagement-and-trust
[35] http://harveywalsh.co.uk/what-we-do.aspx

“My data”, or “data about me”?

There is an understandable distinction between a civil servant discussing using “data about them” and “their data”. That distinction may be important to those discussing secondary use, and in the abstract, it is indeed data about patients. However, to each patient involved, it is their data.

The abstract of others is not at the forefront of their mind, it is the data that viscerally belongs to them, and is an integral part of their lived experience. To deny to a patient that it is their data undermines a central tenet of health care - that it is intensely personal.

While the term “data about them” may be accurate when describing patient data, when the process has failed, or a patient is engaging for whatever reason, it is most definitely seen as “my data”. The passive voice only applies when there is confidence in the system and patient is disengaged. It is unlikely that either part is currently true.

The practicality of a data usage report

One of the arguments suggested against a data usage report to patients, is that “the system” can’t do it. Each organisation we talk to sees the transparency as a good thing, and they are all willing to do their part, but there is a fundamental lack of confidence in the other parts of the system to deliver on their parts. GPs are happy to allow their web service to be the front end, but need to have confidence there will be something to deliver. While GPs have kept track of the data flows out of their practice, it’s unclear whether others have. HSCIC is capable of producing and managing the information system to record flows and report to patients, but needs to be told by DH to do so - HSCIC now keeps track of where it sends data. Together with GPs, that is 75+% of secondary uses flows. HSCIC already manages the PDS/SCR for patient lookups, and could report to patients if there was a vehicle for doing so. Some care providers don’t keep track of internal systems, because they never had to, and while they may not currently be able to, have no objection in principle to doing so. Researchers who receive data from HSCIC or others are already generally required to report to HSCIC the publications they produce as a result, and the project information is already provided as part of the data application process. There’s little new work here for legitimate data users.

The only people who oppose this form of transparency reaching to outputs, are those organisations, principally commercial in focus, who wish to have the most intimate details of patients’ lives, but refuse to show them the outputs of what was done with that data.

The practicality of a data usage report is clear; it is the intent that is lacking. As with other areas, the systematic lack of confidence is broad and undermines large scale improvements.

A data usage report ensures and facilitates transparency to patients by all projects involved in innovation or research, while not restricting any project at the edges of the NHS. The provision of this core piece of transparency infrastructure is necessary for innovation and accountability to thrive and be seen as a benefit, not a burden.

The opt out model on page 40 of the Review - deeply flawed

The language on page 40 of the Review is unclear and flawed. If this option is likely to be considered going forwards, we request a meeting to understand why, and provide further input, based on the other decisions that DH has made about other aspects of our submission. The brevity of this section is simply down to our believe that this option is a non-starter. We do not consider it substantively elsewhere,[36] but the other aspects of this response are not dependent on the option on page 41 being used.

As a thought experiment for the Review team, we suggest taking the last Data Release Register from HSCIC,[37] looking at each request, and considering which of the opt out options that project would sit in. We suggest that consensus will be difficult. If those who spend their time steeped in these issues are unable to agree which project is which, and why, then communicating that clearly to the public will be impossible. Should this option be picked, we fully expect that it will not be complicated to demonstrate as such.

The scope for nefarious or perversely incentivised actors to perform permission arbitrage to get maximum data is significant. While “marketing” may be banned, “market access” continues; and this model simply encourages those with less than noble intent to game the system. Indeed, it has been suggested to us that the only reason that this option is given consideration is simply to allow precisely that.

It also seems perverse that there is an offer for patients to opt out of bona fide not-for-profit public benefit research, but no way to accept research while opting out of their data being sold for commercial purposes (despite the “McDonald’s amendment”[38]) and private benefit. This seems to be backwards in a publicly funded NHS, for the benefit of all, improving the health of the nation.

While this option reflects a subset of the status quo, it is unlikely to be flexible into the future, with arguments and disagreements about which box a particular project should be in. As an example, we consider the history of Genomics around the NHS, both before and after Genomics England Ltd.

[36] Otherwise this response would be far longer than it already is.
[37] http://hscic.gov.uk/dataregister
[38] 2014: https://medconfidential.org/wp-content/uploads/2014/05/medConfidential-briefing-for-Care-Bill-ping-pong_07May.pdf

Where would Genomics England sit in this choice?

We consider the question, in the model proposed on page 40, would the advances in Genomics have been stalled by the flaws in this model if it had been in place?

Genomics England Limited is an odd entity. It's a private company, entirely Government owned, that sits outside the NHS family, but also right next to them. It is arguably the larger successor to research in academia and related research environments.[39] Genomics England now operates within the NHS, but via independent funding streams, as it creates new diagnoses and treatments which will be entirely part of the NHS.

Into the future, it may simply cease to be relevant as tests are standardised and published, it may be privatised to become a conventional private actor, it may simply become an equivalent of a special health authority within the NHS, providing particular specialised services.

In those different scenarios, it is easy to see that depending on decisions in future, or an alternate telling of the origin myths of the project, that it could easily move between one box and another.

As such, how is a patient, who has little interest in the ownership structure of a govco, able to make a decision on which opt out applies? How will they know that the process has changed tomorrow, as a company has been nationalised, or privatised? For a project created within the organisation before that transition, would they then be able to get data on the state after the transition? Would they be able to keep what they had despite material changes in the governance of the organisation?

It is arguable that this is not the problem of the Review, or even current DH civil servants, but as for future scenario planning, it must be considered as it significantly impacts the future of GeL.

Page 41 of the Review - use this option

This option is clear, understandable, and while we have comments on implementation details elsewhere, it is entirely fine. This option should be placed on a statutory footing.

The clear benefit of this option is that there is absolutely no ambiguity for nefarious actors to perform permission arbitrage between the different gradations of access. It is simple and clear.

[39] http://www.ddduk.org

The examples of data usage should cover the various data uses covered by the dissent when it is implemented. As such, we suggest that the disease registries be added to this category to replace the PROMS.

An unclear example: The PROMS[40]

We would suggest replacing the words “to ask your opinion about the care you have received” from the description of the data option. The option of asking patients for their views on care, begun in a direct care setting, can be remodelled to be a specific opt-in overriding the generic opt out.

This will require some slight changes to the current nature and process of the PROMS, which should happen anyway in light of the consent changes from the Review, but that should be recommended to also consider PROMS as a specifically consented opt-in data flow, with minimal changes to process.

medConfidential supports the idea of a generic “Do Not Contact” flag on the Spine to disable proactive outreach for screening and routine calls (ie, direct care), although this should not be conflated with dissent from secondary uses of data. Such a flag was outside the scope of the NHS, but would address some concerns about patients feeling “bothered” by proactive screening requests, and be used by relatively few.

Doing this again in a few years?

The Department must be clear about the intent, recognising that, at this point in time, it is not necessarily as much of a trusted actor as it may wish to be, or it may believe itself to be.

If this process does not deliver benefits to all, whether they wish their data used or otherwise, for the various types of researchers, and indeed for NHS England / PHE / DH.

The need, or perceived need, for Caldicott 4, will be a statement that the Department of Health has failed in responding to this Consultation. That would be unfortunate.

No one should be left out

The focus of the Review was on the consent language, and data hygiene. Both of these were entirely right. The consent language was broken, and data hygiene is a basic process that must have integrity.

If the outcome of this Consultation does not provide something for everyone, there will be a Caldicott4 to examine the next fiasco. Those who do not wish their data used must have

[40] http://www.nhs.uk/NHSEngland/thenhs/records/proms/Pages/patientinformation.aspx

their wishes respected - this is about 2% of the population at the moment, but if mishandled, could go up to nearer 30%.[41] The 98% of people who have not opted out, and who (theoretically) wish to have their data used, should have it used safely and responsibly to improve the health of the nation.

[41] Wellcome Trust.

Consultation part 5: Equality Issues

Healthy, successful, and particularly male protagonists commonly have no understanding or insight of the type of sensitive information that they will one day have to divulge to their doctor, and the consequences of confidentiality not being respected. That is especially true across the diversity of backgrounds.

The entire range of health and social care issues and stigmas are raised here. We hope specific expert groups for each area will discuss how breaches of confidentiality affect them, but here we only provide a general and high level overview.

This consideration must include the diversity of ethnicity, socio-economic background, disability, cognitive impairment, capacity, as well as the interactions with social care. Each create different and novel challenges, for protecting the individuals involved, both from the service discrimination that allegedly requires the bureaucracy to insist their most intimate data be shared for their own protection, and also for the effects of the overriding of their wishes that it not be used, especially when it has escaped into the local authority systems.

For those who feel they have something to fear from telling a health professional information if it will then be shared, the inability for a doctor to make promises they can keep will have a devastating effect on confidence.

No matter how much data an analyst has, they always want more, as there is some nuance that is unknowable - film directors always wish for the shot they don't quite have.

As such, no matter how much data there is, there will always be a demand for more. However, the only reason to want 100% coverage is to be able to look at anything - which is exactly the fear that those in marginalised groups have, with long memories. Such concerns are why the census does just fine with 95% of data and self-reporting.

Over decades, the repeated desire of officials to demand more data is entirely understandable. The problematic part is the implicit forgetfulness that this data is fundamentally about people, about lives, and about fears.

While that recognition runs throughout the Caldicott Review, it seems to be entirely absent from the Consultation. That will have the most serious effect on those who an equality assessment is supposed to protect. Civil servants or analysts do not provide direct care. They may help improve the health of the nation, but that's not the same thing.

That the bureaucracy requires the ability to interrogate anyone's administrative history, in a manner over which a patient have no control, is exactly the scenario that exacerbates other problems. Hence the importance of an opt out being available, even if the system is so good that people choose not to use it.

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September 2016