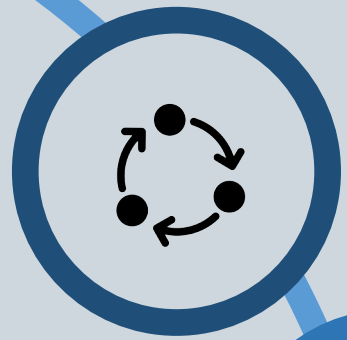# SSNAP & The National Data Opt-Out

SSNAP | **Sentinel Stroke National Audit Programme**

Contents

1. Overview of policy and process

2. How does opt-out affect SSNAP?

3. Consent

4. Example scenarios and FAQs

Overview of the national data opt-out

What is the NDOO?

Allows a patient to choose if they want their confidential data info to be used for research and planning

Who must comply?

All organisations providing or coordinating publicly funded health or social care in England

When is the deadline?

31st July 2022

Is clinical audit exempt?

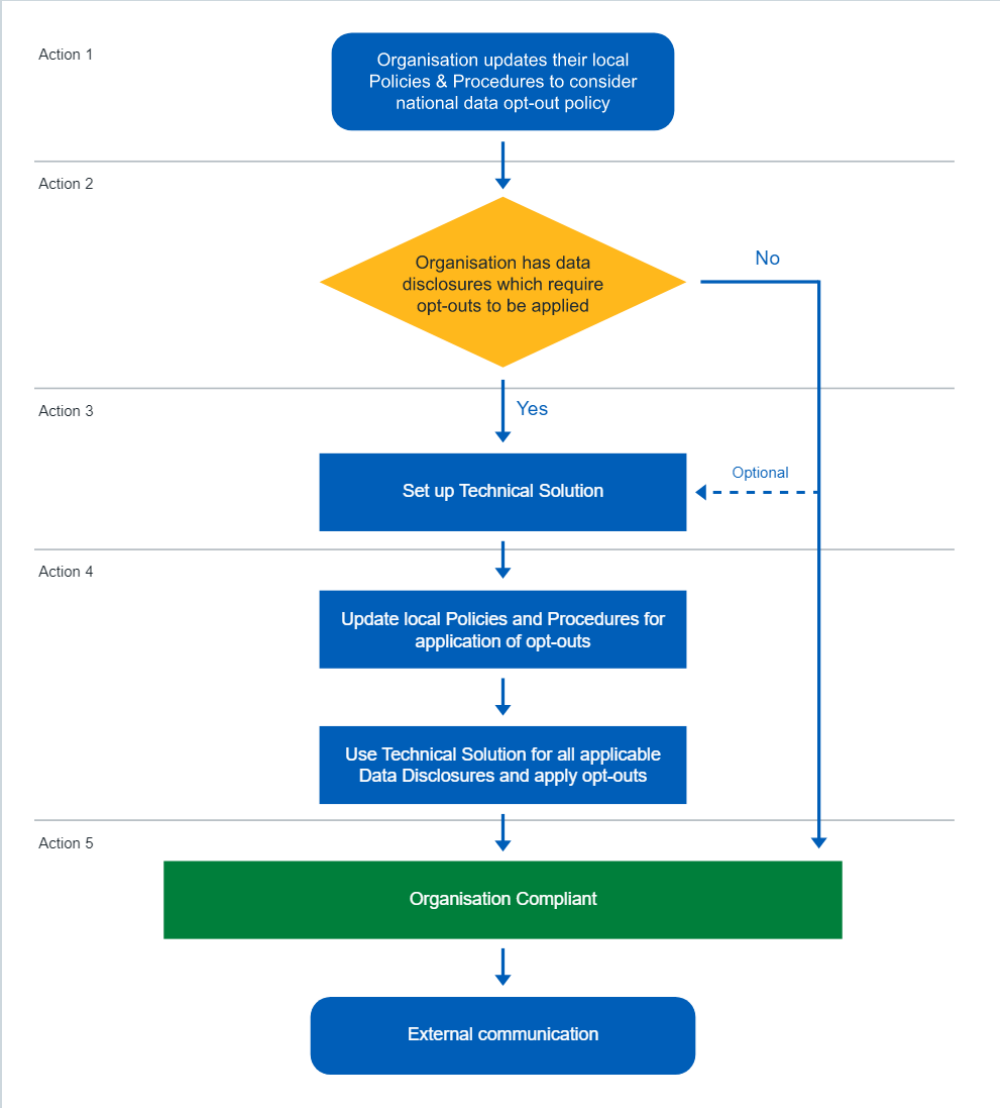*Clinical audit falls under the remit of "research and planning" and is not exempt at the moment*

https://digital.nhs.uk/services/national-data-opt-out/understanding-the-national-data-opt-out

Compliance at organisation/trust level

What does this mean for SSNAP?

Changes to data entry and flow

- Patients **MUST be checked against the opt-out list** before **any data** is entered by **any provider** along the stroke pathway

- SSNAP will not flow any data for patients who have opted out for linkage to ONS or HES
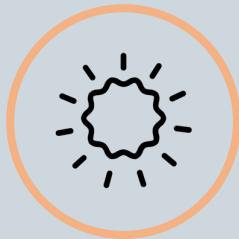
Updates to webtool and guidance

- Additional notifications on webtool when starting and locking a record

- Updated help notes and guidance

- Developing 'flag' to indicate when patient has provided informed consent
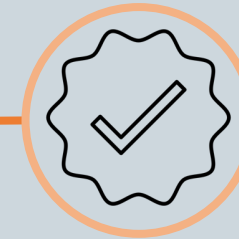
Consent and National Data Opt-Out

If a patient has agreed to a specific use of data, after being fully informed, then the national data opt-out does not apply. Even patients who have registered a national data opt-out can agree to take part in a specific research project or clinical trial, by giving their explicit consent.

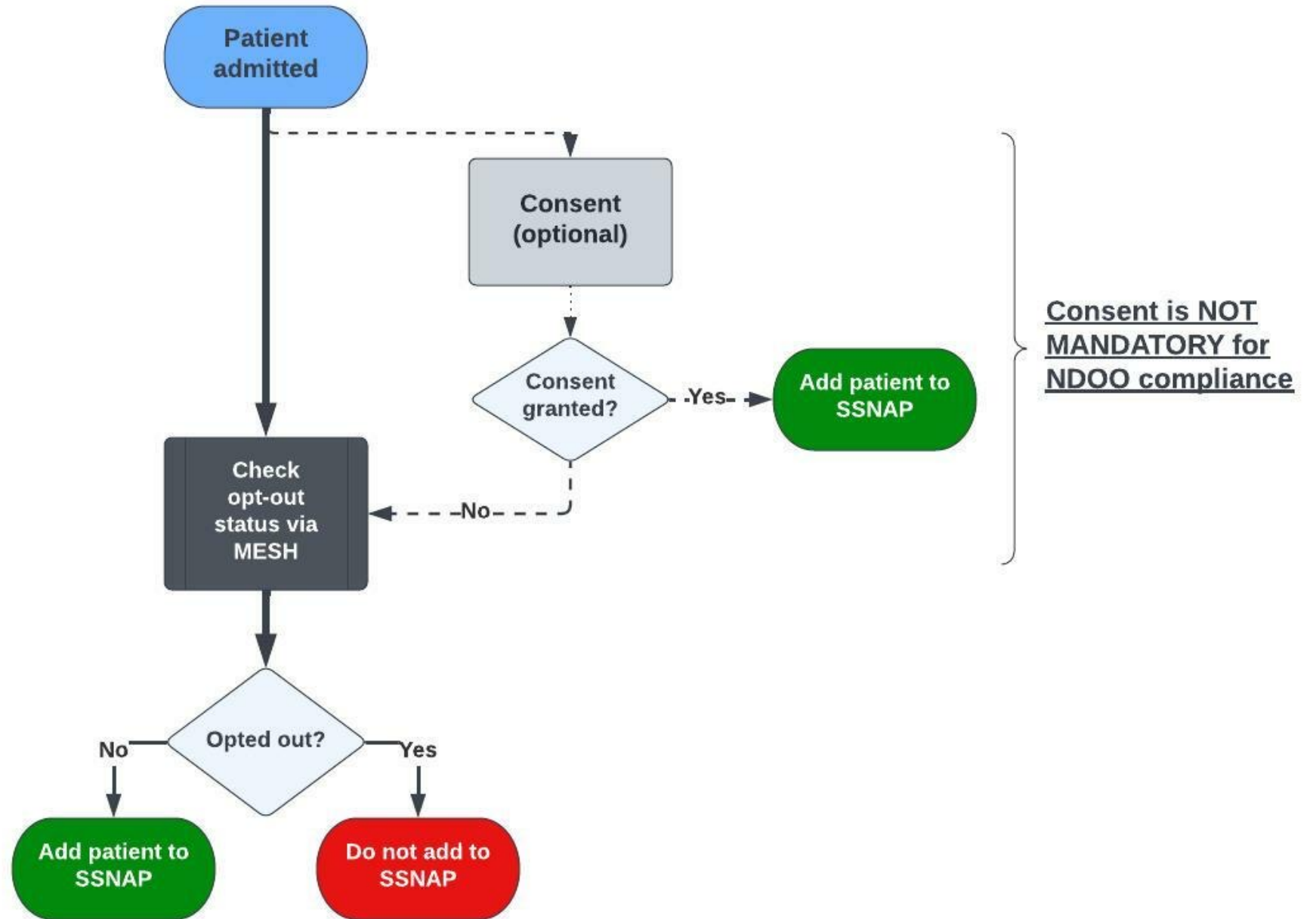SSNAP consent is NOT mandatory (S251 remains intact)

SSNAP consent pertains only to release of patient identifiable information. If a patient refuses consent, they can be added to SSNAP UNLESS they have also opted out
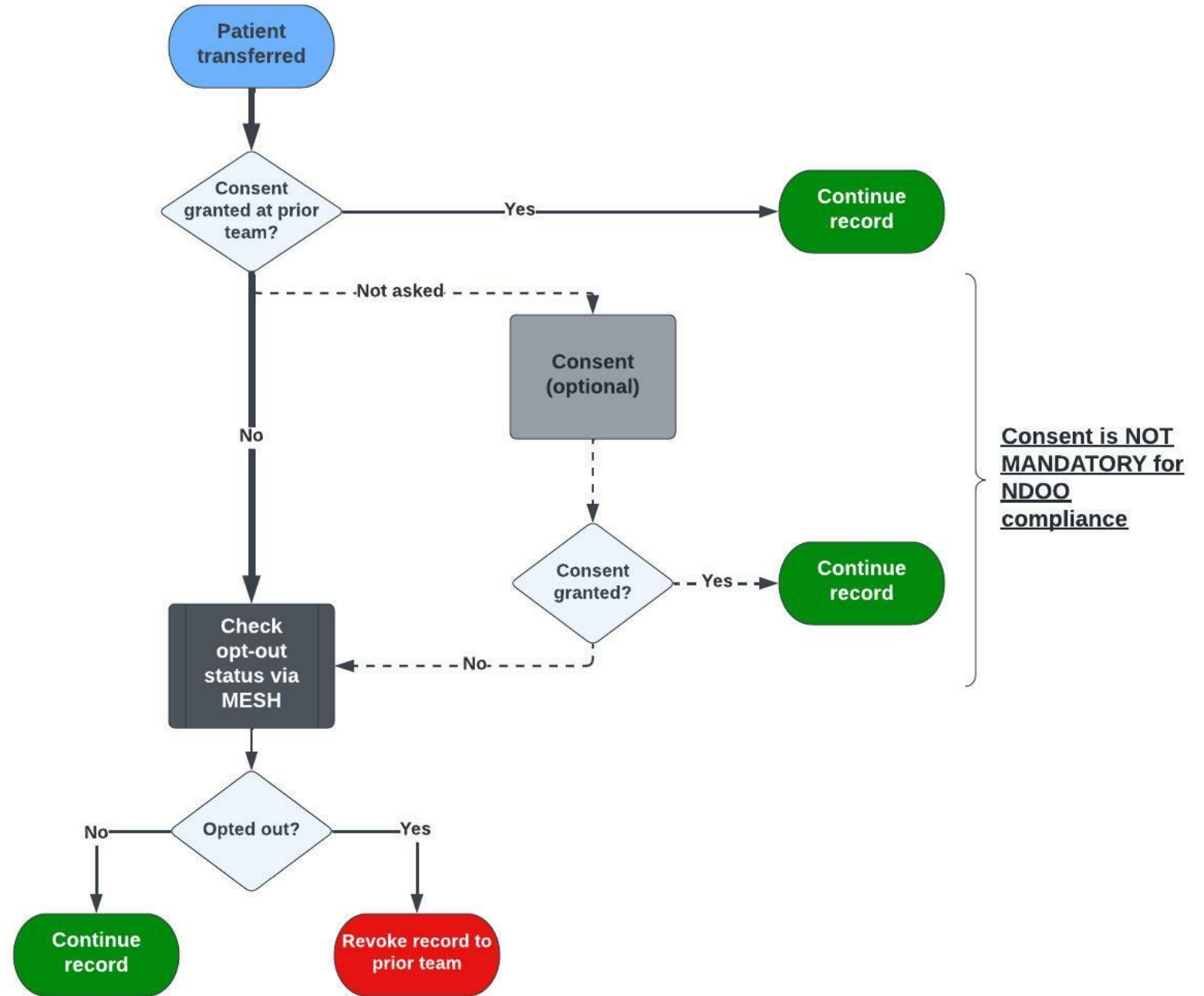
SSNAP consent is required only once, and overrides the national data opt-out

First admitting teams
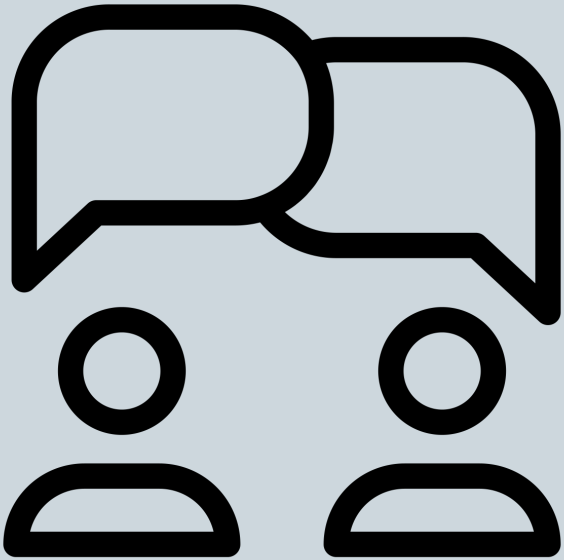
Non-admitting teams

What if….

My stroke unit has registered on SSNAP as two different units (HASU and SU) for the purposes of data entry, but we are one organization. Do we need to check the opt-out list when we transfer a SSNAP record from the HASU to SU?

Local practice is to enter all patients on SSNAP before checking against opt-out list. Before locking, we check against the list and then request to delete all of those who have opted out. Is this best practice?

If my team screens a patient against the opt-out list, and they aren't 'opted-out', can we include them even if they have refused consent?

We are a community rehab team and have just received a record from an acute team. When we checked against the NDOO list, this patient has opted-out. Do we delete the record altogether?
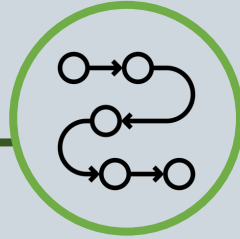
FAQs

- How will this affect expected cases (case ascertainment)?

- Will you be adjusting audit compliance scoring to account for the extra time that the NDOO process add to data entry?

- How does this affect non-admitting providers who don't start records?

- Are patients from Wales or NI subject to the NDOO?

Next steps

Confirm that your organisation is compliant and has access to MESH
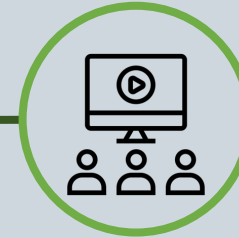
Ensure that SSNAP data entry practices are updated to account for opt-out requirements

Share learning and best practice with SSNAP and other teams

Continue to feed back about how your team is affected by NDOO

SSNAP to continue updating guidance, facilitating discussion and shared learning