

East Midlands Stroke Services – Six month review patient consent process

Patient consent must be obtained when they are invited to their six month review.

The patient is being asked to give permission for their confidential (identifiable) information to be shared with NHS Digital (the new name for the Health and Social Care Information Centre (HSCIC)) in order for it to be linked with Hospital Episode Statistics (HES) and Office for National Statistics (ONS) mortality data.

HES collects information on all medical conditions by way of the ICD-10 coding and ONS holds mortality data. Linking data with these two organisations means that SSNAP can:

- carry out case ascertainment checks using HES data and ensure that hospitals are entering all their stroke cases onto SSNAP (and not being selective)
- look at things like 30 mortality (case mix adjusted) and provide evidence that stroke mortality is decreasing with service improvement.

Enabling this link ensures that SSNAP will never see patient identifiable information but still be able to carry out both these things because the link between HES and ONS is made by the HSCIC and not by SSNAP directly.

Patients are asked for their consent at six month review because the majority of patients are considered well and recovered enough by this stage to make an informed decision about their confidential information being held and used. Prior to this, a lot of patients are often too unwell to give informed consent and any attempt to seek consent prior to this point would risk a complex and difficult process for both staff and patients and their families and carers. SSNAP has permission through Section 251 and the HSCIC to collect patient level data up to this point without consent in order for us to capture as much data as possible.

If a patient lacks the capacity to consent a carer or relative may do so on their behalf as long as they understand what they are consenting for.

Should a patient refuse their consent, there is an option within section 8 of the SSNAP web tool to record this. Selecting this option means that all patient identified information is wiped from the record.

A percentage of six month reviews are conducted by telephone. Where this is the case, information sheets and consent forms must be sent to the patient with their invitation to a review whether that is by post or email. Aphasia friendly versions of the information sheet and consent form are available on the SSNAP website.

Patients participating in a six month review by telephone may give verbal consent.