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PSNC Briefing 012/20: The national data opt-out system for patients, and how to complete the DSPTK opt-out question

This PSNC Briefing explains for pharmacy contractors what the national data opt-out system for patients is and how to complete the [Data and Security Protection Toolkit](#) ('Toolkit') question about the data opt-out system.












What is the opt-out?

The opt-out system allows patients to directly express their opt-out preference about whether health and care organisations can process their personal identifiable information where the only reason (or basis) is *Research or planning purposes*, e.g. to find ways to improve treatments or using data use to improve the delivery of health services. Patients can find more information or express their opt-out preference by:

- visiting the nhs.uk/yournhsdatamatters website portal; using the [NHS App](#); or
- writing **by post using the instructions at the nhs.uk website**; or by
- calling the NHS Digital contact centre - 0300 303 5678 (open workdays Monday-Friday, 9am-5pm).

Contractors are advised to signpost patients that ask about opt-out to one of the patient-facing options above. Patients have been informed their opt-out preference will be honoured by health and care organisations from **31st March 2020**. The opt-out system comes into force the same day as the deadline for assurances from health organisations about opt-out and more (via the Toolkit).

The table below sets out what the opt-out system applies to and how pharmacy contractors generally process identifiable patient data using other reasons, rather than only relying on planning/research – (meaning the opt-out system would typically have little impact on pharmacy data processing).

Processing category	Patient data processing categories (and whether these apply to the opt-out policy and whether pharmacy teams use such data flows)?	Applies to opt-out?	Expected pharmacy data flows (patient data)?
1	 <p>Planning and research is the reason for data processing <i>Research / planning – e.g. finding ways to improve treatments and identify causes of and cures for illnesses, or planning to improve and enable the efficient and safe provision of health and care services (identifying patients personally, i.e. not fully anonymised)</i></p>	 <i>Applies to opt-out</i>	<i>(Pharmacy contractors should not need to use identifiable patient data for planning/ research purposes)</i>
2	 <p>Individual's care & treatment is the reason for data processing E.g. where data is shared between the health and care professionals in a pharmacy and in a GP practice <i>(identifying patients personally)</i></p>	 <i>Exempt from opt-out</i>	 <i>Typical pharmacy data flow</i>
3	 <p>Legal requirement /public interest /consent is reason for processing E.g. there is a mandatory legal requirement such as a court order, to protect the greater interests of the public or there is explicit consent <i>(identifying patients personally)</i></p>	 <i>Exempt from opt-out</i>	 <i>Typical pharmacy data flow</i>
4	 <p>Data is processed but fully anonymised The data shared is fully anonymised e.g. compliant with the Information Commissioner's Office (ICO) Anonymisation: managing data protection risk code of practice <i>(this does not identify patients personally)</i></p>	 <i>Exempt from opt-out</i>	 <i>Typical pharmacy data flow</i>

The PSNC privacy notice template (see psnc.org.uk/dstemplates or [General Data Protection Regulation \(GDPR\) Workbook Template G Privacy Notice](#)) already includes reference to the opt-out system: "You may choose to opt out of the NHS using your data for planning and research purposes – please ask for details.". If you do not use this template, you can add this clause to your own privacy notice wording. A separate Toolkit question enables you to confirm you have a privacy notice.

How can I answer the Toolkit question which asks whether I comply with the opt-out system?

You are recommended to use the [Data Security and Protection Toolkit guidance materials](#) including the 'How to complete' summary briefing to complete your Toolkit as soon as possible and ahead of the final Toolkit deadline (March 31st 2020). PSNC worked with NHS Digital's Toolkit team to produce its guidance. The Toolkit includes a question about whether the pharmacy contractor is "compliant with the national data opt-out policy".

PSNC's [Toolkit question-by-question guidance](#) explains that you may enter 'Yes' within the comments box, because you (and other pharmacy contractors) should be processing identifiable data for other reasons instead of relying only on planning/research. Contractors should reference the opt-out policy within their own privacy notices (which can be made available on websites and/or within leaflets for patients that request information). Within the Toolkit opt-out question you are advised to also click the 'enter document's location' option and type 'Privacy notice' if yours references the opt-out. Patients have also been notified about the opt-out via NHS transparency notices. The images below demonstrate how you may complete the question. You can click 'save' to complete the question.



Frequently asked questions

Q. Why was the opt-out system introduced?

NHS Digital developed the data opt-out system following a recommendation in [Your Data, Better Security, Better Choice, Better Care](#) and within the Government's response to the National Data Guardian's [Review of Data Security, Consent and opt-outs](#). With the expansion of healthcare services being offered in the community, the National Data Guardian (NDG) recommends that healthcare data security standards continue to be reinforced.

Q. What are the arrangements for organisations if they may need to process identifiable patient data with only research/planning as the basis?

Organisations that wish to process identifiable data with only planning/research as the reason must work through the [NHS Digital opt out documents](#) and as needed, access the opt-out system to assist their data processing.

The [Community Pharmacy IT Group](#) considered the opt-out topic and advised that pharmacy contractors should continue to maintain exemplary governance arrangements and should therefore not begin to process identifiable data with only planning/research as the reason.

[PMR suppliers](#) and PMR's [aggregator](#) companies must also complete the Toolkit each year and confirm alignment with the opt-out policy within their Toolkit answers. It is recommended that PMR suppliers and aggregator companies also mention within their own public privacy notices they align with the opt-out policy. Pharmacy contractors that have queries about the opt-out in relation to data processed in their PMR system should direct these to their PMR supplier. NHS bodies such as NHS Digital will also confirm their ongoing alignment to opt-out policy, e.g. via Toolkit submissions.

Further resources

You can read more on this topic at: psnc.org.uk/optout. If you have queries on this PSNC Briefing or you require more information please contact [Daniel Ah-Thion, Community Pharmacy IT Lead](#) or [Layla Rahman, Regulations Officer](#).