

SSNAP Core Community Dataset Help Notes

| Version | Date | Changes |
|---------|------------|---|
| 1.1.1 | 30.03.2015 | Supplementary Helpnotes for community providers following pilot versions |
| 2.1.1 | 07.12.2020 | Updated to KCL logo |
| 3.1.1 | 01.07.2021 | Questions 4.6.1, 4.6.2, 4.8, 4.8.1, 4.8.2, 4.8.3, 4.9, 4.9.1, 4.10, 4.10.1, 7.13, 7.13.1, 7.14, 8.8, 8.8.1, 8.9 (a-f) added |
| 4.0.0 | 01/10/2024 | Updated core help notes with additional questions |

On behalf of the Intercollegiate Stroke Working Party

SSNAP helpdesk

Mon-Fri 09:00-17:00

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Introduction

The Sentinel Stroke National Audit Programme (SSNAP) is the national stroke audit based in the School of Population Health and Environmental Sciences at King's College London. It measures the quality and organisation of stroke care in the NHS across England, Wales and Northern Ireland. The National Stroke Audit was first conducted at the Royal College of Physicians (RCP) in 1998 and 1999 as part of the Stroke Programme. The audit demonstrated that although there were widespread variations in standards across the country, much was being done at local level to change services. Improvements were demonstrated in each of the subsequent rounds of the audit. The Stroke Improvement National Audit Programme (SINAP) began in 2010; this continued to demonstrate improvements in acute care and identified areas for improvement. The audit programme remained at the RCP until in 2017 it was decided that in order to maximise the impact and longevity of SSNAP, particularly in relation to research potential it would be hosted by King's College London. The latest contract commenced on 01 April 2023.

The SSNAP core dataset is based on standards agreed by the representatives of the Colleges and professional associations of the disciplines involved in the management of stroke (current membership of the ICSWP is listed at <https://www.strokeaudit.org/About/Our-governance/Oversight.aspx>).

The overall aim of SSNAP is to provide timely information to clinicians, commissioners, patients and the public on how well stroke care is being delivered.

SSNAP

- Prospectively collects a minimum dataset for every stroke patient
- Follows every patient's care through the entire stroke pathway from acute care to the community and 6 month follow-up assessment
- Collects outcome measures
- Provides regular, routine, reliable data to
 - benchmark services nationally and regionally
 - monitor progress against a background of change
 - support clinicians in identifying where improvements are needed, lobbying for change and celebrating success
 - empower patients to ask searching questions.

Planning SSNAP

This is a multidisciplinary audit. Involving all the disciplines at the planning stage of the audit will help with subsequent stages of the audit, particularly when it comes to taking action on the results. In order to have consistent and reliable results, anyone completing the audit should have access to this help booklet. We would encourage participants to enter data prospectively rather than retrospectively gathering the data from patient records.

Audit web tool

The audit data is collected via a web tool to provide good quality data, and to speed up the analysis and reporting. There are in-built data validation checks.

Data collection time frame

Data collection will be continuous until at least 31 March 2026.

Clinical involvement and supervision

Each hospital should designate a clinical lead for SSNAP who will have overall responsibility for data quality and will sign off that the processes for collecting and entering the data are robust. A deputy (second lead) should also be designated (who may or may not be a clinician). The second lead should be the user most responsible for the day to day submission of SSNAP data. This user will also serve as the first point of contact for SSNAP.

Inclusion Criteria for the audit

- All stroke patients admitted to hospital or who suffer acute stroke whilst in hospital
- Optional: TIA patients (inpatients and outpatients) and patients who elicit a response from the stroke team (stroke mimics)

Exclusion Criteria

- Subarachnoid haemorrhage (I60)
- Subdural and extradural haematoma (I62)
- Patient had the stroke episode more than 28 days before presenting at hospital
- Optional (i.e. you can exclude but do not have to exclude): A patient who had a stroke in another country and were initially admitted to a hospital abroad

From 1 October 2024, the datasets for inpatient and community teams separated to allow for each dataset to be more closely tailored to the differing requirements of the inpatient and community settings and so two datasets were created: the Core Inpatient Dataset and the Core Community Dataset. The SSNAP Core Dataset previously included section 8 (Six month follow-up assessment), however this is now available in a standalone document. These help notes refer to the **Core Community Dataset**.

| Question no | Question | Answer options | Guidance / definitions |
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| When an ESD or CRT team start a record , they will have to answer sections 2 and 3 as usual but are also required to input some patient information normally done by the acute team in section 1. | | | |
| 1.1 | Hospital number | Free text (30 character limit) | The permanent number for identifying the patient across all departments within your hospital. If you are starting the record in the community, please enter the unique identifying number you have for identifying the patient across all departments at your service and continue to enter the record. If you do not have this please enter 0. |
| 1.2 | NHS number | Either 10 character NHS Number OR "No NHS Number" | If the patient does not have an NHS number (if they are an overseas visitor, prisoner, traveller or in the armed forces) please select the option for No NHS Number. Otherwise, please make every effort to find this number. This is a unique national identifier for the patient. The NHS number is used for data linkage, e.g. to link the SSNAP record with Office for National Statistics to retrieve mortality data. |
| 1.3 | Surname | Free text (30 character limit) | If the patient's NHS number is not known, this must be the name used for GP registration. The patient's surname or other name used as a surname. |
| 1.4 | Forename | Free text (30 character limit) | If the patient's NHS number is not known, this must be the name used for GP registration. The patient's first personal name and, optionally, if separated by spaces, subsequent personal names. |
| 1.5 | Date of birth | dd/mm/yyyy | Please ensure: i) Correct year for date of birth and use the format dd/mm/yyyy ii) The patient is over 16 years of age. |
| 1.6 | Gender | Male; Female; Indeterminate | Indeterminate should be chosen if the patient is unable to be classified as either male or female. It should not be used in place of 'Not known'. |
| 1.7 | Postcode of usual address | First box: 2-4 alphanumerics Second box: 3 alphanumerics. The full postcode of the patient's normal place of residence. | Please enter the full postcode of the patient's normal place of residence. The postcode is used for data linkage purposes, particularly where the NHS number is not known or potentially incorrect. For patients from overseas or has no fixed abode please enter the following into the postcode field: ZZ11 1ZZ. |

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| 1.8 | Ethnicity | <p>Either code A-Z OR “Not Known”</p> <p>These are the categories as specified by NHS and HSCIC:</p> <p>England and Wales</p> <p><u>White</u> A British B Irish C Any other White background</p> <p><u>Mixed</u> D White and Black Caribbean E White and Black African F White and Asian G Any other mixed background</p> <p><u>Asian or Asian British</u> H Indian J Pakistani K Bangladeshi L Any other Asian background</p> <p><u>Black or Black British</u> M Caribbean N African P Any other Black background</p> <p><u>Other Ethnic Groups</u> R Chinese S Any other ethnic group Z Not stated</p> | <p>The ethnicity of a person, as specified by the person.</p> <p>‘Not stated’ The person had been asked and had declined either because of refusal or genuine inability to choose.</p> <p>‘Not known’ should be used where the patient had not been asked or the patient was not in a condition to be asked, e.g. unconscious.</p> |
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| | | 99 Not known | |
| 1.9 | What was the diagnosis? | Stroke; TIA; Other; Non-acute stroke | |
| 1.10 | Date/time of onset/awareness of symptoms | dd/mm/yyyy hh:mm | <p>If best estimate or stroke during sleep (for 1.10.1), the date should be the date last known to be well. The time can be the time last known to be well or left blank if a best estimate cannot be made (and not known entered for 1.10.2).</p> <p>However, for patients who had a stroke during sleep, enter the date/ time the patient first woke up (cannot be not known for patient, and should not be time last well, as for patient strokes, standards are measured from time of onset).</p> |
| 1.10.1 | The date given is: | Precise; Best estimate; Stroke during sleep | For patients who had a stroke during sleep, enter the date/ time the patient first woke up. |
| 1.10.2 | The time given is: | Precise; Best estimate; Not known | <p><i>Cannot be "Precise" unless 1.10.1 = "Precise"</i></p> <p>For patients who had a stroke during sleep, enter the date/ time the patient first woke up.</p> |
| 1.11 | Date/time patient arrived at this team | dd/mm/yyyy hh:mm | The date and time the patient began care under this team. |

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| 1.12 | What is the reason for starting this record? | Not seen by an acute team; Seen by an acute team but no SSNAP record – not admitted to hospital; Seen by an acute team but no SSNAP record – stroke outside UK; Seen by an acute team but no SSNAP record – other reason; Seen by acute team in different UK region and so record cannot be transferred; Re-referral within 6 months of stroke onset | <p><i>Please select the reason why this record is being started as a non-acute record.</i></p> <p><i>“Not seen by an acute team”</i> refers to a patient who has not been seen by an acute stroke team. If they have been receiving acute care for another condition and now are referred to you for stroke rehabilitation you can select this option.</p> <p>ESD or CRT teams are able to start SSNAP records for patients who: do not have a previous acute record, were not treated by an acute team; the record cannot be transferred; or the patient was re-referred within 6 months of stroke. This function must only be used after the community team have ensured that the patient does not already have a record.</p> <p>If a record is eventually transferred to the community team, you should contact the SSNAP helpdesk (ssnap@kcl.ac.uk) to request that the record be deleted from the non-acute stroke section. The community team will then have to re-enter their data on the record that was transferred from the acute team.</p> |
| 1.12.1 | If other, please specify: | Free text (30 character limit) | |
| 1.12.2 | If re-referred, what is the patient’s previous SSNAP ID? | 7-character SSNAP ID | |
| | | | |
| 2.1 | Date/time patient received first face-to-face assessment from this service | dd/mm/yyyy hh:mm | <p>This is the date of the first face to face documented assessment, which identifies stroke related needs/patient goals and which guides/ contributes to formulation of a treatment plan. This does not include clinical or administrative phone calls to ‘check how patient is’, or to book a first visit as this does not constitute a comprehensive needs-based assessment.</p> <p>Video assessment must only be used in exceptional cases, where this is the only possible option for the patient and it is categorically known that no environmental, or physical issues exist. In the event of video assessment being completed, the clinician must be satisfied that the definition of a comprehensive assessment has been completed for this to be used as first assessment.</p> |
| 2.2 | Modified Rankin Scale score at first assessment by this service | 0-5 | <p>0: No symptoms at all</p> <p>1: No significant disability despite symptoms; able to carry out all usual duties and activities</p> |

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| | | | <p>2: Slight disability; unable to carry out all previous activities, but able to look after own affairs without assistance</p> <p>3: Moderate disability; requiring some help, but able to walk without assistance</p> <p>4: Moderately severe disability; unable to walk without assistance and unable to attend to own bodily needs without assistance</p> <p>5: Severe disability; bedridden, incontinent and requiring constant nursing care and attention</p> <p>All modified Rankin Scale scores should be entered according to overall level of disability for the patient.</p> |
| 2.3 | EQ5D-5L score at first assessment by this service: | | <p>https://euroqol.org/publications/user-guides/</p> <p>There should be only ONE response for each dimension</p> <p>Missing values are 'unknown'</p> <p>Ambiguous values (e.g. two boxes are ticked for a single dimension) should be treated as missing values</p> <p>Proxy versions are available for use when patients are incapable of reporting on their health-related quality of life: https://www.strokeaudit.org/Clinical/6-Month-Assessment/Introduction.aspx .</p> |
| a | Mobility | Value range: 1-5 OR unknown | <p>1: I have no problems in walking about</p> <p>2: I have slight problems in walking about</p> <p>3: I have moderate problems in walking about</p> <p>4: I have severe problems in walking about</p> <p>5: I am unable to walk about</p> |
| b | Self-Care | Value range: 1-5 OR unknown | <p>1: I have no problems washing or dressing myself</p> <p>2: I have slight problems washing or dressing myself</p> <p>3: I have moderate problems washing or dressing myself</p> <p>4: I have severe problems washing or dressing myself</p> <p>5: I am unable to wash or dress myself</p> |
| c | Usual activities (work, study, etc.) | Value range: 1-5 OR unknown | <p>1: I have no problems doing my usual activities</p> <p>2: I have slight problems doing my usual activities</p> <p>3: I have moderate problems doing my usual activities</p> <p>4: I have severe problems doing my usual activities</p> <p>5: I am unable to do my usual activities</p> |
| d | Pain/discomfort | Value range: 1-5 OR unknown | <p>1: I have no pain or discomfort</p> <p>2: I have slight pain or discomfort</p> <p>3: I have moderate pain or discomfort</p> |

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| | | | 4: I have severe pain or discomfort 5: I have extreme pain or discomfort |
| e | Anxiety/Depression | Value range: 1-5 OR unknown | 1: I am not anxious or depressed 2: I am slightly anxious or depressed 3: I am moderately anxious or depressed 4: I am severely anxious or depressed 5: I am extremely anxious or depressed |
| f | How is your health today? | Value range: 1-100 OR unknown | 100 means the best health you can imagine 0 means the worst health you can imagine If there is a discrepancy between where the respondent has placed the X and the number he/she has written in the box, administrators should use the number in the box |
| 2.4 | Barthel score at first assessment by this service | 0-20 | Barthel should be measured on 20 point scale. The 10-item version with total score ranging from 0 to 20 (Collin and Wade, 1988) should be used. |
| 2.5 | Was the patient considered to require this care or treatment at any point during this stay? | Yes; No for each of: Motor function, Psychological function, Communication/swallowing, Vocational rehabilitation, Healthy living and lifestyle management, Social care needs and care delivery, Other | This collects whether a patient was considered to have any identified needs under each of the categories of therapy or care at any point during their total stay under the care of your team. For each therapy/care category, if a patient is assessed and does not need any further therapy/care, then the patient was not considered to require this therapy/care at any point in this admission. Answer 'No'. If a patient is assessed and requires further therapy/care (even if they do not receive further therapy/care), answer 'Yes'. If the patient receives no further therapy/care, record 0 days. |
| NOTE: For questions 2.6-2.11 (a-f) therapy will be collected in 4 week blocks for the duration of therapy received (up to a total of 6 blocks) For further details on how to answer the questions in section 2 please see the appendix. | | | |
| 2.6(a-f) | During this period was the patient: | Discharged from this service; Died | |
| 2.6.1(a-f) | Date/time of discharge from this service | dd/mm/yyyy hh:mm | <i>Available if 2.6 = Discharged from this service</i> |
| 2.6.2(a-f) | Date of death | dd/mm/yyyy | <i>Available if 2.6 = Died</i> |

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| 2.7(a-f) | On how many days did the patient receive this care/treatment during this 4 week period? | Integer (for each of Motor function, Psychological function, Communication/swallowing, Vocational rehabilitation, Healthy living and lifestyle management, Social care needs and care delivery, Other) | <p><i>Available if 2.5 is Yes.</i> <i>Cannot be more than the number of days they were in this service.</i></p> <p>This is the total number of days on which the patient received each type of therapy/care from the day their care became the responsibility of this team to their discharge date from that team. This is not the number of sessions, but calendar days. It is collected separately for each team and therapy type.</p> |
| 2.8 (a-f) | How many minutes of this care/treatment in total did the patient receive during this 4 week period? | Integer (for each of Motor function, Psychological function, Communication/swallowing, Vocational rehabilitation, Healthy living and lifestyle management, Social care needs and care delivery, Other) | <p>In this case "stay" refers to the time the patient spent with the team answering the question. You should enter the total amount of therapy the patient received while in your care. The unit of measurement is minutes. The number of minutes must be a whole number. There is no 'eligibility' period or 'clock stop' for how long someone was considered to have needs during their stay. Therefore minutes show what was received by the PWS across each 4 week period across the whole stay with the team.</p> <p><u>All</u> minutes for any initial assessment should be included under <u>Other</u>. Any further domain-specific assessments should go under their relevant therapy/care type, i.e. a cognition assessment should go under psychological function.</p> |
| 2.9 (a-f) | How many of these minutes were delivered by a rehabilitation assistant? | Integer (for each of Motor function, Psychological function, Communication/swallowing, Vocational rehabilitation, Healthy living and lifestyle management, Social care needs and care delivery, Other) | <p>This is the number of the total minutes recorded in 2.8 that were provided specifically by a non-registered rehabilitation or therapy assistant or support worker working independently.</p> <p>Where a session has required two members of staff (one qualified and one assistant), assume the session has been led by the qualified therapist, record all minutes as qualified and do not record any minutes as assistant provided. (i.e. do not split minutes across staff groups).</p> <p>If a rehabilitation assistant works on two different categories of rehabilitation during a 60 minutes session, record the number of minutes for each category (e.g. 30 minutes for motor function, 30 minutes for communication). Please refer to patient notes to accurately determine the split.</p> <p>Therapy provided by student therapists should be recorded as assistant delivered (unless jointly delivered with qualified member of staff- see above)</p> |

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| 2.10(a-f) | How many of these minutes were delivered by video/telerehabilitation? | Integer (for each of Motor function, Psychological function, Communication/swallowing, Vocational rehabilitation, Healthy living and lifestyle management, Social care needs and care delivery, Other) | <p>This is the number of the total therapy minutes recorded in 2.8 that were provided specifically via video/telerehabilitation.</p> <p>For the purposes of SSNAP this includes: Includes synchronous practice - i.e. with a therapist present during the session remotely to adapt and give feedback in real time. Includes programmes or devices with real time two way feedback, where activity levels or duration of treatment is reliably captured by the device/platform.</p> <p>Please do not include asynchronous practice where the therapist gives and receives feedback offline. Does not include texts or email reminders to complete exercise or to check in.</p> <p>This is contact with the patient that is therapeutic and focused on their rehabilitation goals. Please do not include activities relating to administration (e.g. booking appointments).</p> <p>This does not include informal phone calls/texts where no objective assessment/measurement or feedback takes place.</p> |
| 2.11(a-f) | How many of these minutes were delivered in a group session? | Integer (for each of Motor function, Psychological function, Communication/swallowing, Vocational rehabilitation, Healthy living and lifestyle management, Social care needs and care delivery, Other) | <p>This is the number of the total therapy minutes recorded in 2.8 that were provided specifically in a group session.</p> <p>This is any session where there is more than one patient working towards a similar task/group aim. This only includes groups where patients are working specifically towards a targeted therapy goal associated with defined categories as in appendix. Groups outside of these categories (such as those aimed at reducing occupational deprivation) should not be included.</p> |
| 2.12 | Date rehabilitation goals agreed: | dd/mm/yyyy OR "No goals agreed" | If rehabilitation goals were set without the direct involvement of the patient you can still enter the date they were agreed into 2.12, though is best practice to involve the patient and his/her family if possible. |
| 2.12.1 | If no goals agreed, what was the reason? | Patient refused; Organisational reasons; Patient medically unwell for entire admission; Patient has no impairments; Not known | <p><i>Available if 2.12 = "No goals agreed"</i></p> <p>Organisational reasons mean any issues with the service which meant that the no goals were set e.g. unavailability of staff.</p> |

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| | | | Patient medically unwell should be answered if the patient was unconscious or deemed to be unable to agree rehabilitation goals |
| 2.13 | Date patient screened for mood using a validated tool | dd/mm/yyyy OR "Not screened" | A validated tool for mood is one which has been approved for use within the trust/health board such as HADS, BASDEC, PHQ9 or for a person with aphasia, a more accessible one such as SAD-Q, BOA or DISCS. |
| 2.13.1 | If not screened, what was the reason? | Not known; Organisational Reasons; Patient Refused; Patient medically unwell for entire admission | <p><i>Available if 2.13 = "Not screened"</i></p> <p>Patients should have a reassessment in the community.</p> <p>Patient medically unwell should be answered if the patient was deemed to be unable to tolerate mood screening by clinical staff.</p> <p>Organisational reasons mean any issues with the service which meant that the screening was not performed by discharge e.g. unavailability of staff.</p> <p>There is no "Patient had no relevant deficit" answer option as this is a screening, and the screening is required to determine if the patient had a deficit.</p> |
| 2.14 | Date patient screened for cognition using a validated tool | dd/mm/yyyy OR "Not screened" | <p>Cognition measure is one which has been approved for use within the trust/ health board such as MOCA/OCS.</p> <p>A standardised measure is one with evidenced validity and efficacy for use in stroke. Locally developed screening tools are not applicable. Screening via assessment in function for those deemed unable to participate in a screen is not applicable.</p> |
| 2.14.1 | If not screened, what was the reason? | Not known; Organisational Reasons; Patient Refused; Patient medically unwell for entire admission; Not clinically required | <p><i>Available if 2.14 = "Not screened"</i></p> <p>Patient medically unwell should be answered if the patient was deemed to be unable to tolerate mood screening by clinical staff.</p> <p>Organisational reasons mean any issues with the service which meant that the screening was not performed by discharge e.g. unavailability of staff.</p> <p>There is no "Patient had no relevant deficit" answer option as this is a screening, and the screening is required to determine if the patient had a deficit.</p> |

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| | | | Not clinically required should only be used if screening/assessment has already been completed and due consideration has been given regarding the value of repeating screens as per national clinical guidelines. |
| 2.15 | Date patient screened for visual impairment using a standardised tool | dd/mm/yyyy OR “Not screened” | A standardised tool is one that is completed the same way by all users, covering all required domains of impairment and activity limitation. A published screen such as VISA, or a locally developed tool, agreed by your orthoptist dept for use with all patients, by staff with appropriate training are applicable |
| 2.15.1 | If not screened, what was the reason? | Not known; Organisational Reasons; Patient Refused; Patient medically unwell for entire admission SPT = Screened by previous team | <p><i>Available if 2.15 = “Not screened”</i></p> <p>Patient medically unwell should be answered if the patient was unconscious or deemed to be unable to tolerate vision screening by clinical staff.</p> <p>Organisational reasons mean any issues with the service which meant that the screening was not performed by discharge e.g. unavailability of staff.</p> <p>There is no “Patient had no relevant deficit” answer option as this is a screening, and the screening is required to determine if the patient had a deficit.</p> <p>Screened by previous team should be used when the patient has been previously screened for visual impairment by a previous team.</p> |
| 3.1 | The patient: | Died; Was discharged from this team; Was discharged to somewhere else; Was transferred to an inpatient care team; Was transferred to another ESD/community team; Was transferred to an inpatient care team, not participating on SSNAP; Was transferred to another ESD/community team, not participating on SSNAP; Completed their SSNAP record at 6 months but continues to receive care/treatment from this team | <p>The transfer in question 3.1 acts as a technical answer which facilitates the ability to transfer the patient record to the next team.</p> <p>“From this team” should be selected when the patient has stopped receiving care from your service and has left the stroke pathway (so is not being transferred on to another team for further stroke care).</p> <p>“Somewhere else” should be used when no other option applies.</p> <p>‘Inpatient care team’ is any team (team as defined within SSNAP) which treats patients in an inpatient setting (e.g. an acute hospital, a community hospital, a bed based rehabilitation setting, an intermediate care setting)</p> <p>‘ESD/ community team’ is for stroke/neurology specific or non-specialist Early Supported Discharge teams and community rehabilitation teams (i.e. treating</p> |

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| | | | <p>patients outside of an inpatient setting). Please select ESD/Community stroke team for integrated community stroke services (ICSS).</p> <p>'Was transferred to an inpatient/ESD/community team' should only be selected if the inpatient/ESD/community team the patient was transferred to is set up on the SSNAP webtool to receive SSNAP record transfers.</p> <p>If the team is not set up on SSNAP then 'Was transferred to an inpatient care team, not participating in SSNAP' or 'Was transferred to an ESD/community team, not participating in SSNAP' should be selected.</p> <p>'Completed their SSNAP record at 6 months but continues to receive care/treatment from this team' should be chosen if the patient is still under the care of this team at 6 months but must be discharged on SSNAP to complete the record.</p> |
| 3.1.1 | If patient died, what was the date of death? | dd/mm/yyyy | <i>Available if 3.1 = "Died"</i> |
| 3.1.2 | What hospital/team was the patient transferred to? | | <i>Available if 3.1 = "Was transferred to another inpatient care team" or "Was transferred to an ESD / community team"</i> |
| 3.1.3 | On discharge, where is the patient living? | Home; Care home; Other | <i>Not available if 3.1 = "Died", "Was transferred to an inpatient care team" or "Was transferred to an inpatient care team, not participating on SSNAP"</i> |
| 3.2 | Date/time of discharge/transfer from team | dd/mm/yyyy hh:mm | <i>Not available if 3.1 = "Died"</i> |
| 3.3 | Modified Rankin Scale score at discharge/transfer | 0-6 | <p>Defaults to 6 if 3.1 is died during stay with this service</p> <p>0: No symptoms at all</p> <p>1: No significant disability despite symptoms; able to carry out all usual duties and activities</p> <p>2: Slight disability; unable to carry out all previous activities, but able to look after own affairs without assistance</p> <p>3: Moderate disability; requiring some help, but able to walk without assistance</p> <p>4: Moderately severe disability; unable to walk without assistance and unable to attend to own bodily needs without assistance</p> <p>5: Severe disability; bedridden, incontinent and requiring constant nursing care and attention</p> <p>6: Dead</p> <p>All modified Rankin Scale scores should be entered according to overall level of disability for the patient.</p> |

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| 3.4 | EQ5D-5L score on discharge from this service: | | https://euroqol.org/publications/user-guides/ There should be only ONE response for each dimension Missing values are preferably coded as '9' Ambiguous values (e.g. two boxes are ticked for a single dimension) should be treated as missing values Proxy versions are available for use when patients are incapable of reporting on their health-related quality of life: https://www.strokeaudit.org/Clinical/6-Month-Assessment/Introduction.aspx . |
| a | Mobility | Value range: 1-5 OR unknown | 1: I have no problems in walking about 2: I have slight problems in walking about 3: I have moderate problems in walking about 4: I have severe problems in walking about 5: I am unable to walk about |
| b | Self-Care | Value range: 1-5 OR unknown | 1: I have no problems washing or dressing myself 2: I have slight problems washing or dressing myself 3: I have moderate problems washing or dressing myself 4: I have severe problems washing or dressing myself 5: I am unable to wash or dress myself |
| c | Usual activities (work, study, etc.) | Value range: 1-5 OR unknown | 1: I have no problems doing my usual activities 2: I have slight problems doing my usual activities 3: I have moderate problems doing my usual activities 4: I have severe problems doing my usual activities 5: I am unable to do my usual activities |
| d | Pain/discomfort | Value range: 1-5 OR unknown | 1: I have no pain or discomfort 2: I have slight pain or discomfort 3: I have moderate pain or discomfort 4: I have severe pain or discomfort 5: I have extreme pain or discomfort |
| e | Anxiety/Depression | Value range: 1-5 OR unknown | 1: I am not anxious or depressed 2: I am slightly anxious or depressed 3: I am moderately anxious or depressed 4: I am severely anxious or depressed 5: I am extremely anxious or depressed |
| f | How is your health today? | Value range: 1-100 OR unknown | 100 means the best health you can imagine 0 means the worst health you can imagine |

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| | | | If there is a discrepancy between where the respondent has placed the X and the number he/she has written in the box, administrators should use the number in the box |
| 3.5 | What was the patient's Barthel score on discharge from this service? | 0-20 | Barthel should be measured on 20 point scale. The 10-item version with total score ranging from 0 to 20 (Collin and Wade, 1988) should be used. |
| 3.6 | If living in a care home, was the patient: | Previously a resident; Not previously a resident | <i>Available if 3.1.3 = "Care home"</i> |
| 3.6.1 | If not previously a resident, is the new arrangement: | Temporary; Permanent | <i>Available if 3.6 = "Not previously a resident"</i> |
| 3.7 | If living at home, is the patient: | Living alone; Not living alone; Not known | <i>Available if 3.1.3 = "Home"</i> |
| 3.8 | Did the patient require help with personal activities of daily living (ADL)? | Yes; No | Unavailable if 3.1.3 = "Care home" Answer this for requirements at the point of discharge (not during patient stay) Personal activities of daily living (PADL) refer to a range of basic activities such as washing, dressing, bathing, going to the toilet, eating and drinking. Help means physical assistance. This is not applicable if the person is able to be independent in PADL with the use of aids and adaptations. |
| 3.8.1 | What support did they receive? | Paid carers; Informal carers; Paid and informal carers; Paid care services unavailable; Patient refused | <i>Unavailable if 3.8 = No</i> Paid carers can include self funded or via local authority/social services or reablement. Informal care may be provided by family, friends or voluntary organisations |
| 3.8.2 | At point of discharge, how many visits per day did the patient require? | One; Two; Three; Four; 24 hour care; Not known | <i>Unavailable if 3.8 = No</i> <i>Unavailable if 3.8.1 = "informal carers" OR "Paid care services unavailable" OR "Patient Refused"</i> Please include all formal care visits provided by social services, via external reablement services, self-funded or care visits provided by community rehabilitation teams. |
| 3.8.3 | How many carers? | One carer; Two carers; Not known | <i>Unavailable if 3.8 = No</i> <i>Unavailable if 3.8.1 = "informal carers" OR "Paid care services unavailable" OR "Patient Refused"</i> |

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| | | | If number of carers varies per visit, please indicate the higher value. |
| 3.9 | What was the patient's employment status on discharge from this service? | Working full-time; Working part-time; Retired; Studying or training; Unemployed; Other | <p><i>Unavailable if 3.1 = "Died"</i></p> <p>Full-time is the equivalent of 35 hours a week Full-time and part-time work includes paid, unpaid and voluntary work</p> <p>This question aims to identify if the stroke survivor is back at work and in meaningful employment to the extent that they were before their stroke. If the survivor is employed but not yet ready to return to work, please record this as 'Other'.</p> |
| 3.10 | It is not a requirement that the patient provides explicit consent for their patient identifiable details to be included in SSNAP at this stage. However, where efforts have been made to seek consent from the patient, please state if the patient gave consent for their identifiable information to be included in SSNAP? | Yes, patient gave consent; No, patient refused consent; Patient not asked | <p><i>Unavailable if 3.9 or 7.14 in inpatient dataset is "No, patient refused consent"</i></p> <p>SSNAP currently has approval under Section 251 to collect patient level data on the first six months of patient care, and so it is not a requirement that the patient is asked for consent at this stage. If the patient was not asked for consent, please record "patient not asked".</p> <p>If the patient refuses consent, all patient identifiable information will be wiped from the webtool</p> <p>If patient medically unwell and cannot be asked, indicate 'patient not asked'</p> |
| 3.11 | Please state if the patient gave consent for their information to be included in research using SSNAP data? | Yes, patient gave consent; No, patient refused consent; Patient not asked | <p>Please record if the patient has given or refused consent specifically for the use of their data in research.</p> <p>It is not a requirement to ask this question however if the patient has been asked or has given or refused consent for research without being asked then this should be recorded here. If the patient refuses consent, none of their data will be used for research.</p> <p>This question refers specifically to the use of data in research and not for audit purposes. If the patient has given or refused consent for the use of their patient identifiable data in SSNAP, this should be recorded in the appropriate question in the dataset.</p> <p>If the patient was not asked for consent, please record "patient not asked". If patient medically unwell and cannot be asked, indicate "patient not asked".</p> |

Appendix

Questions 2.4-2.11

Guidance for recording days and minutes of therapy and care:

You are asked to record days and minutes of therapy or care delivered by any staff member that addressed the needs or functions identified by each category heading.

Days are the total number of days on which the patient received each type of therapy from the day their care became the responsibility of this team to their discharge date from that team. This is not the number of sessions, but calendar days.

Please attribute minutes to the category that best describes the main focus of that therapeutic session, or part of a session. Please do not count the same minutes under more than one category, and do not double-count within the same category i.e., if 45 minutes of treatment towards one of these functions is delivered by two therapists of the same or different disciplines, record that only as 45 minutes of treatment. Where there is more than one focus to a single session then minutes would be apportioned for each part and added up under each category appropriately.

For example:

- If a therapist works on two different categories of rehabilitation during a 60 minute session, record the number of minutes for each category (e.g. 30 minutes for motor function, 30 minutes for communication). Please refer to patient notes to accurately determine the split per each.
- If two therapists (of different disciplines or the same discipline) treat a patient at the same time, focused on the same category of rehabilitation, record the number of minutes of therapy the patient received e.g. 2 therapists providing rehabilitation for motor function to a patient for 45 minutes counts as 45 minutes of motor function therapy (not 90 minutes), therefore recording how many minutes the patient received rather than recording the time therapy staff spent providing the session.
- Where a 60 minute session has required two members of staff and one is qualified and one is an assistant and they are both providing the same category of rehabilitation, assume the session has been led by the qualified therapist, record 60 minutes of therapy received by the patient as qualified and do not record any minutes as assistant provided. (i.e., do not split minutes across staff groups), therefore recording how many minutes the patient received rather than recording the time therapy staff spent providing the session.

The recorded treatment or care minutes can be provided by any clinician, assistant, support worker or student under supervision, with stroke specific knowledge and skills pertinent to the rehabilitation being undertaken, the underlying impairment and treatment modality. The input provided should form part of delivery of a documented evidence-based therapy treatment plan; be informed by assessment and patient specific goals; be progressive in nature, with capability for concurrent (re-)assessment and grading where appropriate.

Team members employed by different organisations (such as charities or local authority colleagues) who work within the service; have regular access and discussions with clinicians (may attend MDTs); are aware of treatment plans, goals.

Services/team members external to the registered team on SSNAP who work within/alongside the stroke team with honorary contracts, SLA's, MOU's.

AND where robust and reliable data can be collected regarding patient contact

AND where staff providing this input are regularly updated regarding stroke knowledge and skills.

Therapy includes:

- assessment and goal-directed therapy (i.e., towards goals that have been set and agreed by the team)
- either individual or group therapy
- training patients and carers around issues related to a specific patient (i.e. not general training)
- Setting up, supporting and advancing self-directed exercise programmes
- Semi supervised practice (such as in open gyms with oversight and interaction with practitioner)
- Independent practice
- App-based therapy (face-to-face or synchronous)

Care includes:

- Assessment (of patients and carers)
- Advice and support (with patients and carers)
- Assessment, trials and evaluation of home adaptation
- Training of care staff

In this definition therapy does not include

- time for the therapist to travel to and from the patient
- documentation
- multidisciplinary team meetings
- case conferences/case reviews (where PWS is not present)
- development of resources
- App-based therapy (asynchronous)

To help decide which therapeutic interventions should come under which category, examples have been provided under the category headings below. These categories reflect a patient focused approach and are designed to help record the dose and frequency of therapy and care delivery in a more meaningful way. They have been informed by recommendations in the National Clinical Guideline for Stroke 2023.

It is not the intention to capture all the activity of members of your team. This approach is designed to focus on functions for which there is evidence that increased dose and frequency of therapy is more beneficial for patients. These functions reflect the types of rehabilitation and care that services are required to deliver as components of the Integrated Community Stroke Service model (in England).

Only record time spent in treatment or rehabilitation under the supervision of a healthcare professional, either one-to-one or in a group session, and either face-to-face or by video telerehabilitation (synchronous). Do not include independent practice by the patient on their own or without a healthcare professional present.

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| <p>Motor function</p> | <p>Only included where there is professional direction in person or virtually to adapt and advise (in real time). This includes semi-supervised sessions e.g. open gym but does not include independent practice outside of these sessions.</p> <p>Includes:</p> <ul style="list-style-type: none"> • Repetitive task practice • Functional tasks with a therapeutic approach to improve motor function i.e. improve standing tolerance, dynamic balance, trunk control (midline), reach to grasp in a task • Mobility practice, real world walking • Progressive balance training • Treadmill training • Strength training • Trunk/Sitting balance work • Sensory retraining • Functional Electrical Stimulation • Mirror therapy • Constrained Induced movement therapy • Mental imagery • Spasticity management • Exercise targeted at motor recovery including sensorimotor, strength or coordination • Further assessment specifically aimed at motor function • Outcome measures specifically aimed at motor function (i.e. not holistic outcome measures required by SSNAP e.g., Barthel which are captured in 'other') <p>Does not include independent practice; wandering between therapy sessions or as part of normal daily living (such as to and from the toilet); sitting out; normal daily eating and drinking; splint wearing. Exercise for cardiovascular fitness should not be included (it is included under healthy living and lifestyle management). This does not include initial assessment.</p> |
| <p>Psychological function</p> | <p>Includes:</p> <ul style="list-style-type: none"> • Cognitive assessment • Perceptual assessment (including for visual neglect) • Mood assessment • Level 1,2 or 3 psychological support including; <ul style="list-style-type: none"> • Low level interventions such as supportive conversations, goal setting, relaxation methods such as tai chi • Psychoeducation • Psychological interventions e.g. Motivational interview, Cognitive Behavioural Therapy, Acceptance + Commitment Therapy, anxiety management. • Impairment based training e.g. attention work, memory training, insight work, Inattention training |

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| | <ul style="list-style-type: none"> • Fatigue management including patient education • Functional tasks focussed on assessment of/improvement of functional impact of cognitive/perceptual impairments- i.e. improvement in sequencing, planning, object use, problem solving, self-monitoring and self-awareness, risk management, apraxia, agnosia, neglect. This may include assessment of functional tasks such as multiple errands, road crossing, money management, driving • Functional tasks focussed on mood e.g. meaningful activity, anxiety management, self-care • Capacity assessment (where the predominant reason for assessing capacity is due to cognitive or mood issues) • Training the patient in the use of phones, emails etc for the purpose of communicating with others where the approach is related to cognitive deficits i.e. learning, memory, attention, navigation of device <p>Does <u>not</u> include report writing or activity pertaining to work which is not patient facing such as MDT formulation or education of staff. Does not include obtaining social history, initial assessments or discharge discussions. Note therapy pertaining to cognitive communication disorders sits within communication/swallowing function.</p> |
| Communication/swallowing | <p>Includes:</p> <ul style="list-style-type: none"> • Assessment, intervention, education and support provided for <ul style="list-style-type: none"> • Aphasia – including interventions targeting impairment, participation and activity. • Dysphagia – including behavioural exercises, swallow stimulation, neurostimulation, supervised oral trials. • Dysarthria – including motor exercises for facial weakness or dysarthria, communication and intelligibility techniques. • Apraxia of speech – including motor training exercises, communication strategies and techniques. • Cognitive communication disorders • Reading, writing, speech, numerical work • Assessment for and training with communication aids and assistive devices • Communication partner training • Communication stimulation – creating opportunity for supervised communication practice 1:1 or in groups. • Facilitating communication in important discussions/decisions- including capacity assessment for those with significant aphasia (i.e. where aphasia is the primary issue impacting demonstration of capacity). Where discussions/capacity assessment is carried out by two professionals, enter under psychological only, so not to double count minutes. <p>Does <u>not</u> include report writing or activity pertaining to work which is not patient facing, such as creation of individualised resources. Does not include initial assessment.</p> |
| Vocational rehabilitation | <p>Includes:</p> <ul style="list-style-type: none"> • Assessment of potential barriers and facilitators to returning to work including work place assessment • Collaborative development of an action plan, with patient, for how barriers may be overcome • Interventions as required by the individual, which may include vocational counselling and coaching, trialling adaptations or equipment in the workplace, work hardening |

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| | <ul style="list-style-type: none"> Meetings between the person with stroke, their employer and healthcare professional in planning, facilitating and monitoring their return to work <p>Does <u>not</u> include report writing or activity pertaining to work which is not patient facing, such as organisation of equipment or adaptation, administrative emails/telephone calls.</p> |
| Healthy living and lifestyle management | <p>Includes assessment, advice or intervention regarding;</p> <ul style="list-style-type: none"> Wound management/ skin care Medications management Secondary prevention e.g. management and education for blood pressure, lipids, diabetes Taking physical observations as part of a physiological treatment plan or monitoring plan Healthy eating Smoking cessation or alcohol intake Continence management Sex and intimacy Assessment/facilitation to engage in in social/leisure activity Exercise for cardiovascular fitness Medication review – including pain relief <p>Does <u>not</u> include independent social activity or independent exercise.</p> |
| Social care needs and care delivery | <p>Includes:</p> <ul style="list-style-type: none"> Care act assessment Training of care staff related to individual’s specific needs Advice, support and assessment regarding housing and benefits Carer assessment and support Assessment regarding home adaptation Delivery of care* I.e., for personal activities of daily living, meal preparation (reablement) <p>Does <u>not</u> include report writing or activity pertaining to work which is not patient facing, such as brokering for care, meetings regarding care allocation, equipment ordering, administrative emails/telephone calls. Minutes collected under this category can be delivered by any member of the team (ie not limited to social workers)</p> <p>*Care visits are those that would ordinarily be provided by social care and are not targeted therapy treatment sessions.</p> |
| Other | <p>Including:</p> <ul style="list-style-type: none"> Initial assessment (comprehensive/holistic assessment carried out by Stroke specialist professional) Goal setting meetings Visual assessment |

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| | <ul style="list-style-type: none"> • Ocular motor and visual field interventions. (Note interventions associated with visual perception and visual neglect are included in psychological domain) • Social History Gathering - with patient (not by proxy) • Discharge planning discussions - with patient (not by proxy) • Wheelchair assessment • Wheelchair training • Collection of SSNAP required outcome measures (EQ5DL, Barthel and MRS) • General pain management (not related to spasticity management – see motor, or medication review – see healthy living and lifestyle management) • Chest physio (to reduce aspiration pneumonia) • Other patient facing therapeutic activity that is not covered by the categories above but that fit the criteria under “Guidance for recording days and minutes of therapy and care” above. <p>Does <u>not</u> include report writing or activity pertaining to work which is not patient facing, such as discussions with family, meetings regarding care allocation, equipment ordering, administrative emails/telephone calls.</p> <p>Domain specific outcome measures (not required by SSNAP) should be entered under the most relevant therapy domain (i.e. balance measures recorded as minutes under motor function).</p> |
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