Data Provision Notice

All Age Continuing Care Data Set v2.0

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Background

The Health and Social Care Act 2012 (the Act) gives NHS England statutory powers, under section 259(1)(a), to require data from health or social care bodies, or organisations that provide publicly funded health or adult social care in England, where it has been directed to establish an information system by the Secretary of State for Health and Social Care.

The data, as specified by NHS England in this published Data Provision Notice, is required to support a direction from the Secretary of State for Health and Social Care to NHS England. Therefore, organisations that are in scope of the notice are legally required, under section 259(5) of the Act, to provide the data in the form and manner specified below.

Purpose

The All Age Continuing Care (AACC) data set is a patient-level data set that will cover all aspects of AACC, where AACC refers to the following commissioned services, as described in the National Framework for NHS Continuing Healthcare and NHS-funded Nursing Care[1] and the National Framework for Children and Young People's Continuing Care[2]:

- NHS Continuing Healthcare (NHS CHC)
- NHS-funded Nursing Care (FNC)
- Joint packages of health and social care
- Children and Young People's Continuing Care (CYPCC)

Integrated Care Boards (ICBs) and their associated sub ICBs (responsible commissioner) are the bodies responsible for submission of the AACC data set. Please see the Source section of this document for details of submitting bodies at time of publication of this document. The AACC data set User Guidance will be updated with the latest information regarding submitting organisations.

The AACC data set will capture the end-to-end commissioning of AACC services, from initial checklist through to assessment, to the commissioning and monitoring of individual care packages, regular and ad-hoc care package and eligibility reviews, and eligibility disputes.

Prior to the development of the AACC data set v2.0 in relation to the AACC Information Standard, continuing care data was gathered in accordance with the NHS Continuing Healthcare Patient Level Data Set (NHS CHC PLDS) v1.0 information standard (DCB3085)[3] and through a quarterly aggregated return (DCB2117[4]), both submitted by responsible commissioners. The scope and potential for further development of the aggregate return is limited due to the practical size constraints of a template-based data collection and the suitability of some data for an aggregated return.

The CHC PLDS v1.0 standard was based upon the National Framework for NHS Continuing Healthcare and NHS-Funded Nursing Care, which applies to persons aged 18 or over only and as such the v1.0 standard was designed to only accept data on patients of this age range and was submitted by responsible commissioners in accordance with the NHS

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[1] https://www.gov.uk/government/publications/national-framework-for-nhs-continuing-healthcare-and-nhs-funded-nursing-care

[2] https://www.gov.uk/government/publications/children-and-young-peoples-continuing-care-national-framework

[3] https://digital.nhs.uk/data-and-information/information-standards/information-standards-and-data-collections-including-extractions/publications-and-notifications/standards-and-collections/dcb3085-nhs-chc-patient-level-data-set

[4] https://digital.nhs.uk/data-and-information/information-standards/information-standards-and-data-collections-including-extractions/publications-and-notifications/standards-and-collections/dcb2117-nhs-continuing-healthcare-data-set

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Continuing Healthcare Directions 2022[5] (Original Directions). The AA2CC data set v2.0 standard is expanded to include under 18s receiving continuing care under the National Framework for Children and Young People's Continuing Care and replaces the CHC PLDS v1.0 and is collected in accordance with the new AACC Directions, which revoke the Original Directions.

This data set is being developed to support three aims of delivering:

1. better outcomes for patients
2. better experience for patients and
3. better use of resources

by providing detailed evidence that is currently unavailable.

The enhanced data set will identify where patients are being placed out of area, where care packages are being changed frequently, and other evidence that may indicate poor outcomes for the patient that can be identified and addressed.

Patients going through local appeals processes will be monitored to ensure appeals are resolved in a timely manner and that the rate of overturned or accepted appeals is within a typical range.

The data set allows linkage at patient-level to other data sets, so that increased/reduced hospital admissions, medication and other important attributes are visible.

Development of this data set will align AACC data with the Digital Transformation area of the NHS Long Term Plan[6].

Benefits

AACC refers to a package of ongoing care that is arranged and funded solely by the National Health Service (NHS) where the individual has been assessed and found to have a ‘primary health need’ as set out in the National Framework for NHS Continuing Healthcare and NHS-funded Nursing Care (patients aged 18 and over) and the National Framework for Children and Young People’s Continuing Care (patients under 18). These are referred to as NHS CHC and CYP continuing care respectively. Such care is provided to meet health and associated social care needs that have arisen as a result of disability, accident or illness, as defined in the national frameworks.

Provided data covers the end-to-end commissioning of AACC services in England for each patient, including submission of the following activity carried out by, or on behalf of, responsible commissioners:

- Checklist activity, including receipt of checklist and recommendation
- Assessment activity, including receipt of assessment outcome and responsible commissioner eligibility decision
- Regular (3 month, 12 month) or ad-hoc care package review activity, including review outcome
- Changes to eligibility, either resulting from a care package review outcome or dispute decision

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[5] NHS Continuing Healthcare Directions 2022. The Directions were given by NHS England to the Health and Social Care Information Centre (NHS Digital) on 9 March 2022. NHS Digital was abolished, and its functions transferred to NHS England, with effect from 1 February 2023, by the Health and Social Care Information Centre (Transfer of Functions, Abolition and Transitional Provisions) Regulations 2023 (S.I. 2023/98). By virtue of regulation 3(1), the Directions are treated as if contained in a direction given by the Secretary of State to NHS England.

[6] https://www.longtermplan.nhs.uk/areas-of-work/digital-transformation/

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- Eligibility dispute activity, including receipt and decision.

As well as capturing AACC referral, assessment, and eligibility activity, the information standard also covers details of the type and cost of all care packages active within the reporting period. Analysis of this information is key in turning raw data into understandable intelligence on all aspects of performance, patient care, and efficiency relating to AACC including:

- where patients are being placed out of area
- where care packages are being changed frequently
- efficiency of local appeals processes
- number of eligibility decisions being overturned on appeal
- number of inappropriate referrals
- adherence to the regular review process
  general adherence to the national frameworks; and
- other evidence which indicates poor outcomes for the patient.

The AACC data set will be used to generate key performance metrics for across the service and at the ICB level:

- Percentage Decision Support Tools Completed in Acute
- Percentage Referrals Completed Within 28 Days
- Referrals Exceeding 28 days
- New Fast Track Referrals
- New Standard Referrals
- Number Eligible for Fast Track
- Number Eligible for AACC.

Continuous monitoring of these metrics will allow for informed and targeted allocation of resources to improve service delivery. These metrics were previously unavailable for CYP continuing care.

AACC data and metrics will be used to check and monitor adherence to the National Frameworks, particularly in CYP continuing care where there is known to me more variation in local procedures.

The burden assessment for the quarterly CHC data collection (DCB 2117) estimated the annual cost of £200K, including 669 staff days. Submission rates and data quality improvements in the AACC data set will enable the retirement of this collection, saving the associated financial and staff burden.

Legal basis for collection, analysis, publication and dissemination

Collection

NHS England has been directed by the Secretary of State for Health and Social Care under section 254 of the Health and Social Care Act 2012 to establish and operate a system for the collection and analysis of the information specified for this service. The direction and accompanying requirements specification are published on the NHS England website here https://digital.nhs.uk/about-nhs-digital/corporate-information-and-documents/directions-and-data-provision-notices/secretary-of-state-directions/all-age-continuing-care-directions-2024.

This information is required by NHS England under section 259(1)(a) of the Health and Social Care Act 2012.

In line with section 259(5) of the Act, all organisations in scope, in England, must comply with the requirement and provide information to NHS England in the form, manner and period specified in this Data Provision Notice

The AACC data set specifies for collection individually identifiable and confidential patient information, including local patient identifier, organisation identifier (organisation that generated the local patient identifier), NHS number, NHS number status, person birth date, postcode of usual address, person stated gender code*, person stated sexual orientation code*, ethnic category*, religion or belief system affiliation code*, person death date, and disability indicator.[7]

Medical information such as patient condition and diagnoses information are not collected in this data set. The onus is on the data provider not to submit this data, as instructed in the provided User Guidance.

In line with the national data opt-out operational policy guidance, national data opt-outs will NOT apply to the flow of AACC data to NHS England, as the data collection is legally required under section 259 of the Act.

National data opt-outs will be applied to any dissemination of data collected via this DPN, including any products derived from such data, in line with the national data opt-out operation policy guidance: https://digital.nhs.uk/services/national-data-opt-out-programme/operational-policy-guidance-document.

Analysis

Standard validation routines are applied at the record value level to check the submission meets the required mandate and format, as defined in the Technical Output Specification.

Further custom validation routines are applied at the record value level to check that expected values are present and correct based on the context of the record. These are defined in the Technical Output Specification.

A pseudonymisation process is applied at the record level to item values that could conceivably identify a patient (e.g. PersonBirthDate, PostcodeOfUsualAddress), prior to entry into the NHS England National Commissioning Data Repository (NCDR) (see Data Linkage section below), for use by internal teams. The AACC Data Team within NHS England, part of NHS England’s AACC Business Unit, and AACC Strategic Improvement Programme, are responsible for carrying out analysis of the AACC data to fulfil the data set purpose in accordance with directions, using the NCDR data to realise the benefits described in the Directions Requirements Specification, to support their legal function and to carry out their roles effectively. The AACC data team also produce and disseminate dashboards for consumption by responsible commissioners (see Dissemination section).

Data linkage

Intended linkages are for the derivations of MPS (Master Patient Service) ID and Registered GP using the Patient Demographic Service (PDS), and geographies using corporate reference data. These links are made using identifiable data.

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[7] *as defined in the NHS Data Dictionary, November 2023 release.

There is potential for AACC data sets to be linked to other data obtained by NHS England under other directions made under section 254 of the Health and Social Care Act 2012, which could provide richer information, enable enhancement of existing publications and the development of new publications. If there is a proposal to link AACC data with other data that NHS England has obtained, the Specification will be reviewed in line with the change control process to ensure the linkage is aligned with the purpose of the AACC Directions. Where the linkage is approved, this Specification will be updated. More information about the data sets and collections that NHS England holds and that may be used for linkage can be found on the NHS England Data Collections and Data Sets webpage.

Dissemination

NHS England may use its discretionary powers under section 261 of the Health and Social Care Act 2012 to disseminate any information collected or obtained as a result of these Directions via the Data Access Request Service (DARS) where there is a suitable legal basis.

The AACC flows update the existing CHC flows to ICBs for Commissioning and is part of the suite of Commissioning data products approved to flow to ICBs under and for transparency noted here https://digital.nhs.uk/services/data-services-for-commissioners/commissioning-datasets. The flows are provided under s261(5)(d) of the 2012 Act.

Persons consulted

Consultation has been conducted in three phases with external organisations involving:

- General awareness raising prior to the commencement of the project
- Engagement exercise to agree the data set content and specification
- Ongoing engagement to keep internal and external stakeholders informed of the progress of the data set development.

Organisations consulted:

- Integrated Care Boards
- Commissioning Support Units (CSUs)
- NHS England AACC Programme Delivery
- NHS England AACC Data Team
- NHS England Data Set Development Service
- Local authorities (England)
- System suppliers
- Third sector organisations.

An online public consultation was also carried out, open for anyone to participate. Feedback was received from 20 ICBs, 5 system supplies, 2 local authorities, a CSU, the CHC Alliance and Dementia UK.

Information has been published on the NHS England website for patients in relation to the AACC data set to ensure fair processing. Note that the AACC data set relates to finance packages associated with patient support and does not collect any medical information.

The AACC data set was developed in consultation with the NHS England Data Standards Assurance Service for approval by the Data Alliance Partnership Board. The Data Alliance Partnership Board (DAPB) has been established as part of a system-wide information and technology governance model. The DAPB acts with delegated authority from the Secretary of State as the main governance route through which all data collections and standards requirements are agreed and priorities assigned.

Scope of the collection

Under section 259(1)(a) of the Health and Social Care Act 2012, this Notice is served in accordance with the procedure published as part of the NHS England duty under section 259(8) on the following organisations:

- All commissioning bodies responsible (Integrated Care Boards) for AACC services in England.

Under section 259(5) of the Health and Social Care Act 2012 the organisation types specified in the above Scope must comply with the Form, Manner and Period requirements below:

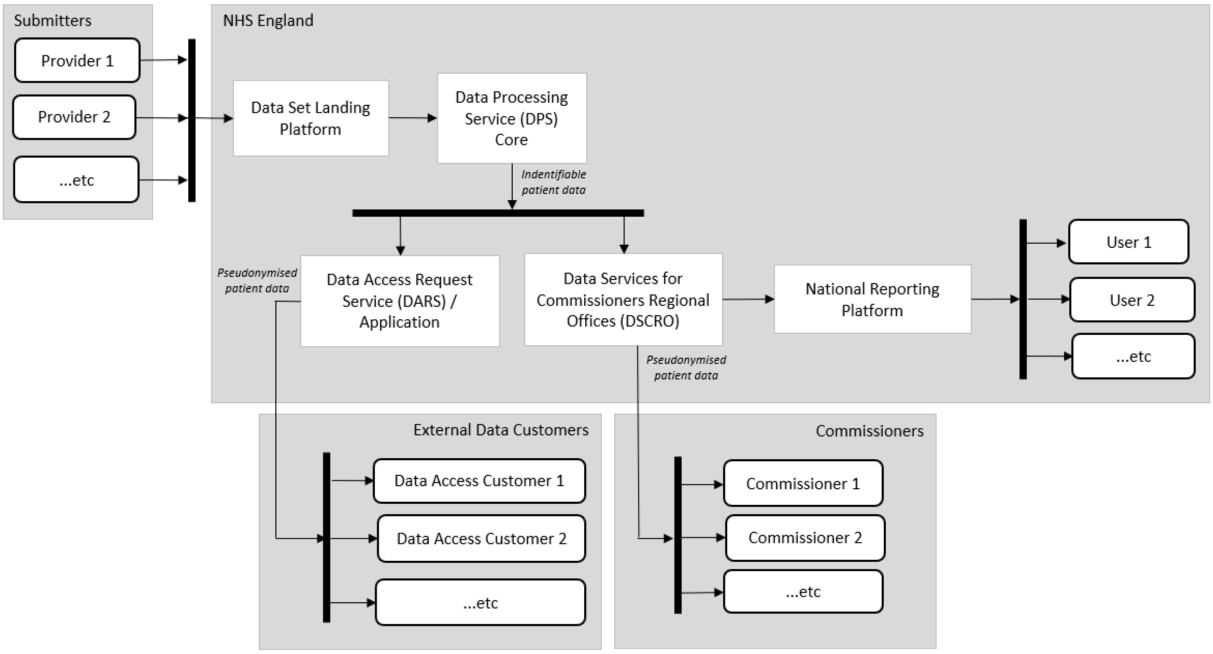
Form of the collection

The requirement relates to the extraction and submission of patient identifiable data.

Full details of the data to be submitted to the AACC data set can be found in the AACC v2.0 Technical Output Specification, which is available from the AACC Tools and Guidance webpage.

Manner of the collection

Data will be extracted from the management systems of bodies commissioning AACC services in England at ICB locality level and submitted to NHS England. NHS England will collect and process the AACC data provided by the ICBs management systems via the landing portal MESH4.



Period of the collection

- Continued collection of the CHC PLDS ends at the commencement of the collection of the AACC data set* (see below)

- Commencement of collection of the AACC data set starts: 01/04/2025
- First submission window for AACC data set opens: 01/05/2025
- First submission window for AACC data set closes: 31/05/2025
- Subsequent submission dates: Monthly
- Collection end date: Ongoing.

*To note, the NHS CHC PLDS data gathered by virtue of the Original Directions, may continue to be used under the AACC Directions.

Data quality

As per the AACC Data Set Requirements Specification, providers of AACC services must review the documentation provided as part of Information Standard DAPB0385 to understand the data quality rules that will be applied. To access these documents and guidance, please follow the links below.

- AACC Data Set v2.0 Change Specification
- AACC Data Set v2.0 Requirements Specification
- AACC Data Set v2.0 Implementation Guidance
- AACC Data Set v2.0 Technical Output Specification
- AACC Data Set v2.0 User Guidance
- All Age Continuing Care Directions 2024
- AACC Data Set v2.0 Data Provision Notice
- Any other guidance documents and tools provided on the AACC Data Set Guidance pages.

Data quality issues are highlighted in data quality reports made available to the Commissioning bodies (data providers) for them to take further action. Providers of NHS AACC data should make every effort to resolve inherent systemic errors and address recurring data quality issues.

Burden of the collection

Steps taken by NHS England to minimise the burden of collection

In seeking to minimise the burden it imposes on others, in line with sections 253(2)(a) and 265(3) of the Health and Social Care Act 2012, NHS England has an assessment process to validate and challenge the level of burden incurred through introducing new information standards, collections and extractions.

This process is carried out by the Data Standards Assurance Service (DSAS) which assures burden assessment evidence as part of the overarching Data Alliance Partnership Board (DAPB) approval process. The DAPB, acting under authority of the Secretary of State, oversees the assurance, approval and publication of information standards and data collections for the health and social care system in England.

Assessed costs

The associated burden of the data collection is:

Data provider set-up costs	£1,001,009	Includes costs of implementing the changes of

		the data collection within the data provider organisation.
Data provider ongoing cost of collection (annually)	£1,692,511	Includes the costs of providing data for 12 monthly reporting periods.
Other costs of the collection	£354,237	Data provider costs given for analysis and decommissioning.

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