

Matthew Gould
Chief Executive Officer
NHSX
23rd April 2020

~via email

Dear Matthew,

I am writing to seek clarification and assurances on the recent increase of requests for local data sharing citing COPI regulations.

The recent notices issued by the Department of Health and Social Care under Regulation 3(4) of the Control of Patient Information (COPI) regulations allow for data sharing to be made to enable various public health protection purposes and planning between multiple organisations as part of the response to Covid19. Our concerns are threefold:

Clarification on the use of COPI regulation 3 for medical research;
Inappropriate use of COPI regulation 3 to obtain confidential data for non COVID-19 related purposes;
Organisations citing COPI regulation 5 without having secured the necessary approval from the Health Research Authority (HRA).

The purposes for which confidential data can be used under regulation 3 are set out in regulation 3(1). We note that research is not included in this list, however, the COPI notice to GPs states that confidential information can be processed for research. It is our understanding that regulation 5, rather than regulation 3, is the correct route for processing confidential data for medical research purposes. Reliance on regulation 5 is dependent upon formal approval from the HRA via the Confidentiality Advisory Group (and having research ethics committee approval in place). This uncertainty about the use of regulation 3 in preference to regulation 5 is causing difficulty for our members who are keen to share data appropriately to aid efforts in tackling COVID19 but wish to do so with assurance that they remain compliant with confidentiality rules. Please can you clarify the legal position about the use of regulation 3 for medical research so that we can assure our members on this point

Turning to our second concern. Our members are reporting that a number of stakeholders are inappropriately citing regulation 3 in order to obtain confidential data for non-Covid19 purposes. One example is requests for large GP datasets for population health management tools. Such work is unrelated to Covid19 and is not covered by the list of public health purposes set out in Regulation 3(1). To help GPs refuse these inappropriate and unlawful requests, it would be helpful if NHS X could issue a notice or guidance which sets out the purposes, with case

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examples, for which regulation 3 can be used. It would also be helpful if this note could confirm that non-Covid-19 purposes are not captured by regulation 3.

Finally, many GPs have conveyed anxiety about the fact that organisations are approaching GPs and citing regulation 5 to obtain confidential data for research purposes. These requests are not being accompanied by the approval documentation from the HRA CAG which confirms that section 251 support under regulation 5 is in place. We are not aware that a blanket approval for COVID-19 research has been given, please can you confirm that if an organisation wishes to rely on regulation 5 it must seek approval from the HRA CAG via the well-established processes. This point could also be addressed in our request for a notice or guidance from NHSX as mentioned above.

I appreciate that in many cases health data may represent a useful source of information for organisations involved in broader efforts to support the UK's response to Coronavirus, but this does not mean that high standards of information governance should be set aside to permit unlawful data collections which may risk a loss of patient trust.

Dealing with inappropriate requests is also placing additional burdens on GPs at this busy time. This is being exacerbated by the areas of confusion described in this letter. As well as giving GPs the confidence and assurance to decline inappropriate requests, it is essential that we avoid busy practices risking breaches of confidentiality because they are under pressure to share data.

I understand that steps are in place to establish a national, centrally coordinated system for providing extracted data for the purposes of planning and research around Coronavirus, however in the interim I urge you to take steps to ensure that COPI regulations are not misappropriated by companies or organisations seeking data or data sharing agreements from GPs and that any interim measures do not add to the already considerable burden being placed on GPs at this time.

I look forward to discussing this issue further with you in the coming weeks.

Yours



Dr Farah Jameel
BMA GPC England Executive

cc. National Data Guardian Dame Fiona Caldicott

Caldicott Guardian NHSD Dr Arjun Dhillon

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