National Wheelchair Data Collection Guidance

NHS England and NHS Improvement

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Contents

1 Introduction

The national wheelchair data collection (Data Coordination Board reference: DCB2097) is part of a programme of work focussed on improving wheelchair services and was first introduced in July 2015.

Wheelchairs provide a significant gateway to independence, wellbeing and quality of life for thousands of adults and children, carers and families. NHS England and NHS Improvement are supporting clinical commissioning groups (CCGs) to commission wheelchair services which are efficient, effective and personalised, ensuring services are commissioned to meet the health and wellbeing outcomes identified by people who access wheelchair services. The national wheelchair data collection established the first centralised dataset to improve transparency and provide the ability to benchmark services. Since 2016 CCGs have been held to account for performance for children through the CCG assurance programme and now NHS England and NHS Improvement have signaled the intention to introduce this performance target for adults by 2021/22 as shown in the technical annex of the planning guidance. The implementation of personal wheelchair budgets and a subsequent new legal right in this area has driven the personalisation of services, alongside ongoing work to consider outcome measures, develop currencies and best practice guidance which is planned for release in 2020/21.

The dataset has now been refined and updated for 2020/21 to support the ongoing overview of CCG performance. This document intends to provide clear guidance for CCGs and providers in order to report local area performance. The intention of these changes is to provide clarity, improve data quality and demonstrate an overarching performance of services nationally, as well as identifying areas where performance requires support to improve. CCGs will also be able to benchmark their own performance. The changes have been informed by feedback from service providers, CCGs, clinicians, people with lived experience and agreed through NHS England and NHS Improvement's NHS Wheelchair Advisory Group which consists of a wide range of stakeholders.

Collection information

All CCGs collect data from their wheelchair service provider(s) on a quarterly basis. Data should then be submitted to NHS England and NHS Improvement via upload to the Strategic Data Collection Service (SDCS) by the middle of the month following the end of the last quarter; as illustrated in the table below.

National wheelchair data collection dates

Timing: This collection will take place every quarter			
Quarter	**Data collection period**	**Collection opens**	**Collection closes**
1	1 April – 30 June	1 July	16 July
2	1 July – 30 September	1 October	16 October
3	1 October – 31 December	1 January	16 January
4	1 January – 31 March	1 April	16 April
The above dates for collection/closing are indicative and in practice will be adjusted to the nearest working day			

Commissioners might wish to review how the national data collection fits with their wider wheelchair service improvement, and can do so by accessing NHS England and NHS Improvement's model wheelchair service specification.

For more information about the national data collection or any of the work NHS England and NHS Improvement is doing to support the commissioners of wheelchair services please contact england.wheelchairs@nhs.net

2 Definitions

Term	Question(s)	Definition
Adult	Throughout	A patient is considered to be an adult from the date of their 18th birthday onwards.
Child	Throughout	A patient is considered to be a child from birth to their 18th birthday.
Closed episode of care	3,4	Patient pathway is complete, i.e. equipment, assessment, accessories or modification received by patient.
Current expenditure	5	This is the financial value (£0,000,000 in whole pounds), for total annual CCG spend to include assessment, service and equipment provision, repair and maintenance. This should also include specialised/complex wheelchair services. If there are any specific issues with providing this, please highlight these in the comments section.
Currently registered	1	Patients active with the service either through the long-term loan of a piece of equipment or through an open episode of care or provision of a personal wheelchair budget. This should be the total number of patients currently registered with the service on the last day of the reporting period.
Handed over	3,4	Where all equipment identified at the assessment is delivered to the wheelchair user or where existing equipment is modified / adjusted to meet the 'prescription decision'.
Level of need	3,4	See Appendix I: Definitions of level of need
New patients	2a	New patients to the service, i.e. has never previously been known to the specific service for wheelchair requirements or has previously been registered with the service but has been discharged and all equipment has been returned.

Term	Question(s)	Definition
Inactive/discharged service user	2a	If the patient has previously been registered with the service but is 'Inactive', patient discharged and all NHS equipment has been returned, this would be a new referral
Open episode of care	3,4	Patient pathway not complete, equipment not yet handed over or received by patient i.e. patient is still awaiting assessment, equipment, or accessories (or a necessary modification to equipment or accessories).
Referral date	3,4	The date the referral is received at the local wheelchair service
Reporting period	Throughout	This is the three months of each quarter as indicated on page 5.
Re-referral	2b,3,4	An active patient already registered with the service, where a request is received for a new episode of care - this includes requests that may result in advice, minor reviews, assessments, visits or further equipment. If equipment is still on loan then this is a re-referral and should be recorded in Q2B.
Transitioned from vouchers to personal wheelchair budgets	6	The CCG have a personal wheelchair budget offer in place to new or existing patients.

3 Questions

1. The total number of patients currently registered with the service

This will be the total number of patients (split by adults and children) registered with the service at the end of the reporting period, either through the **long-term loan** of a piece of equipment or through an open episode of care or a provision of a budget 'including those who are in receipt of a third party personal wheelchair budget'.

The collection is solely concerned with new or open episodes of care on the wheelchair pathway which require equipment on a long-term basis (For the purpose of this dataset it is understood that broadly long-term means six months or more). There is no requirement to record short-term loans of equipment (for example, a six week loan period to address an acute medical episode which is recoverable).

2a. The number of new patients referred to the service within the reporting period

This will be all those who have been referred to the service within the three-month reporting period but not those who have been re-referred. These figures should be split by adults and children.

- Example 1: GP or healthcare professional refers patient who has never required a wheelchair before for long-term needs.
- Example 2: Patient has returned all previous NHS equipment and been marked as inactive/discharged but now requires a wheelchair again.
- Example 3: Transferred into the service from another wheelchair service.

2b. The number of patients re-referred to the service within the reporting period

This will be those who have equipment on loan but who are re-referred to the service for a re-assessment. These figures should be split by adults and children.

3. The number of new patients whose episode of care was closed in the reporting period and is assessed as:

A. Low need
B. Medium need
C. High need
D. Specialist need
E. Modification made/No equipment provided

Where assessment was complete and equipment was delivered in the following timescales:

1. 18 weeks or less
2. Over 18 weeks

All data collected here relates to episodes of care which have been completed (equipment and/or accessories or a necessary modification to prescribed equipment or no change identified handed over to patient) within the reporting period, the initial new referral may have been made before the reporting period.

This question relates to all new referrals into the wheelchair service as defined in question 2a above.

The starting point for this element is the date that the patient is referred in to the wheelchair service and the end point is when equipment was handed over which meets the prescription decision and/or when necessary modifications are completed.

Example: Equipment was handed over to the patient within the reporting period/quarter. Although the referral was initially received before the current reporting period this patient would be included in the response to this question in the submission as the episode was closed in within the reporting quarter.

Please refer to Appendix I for definitions of (a) low need, (b) medium need, (c) high need, (d) specialist need.

4. The number of re-referred patients whose episode of care was closed in the reporting period and is assessed as:

F. Low need
G. Medium need
H. High need
I. Specialist need

J. Modification made/No equipment provided

Where assessment was complete and equipment was delivered in the following timescales:

K. 18 Weeks or less

L. Over 18 weeks

This question should be answered in the same way as the previous question, except this question is for patients who are **re-referred** into the wheelchair service as defined in question 2b above.

For both questions 3 and 4, patients should be included in the "Modification made/No Equipment required" category if they have had an assessment and no equipment has been prescribed. This category is also appropriate if the outcome of the assessment is an agreement about an adjustment or a modification to current equipment.

The children's data from both questions 3 and 4 will be used to monitor performance against the Wheelchair CCG operational performance indicator. The data should be consistent for both questions with the only difference being whether a person was newly or re-referred into the wheelchair service and therefore opening an episode of care.

5. The current expenditure on wheelchair services annually by the CCG

This question should be reported on an annual basis and be included within the submission for Quarter 4. The amount reported should be wheelchair related spending over 12 months, regardless of the funding source. Total annual CCG spend to include assessment, service and equipment provision, repair and maintenance. This should also include specialised/complex wheelchair services. If there are any problems with the answer to this question, please advise us of this in the comments section.

6. Have you transitioned from a voucher system to a personal wheelchair budget?

CCGs should mark themselves as having transitioned from vouchers to personal wheelchair budgets when they are offering a personal wheelchair budget to all new eligible patients and patients already registered with the wheelchair service when they require a new wheelchair, either through a change in clinical needs or in the condition of their current chair. This would include all deployments options such as notional, notional plus top up and third party.

4 Frequently Asked Questions

1. Should clock stopping/pausing take place during the 18 week reporting period?

NHS England and NHS Improvement's overarching aim is for people to access wheelchair services which are effective, efficient and personalised. The introduction of personal wheelchair budgets has promoted the ability for wheelchairs to be included in wider care assessments and integrated funding options. It is recognised this way of working has the potential to lengthen the patient pathway but ultimately improves outcomes, and we are keen to incentivise this behaviour. Local CCGs will need to ensure safety and minimising any risk of harm to patients through local contract monitoring. In 2020/21 NHS England and NHS Improvement are also evaluating patient centred outcome measures within the personal wheelchair budget pathway.

Through consultation and working with the National Wheelchair Advisory Group it is apparent there is an inconsistent approach in applying clock pausing. A contributory factor could be historical provider-led guidance and customs and practice. There is guidance in in the National Wheelchair Managers Forum: Operating Model for NHS-Commissioned Wheelchair Services 2018.

It states: **Clock starts – receipt of completed referral at the Wheelchair Service Clock stops - receipt of wheelchair equipment by the client**

Clock may be paused by the client e.g. do not attend (DNA), admission to hospital, holiday, other wishes to delay.

Therefore, in order to incentivise integrated working and ensure all submissions are adhering to the same standards we are introducing in 2020/21 the ability to clock pause with the following guidance and examples, which are **patient led** only:

The clock may be 'paused', at any point in the pathway, by the patient following the initial referral that started the clock, to include DNAs, holidays, hospital admission, to access a personal wheelchair budget (see specific guidance) or any other reason the person wishes to delay.

Clock pause guidance for decision regarding personal wheelchair budgets:

Patient chooses to pause in order to either make a decision regarding a personal wheelchair budget or access a personal wheelchair budget with contribution to meet wider health and wellbeing needs i.e. accessing other statutory funds, own or voluntary, community and social enterprise (VCSE) contribution. For example: An integrated personal wheelchair budget across health and social care reduces the requirement of a formal package of care and increases independence – the clock can be paused while the multi-disciplinary team (MDT) decision and outcome of joint funded provision is achieved. Or An integrated personal wheelchair budget across health and housing negates the need for housing adaptions – the clock can be paused while MDT decision and outcome of joint funded provision is achieved. The wheelchair provision in place during the clock pause **must** continue to meet assessed clinical and postural needs.

For integrated options local commissioners should outline a reasonable time frame agreed locally across organisations in agreement with the patient.

Local commissioners should be assured clinical needs are met through the period of pause and these cases should be raised and monitored as exceptions through contract management.

Note: It is expected the national wheelchair data collection and guidance is used in conjunction with local contract expectations and that CCGs would have local KPIs and exception reporting as part of contract monitoring to reflect the needs of their population. The national wheelchair data collection aim is to provide an overarching performance indicator for NHS England and NHS Improvement to monitor and assure and does not replace local commissioning and contracting performance expectations.

It is recommended local commissioners should monitor the use of clock pausing and DNA performance closely and DNA performance is included in local KPIs alongside other performance indicators for example, fast track, and response times for repair and maintenance.

2. When a person receives a personal wheelchair budget, when is the episode of care considered to be closed?

There are three methods of delivery for a personal wheelchair budget: notional, third party and direct payment. Each method is outlined below.

- **Notional personal wheelchair budget:** This is where the person chooses to use their personal wheelchair budget within the NHS commissioned service and the service purchases and provides the chair or modification. This also offers the **option for contributions** to the personal wheelchair budget to enhance the wheelchair people can access. This contribution may come from an integrated package with other agencies such as education, social care, a voluntary or charitable organisation, or through self-pay. Local personal wheelchair budget offers often refer to a Notional with contribution or ‘top up’ personal wheelchair budget when a contribution has been made.

The episode of care is considered to be closed when the wheelchair or adaptation has been handed over.

- **Third party personal wheelchair budget:** This is where the person chooses to use their personal wheelchair budget outside of NHS commissioned services. An independent provider receives the personal budget via invoicing the NHS. This may also be contributed to as above.

The episode of care is considered to be closed once the amount for the wheelchair or modification as part of the of the third-party budget has been agreed with the person, and all the relevant processes for setting up the third-party budget have been completed. This is the point at which the NHS has taken every action needed to put the third-party budget in place.

- **Direct payment:** This is where the budget holder holds the money in a bank account or an equivalent account, and takes responsibility for arranging the care and support, in line with the agreed personalised care and support plan. This could include provision of a wheelchair or modification as part of a package of support.

  Note: Direct payments are currently not routinely available as an option for managing a standalone personal wheelchair budget. NHS England and NHS Improvement and the Department of Health and Social Care are currently reviewing existing regulations to establish whether additional contributions are permissible under the Direct Payments in Healthcare Regulations.

The episode of care is considered to be closed once the amount of the direct payment has been agreed with the person, and all the relevant processes for setting up the direct payment have been completed. This is the point at which the NHS has taken every action needed to put the direct payment in place, and where any delays to the client receiving the payment are not within the control of the NHS.

More information about personal wheelchair budgets can be found in the personal health budget mandatory data collection guidance and in the guidance on legal rights to personal health budgets.

5 Appendices

Appendix I – Definitions of levels of need

Low Need

- Occasional users of wheelchair with relatively simple needs that can be readily met.
- Do not have postural or special seating needs.
- Physical condition is stable, or not expected to change significantly.
- Assessment does not typically require specialist staff.
- Limited (or no) requirement for continued follow up/review.

Medium Need

- Daily users of wheelchair, or use for significant periods most days.
- Have some postural or seating needs.
- Physical condition may be expected to change (e.g. weight gain / loss; some degenerative conditions).
- Comprehensive, holistic assessment by skilled assessor required.
- Regular follow up / review.

High Need

- Permanent users who are fully dependent on their wheelchair for all mobility needs.

  and
- Complex postural or seating requirements (e.g. for high levels of physical deformity).

  or
- Physical condition may be expected to change / degenerate over time.

  or

- Very active users, requiring ultra-lightweight equipment to maintain high level of independence.

In all cases …

- Comprehensive, holistic assessment by skilled assessor required.
- Regular follow up / review with frequent adjustment required/expected.

Specialist Need

- Permanent users who are fully dependent on their wheelchair for all mobility needs.

and

- Highly complex postural or seating requirements (e.g. for high levels of physical disability) and/or are at greatest risk to their health and well-being.

and

- Physical condition may be expected to change / degenerate over time.

or

- Have complex and /or fluctuating medical conditions and multiple disabilities, which may include physical, cognitive, sensory and learning aspects.

or

- They are likely to require 24 hour postural management due to; poor trunk control, inability to sit without support, limited upper limb function, possible spinal curvature and joint contractures.

or

- They are at high risk of secondary complications due to their levels of disability such as contractures, chest infections and respiratory diseases.
- The most common diagnoses for people who need specialist wheelchair services are: cerebral palsy, muscular dystrophy, multiple sclerosis, brain injury, motor neurone disease, high level spinal cord injuries.

In all cases …

- Regular follow up / review with frequent adjustment required / expected.
- Comprehensive, holistic assessment by skilled assessor required.

Appendix II – The Strategic Data Collection Service (SDCS) upload template

	Question	Quarterly Actuals	
		Adult	Child
1	The total number of patients currently registered with the service?		
2	The number of patients referred to the service within the reporting period split by:		
	(A) The number of new patients referred?		
	(B) The number of patients re-referred?		

		Quarterly Actuals			
		Adult		Child	
3	The number of new patients whose episode of care was closed in the reporting period and is assessed as:	18 weeks or less	over 18 weeks	18 weeks or less	over 18 weeks
	(A) Low need				
	(B) Medium need				
	(C) High need				
	(D) Specialist need				
	(E) Modification made/No equipment required				
		Adult		Child	
4	The number of re-referred patients whose episode of care was closed in the reporting period and is assessed as:	18 weeks or less	over 18 weeks	18 weeks or less	over 18 weeks
	(A) Low need				
	(B) Medium need				
	(C) High need				
	(D) Specialist need				
	(E) Modification made/No equipment required				
5	The current annual expenditure on wheelchair services				
6	Have you transitioned from a voucher system to a personal wheelchair budget?				