GP Data Access for Direct Care (in the first half of this Parliament) – covering GP Connect and overlapping plans for a Central Care Record in the Department of Health in England

(The small number of questions are numbered, decision influencing facts/beliefs are letters to understand why questions are being asked and the underlying points of disagreement)

While individual GPConnect / Central Care Record topics may not be immediately in scope of the overlapping policy teams in the Department of Health in England, medConfidential understands a series of things:

a) medConfidential seeks services that are consensual, safe, and transparent, and there need be no conflict between good medical care, good ethics, and good data uses.
b) DH/E sees GPConnect Update as a policy to deliver, technical capacity to offer, and to move onto the next features. GPs will have to use the system for years. Similarly, DH/E aims to deliver what it can within constraints, which may make what is delivered the best it can be, but that may still not be good enough for use. We'll pick this up in the SIT committee evidence.

DH/E

c) DH has announced NHSE will be abolished over time – we refer to the current and new entities as the Department of Health in England (DH/E).[1] The differences are largely irrelevant for the purposes of this document.
d) Ministers decide policy, and Ministers communicate that policy both privately and in public statements which may not entirely align, and can be contradictory. Some may be fundamentally incorrect on the policy as it is today, but may indicate a future response to the as yet unwritten policy submission; others may be entirely fictional.
e) DH/E makes new decisions, sometimes unilaterally, that may change past decisions.
f) DH/E suffers from a lack of trust from stakeholders due to their past actions.
g) SofS has said "I couldn't look that person in the eye and say they should wait longer because my principles trump their timely access to care." amongst other similar quotes equating private and NHS care.

FDP

h) It is the position of DH/E that FDP will continue.
i) DH/E makes strong public assertions of integrity through actions that it fails to deliver (e.g. where are all the FDP DPIAs?; incoherent statements in the privacy notices reflect dissonance in the programme). The substance of these failures is largely out of scope here, but the fact that this is not uncommon is relevant.
j) DH/E assert that because a professional says they will only access records when it is part of a legitimate direct care relationship, that is what happens, and so there is no reason to believe that any access would be otherwise; despite all the evidence of accesses that are otherwise.
    i) Currently getting that evidence requires an active police investigation
k) Many of the features of tomorrow's government controlled central single care record are likely to be part of GP Connect today

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[1] In this note, if we mean a body exclusively we'll note it, but DH/E should cover both/either.

l) Suppliers have already considered how GP Connect can read off a central care record within of FDP.

m) The reason that part of one ICB believes FDP is a good idea is it will (eventually) allow them to rewrite prescriptions in flight between prescriber and pharmacy to combat AMR. While we are aware this is not an immediate feature of FDP, that's what they will seek to use FDP and central care record for.

Pharmacy First

n) Pharmacy First is a programme to allow Pharmacists to be "practicing at the top of their licence".

o) Currently Pharmacy First is limited to seven conditions.

1. **Will patients be able to see when/where their GP Connect record was accessed from outside the GP practice (ie in a Pharmacy or elsewhere)?**

Tech

p) Currently a Pharmacy can send a message (basically an email) to a Practice notifying them of a consultation and prescription, giving the Practice agency over what to do with that message (although there are workload/workflow implications).

q) DH/E desires a system which allows a Pharmacy to write the consultation straight to the GP record. The quality of this system is unclear, the quality of the diagnoses are unclear, and the future roadmap is unclear.

   i) There is no in principle objection to write being possible

r) As currently constituted, safeguards on access to NHS records largely assume the other party is within the NHS family. The Caldicott Principles/Guardian requirements only apply to the publicly funded work of an organisation – it is considered best practice by UKCGC that others processing confidential patient information have a Guardian, but there is no obligation and UKCGC/NDG have no powers.

s) It is reasonable to say that there are likely to be very few disputed Update messages initially.

t) It is entirely reasonable that Pharmacy First can add more conditions in future.

2. **How does a GP disagree with a diagnosis from the Pharmacist? What happens from the perspective of i) the GP, ii) the Pharmacy, iii) the patient? Is that process reasonable?** (or, as now, does the process only do what E cares about?) If a document is rejected, why is the sender not notified? **Why is handling this not implemented in the system?** [this last question is one we'll return to]

u) It's not about messages going to the wrong place, but inappropriate content of messages that the GP doesn't wish to accept into the patient record (and which the patient will then see)

v) If preventing mis-filed updates is an important feature of the tech implementation, then it is reasonable that the implementation applies to the other locations which seek to send documents to GP for either no review or for active review where misfiling can occur.

w) Since GPs are now eligible for “Advice and Guidance” (A&G) payments around hospitals, if a Pharmacy wants GP review, it is unclear whether the “A&G” payment should/would cover that.

x) There are seemingly contradictory policy decisions from E on handling workflow for pharmacy first and on workflow for advice and guidance. A&G has lots of scope for rejecting as inappropriate, and this has none… DH accepts that the A&G process is important and needs to be funded and has been, but here there’s no way to have any form of dialogue… should we ask for this sort of unrejectable message to be sent to hospitals when they’re trying to avoid growing waiting lists?

Roadmap

y) The argument has already been made that if a private pharmacy can both read the NHS GP record for one of those conditions, then a private GP should be able to do the same for the exact condition. It may not be the policy position of DH/E today, but it is difficult to argue against this logic in the medium term given SofS’s views on equality of care.
    i) medConfidential understands ‘a large private healthcare provider’ has already made this case

z) It is not unreasonable for private GPs to desire to have equal functionality to Pharmacies – ie update

aa) It is entirely reasonable that those private GPs can justify access to more information than Pharmacists need

bb) If “practicing at the top of their licence” applies to Pharmacists, it is difficult to argue it doesn’t apply to private GPs[2]

3. **Where DH/E proposes that it should be impossible to disagree with a diagnosis from the original seven conditions, does DH/E expect that to apply to all diagnoses? Should a GP be able to disagree with a complex diagnosis that may or may not have been made to NHS standards (e.g. ADHD/gender/etc), What is the process for deciding which is which?** (is there one?) How is DH/E thinking of drawing these lines?

4. **If an NHS Pharmacy can write a diagnosis with or without need for GP follow-up back into the GP record, will NHS hospital EPRs be able to do so for equivalent updates? How would Update operate for hospital based prescribing?**

cc) There are two separate issues in GP Connect Update – firstly what it does today and the method DH/E are imposing on the Profession to accept it; and secondarily what those impositions allow DH/E to do tomorrow and the consequences for GPs.

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[2] Private doctors are not required to follow the same rules as NHS GPs, and DH/E can’t assume they will always do so, nor can it punish them when they breach NHS rules. The fig leaves of reassurance for patients in the NDG’s annual report do not apply to the private (non-NHS) GP sectors, and NHS IG policy does not entirely apply to them. Under the previous government, DH/E made the minimum necessary effort to justify their inaction and to side with creeps by dismissing simple and practical protections for patients and GP practices – pre-election DH/E framed perfect as the opposite of safer and blamed other data controllers (without asking them) by simply assuming they would not do for their patients anything DH/E was unwilling to do itself.

dd) The process is insufficient for uses of prescribing. When a Pharmacy sends an update message to the GP, E should provide written clarity on:
    i) Who is data controller for the written item?
    ii) When a contested coded diagnosis is written, who sees it and on what basis?
    iii) Does it appear accepted by the GP?
    iv) How does DH/E expect recorded diagnoses to be assessed by those who may be asked to prescribe off them later?
    v) What information about diagnosis/location/process etc will be disclosed and what does that also mean for care?

    and those topics should be assessed for credibility.

ee) E's argument that some topics are out of their scope is simply a flaw in the definition of scope within/by E, rather than the problem of anyone else; but is also an example of why E is getting abolished by Secretary of State (when issues will all become political).
ff) All of the questions above will need to be answered for the Central Care Record.

Central Government Single Central Health and Care Record

gg) Many of the more complex questions for GP Connect are simpler questions around the proposal for a central care record.That NHSE refuses to address them under one programme/silo shouldn't mean they refuse to address them at all. From a patient and Profession and perspective the standards should be identical whether single care record or GP Connect is used. In practice, it is expected that the tech APIs to single care record will be GP Connect from all places that GP Connect is already implemented (as it will be Summary Care Record where that is implemented), with the backend provider being Palantir servers rather than existing GPConnect providers.

hh) For example: DH/E's concerns around ADHD prescribing shows the consequences when private diagnoses are easier to get outside of NHS standards, but if a private GP were to write an ADHD diagnosis back to the GP record, what is the obligation on the NHS GP to prescribe? Or a "Pharmacy First" diagnosis that GLP1s were appropriate for weight loss? Where does the expansion of "pharmacy first" become inappropriate in a "single care record" world? Does DH/E policy have any clarity on any of these issues, and is that clarity shared with the Profession? The answer on clarity may not be final, but indication reduces scope for confusion.

ii) The primary distinction between GP Connect and the central care record being the GP record is one where the data controller feels some sense of direct personal responsibility to the patient, whereas when SecState is data controller of the national records future holders of the office may not feel responsibility at all.

jj) The FDP and dissolution of NHSE will mean Secretary of State becomes joint data controller for all patient data in every hospital in England,

kk) "cast iron guarantees" in primary legislation were promised. Right intent, timing… tbc?

5. **Does DHSC want having a central care record to be a direct consequence of having an NHS number – ie will a central care record be mandatory?** We have assumed that it will be, but that is not necessarily certain? If it isn't mandatory, how will people make informed choices about it? If it is mandatory, that places a very high bar on protecting the data within it, and will require very careful drafting of primary legislation to get there from here. If everyone must have a central care record, and GPs must check it before prescribing as it is the system of record for the patient, in the medium term what is the need for TPP/EMIS?

6. **Today, a patient can request that their record be blocked from GP Connect – will that same option be available for the central care record?**
    a. What will happen to those people who have S-flags today? How will the evolution of them be managed? (ie what protection will be put on Wes Streeting's central care record? Or their family? Can a domestic violence victim whose abuser works in A&E get the same protections? What do they have to do to get that? What happens about individual sensitive records – can a new MP hide their depressive episodes as a teenager from their records? What does that do for clinical care? - lots of questions, need a framework to understand where and how answers will be discussed)

ll) Central Care Record is a new system with new policy, so should have a cleaner implementation of the National Data Opt Out – and the opt out should mean opt out; if you have an NDOO, then no data leaves the central care record for any secondary uses. Secondary uses opt out means secondary uses opt out. NHSE has obstinately refused to adapt NDOO policy to reflect what it would have said if the programme had existed at the time – old programmes may have been covered but new programmes escape NDOO restrictions. Abolishing NHSE means SecState's responsibility is to both policy for programmes and policy for NDOO, so new programmes don't get to inherit E's practice that the NDOO never applies to them.

mm) For those who wish their data used for research, there will need to be proper minimisation processes, selecting only the variables needed etc (the model for openSAFELY works here, but we've also previously mocked something up for DARS). The notion of "take all of HES" will degrade in the longer term as HES will degrade as a cohesive entity. We have a separate note on available next steps for secondary uses.

7. **Will accesses to a central care record be hidden away from patients, or will the NHS App show people where/when their central care record has been accessed?** (by default, almost immediately, for everyone who can see prospective access to GP documents)

    If the answer to that question is "be hidden", if there is secrecy, or if NHS England covers access up, or if others can cover it up, then the entire system will be untrustworthy by design. It doesn't have to be, but it is a choice for DHSC/E. Choose better.

    If the answer to that question is yes – everyone with prospective access to documents can see when/where their central care record has been accessed

– then Ministers can (and must) clearly and repeatedly say that one of the principles underpinning the project will be no secrecy from patients about where their record has been accessed. People may have concerns about their record, but they will have evidence in the app to support or assuage those concerns. Secrecy and obfuscation is the main reason none of this happened already - care.data could have worked in 2014 with minor tweaks to be consensual, safe, and transparent.
If Ministers really want to demonstrate their commitment to this direction of travel, and have quick wins, demonstrate change from past failed approaches and renew political direction, the existing audit trails for Summary Care Records (held by E) and then GP Connect (held either by E or TPP/EMIS with approval of the Profession) could be made available in the app relatively rapidly as a quick win (Shared Care Records would depend on the area and may not be worth the opportunity cost for DH).

Social care

8. **What is DH/E current thinking on social care access to central single care record or GP Connect? Recent announcements have covered how DH/E will provide the infrastructure to support social care to know whether someone has taken their medication at the right time, and to support those who help them do so. This may be via an expansion of the FDP and Single Central Care Record into social care. Is it DH/E's expectation that the monitoring of whether medication was taken at the right time in social care will also apply to secondary inpatient care? If DH/E is going to be writing algorithms to monitor social care delivery via the FDP, is it going to do the same for secondary care? For primary care?**

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