

Community Rehabilitation Alliance (CRA)

Making Community Rehabilitation Data Count

The CRA Data and Evidence
Task and Finish Group Report



November 2022

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Abbreviations

AHP	Allied Health Professions
CRA	Community Rehabilitation Alliance
CSDS	Community Services Dataset
PREMS	Patient Reported Experience Measures
PROMS	Patient Reported Outcome Measures
SSNAP	The Sentinel Stroke National Audit Programme
TaFG	Task and Finish Group
UKROC	United Kingdom Rehabilitation Outcomes Collaborative



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Foreword

I am pleased to introduce this important report, which has the potential to improve the quality of community rehabilitation and recovery that millions of individuals with disability receive. As Mahatma Gandhi said: “The true measure of any society can be found in how it treats its most vulnerable members”. To plan investment in rehabilitation and recovery services, commissioners need robust data. This data can track unmet need and the impact of services in improving the function and quality of life of those with long-term conditions and disabilities, such as stroke, heart disease, cancer, and frailty. Rehabilitation needs to be integrated into routine medical care, individualised, goal-centred, and involve a multidisciplinary team of rehabilitation professionals.

The Community Rehabilitation Alliance (CRA) is a collaborative network of more than 50 charities, trade unions and professional bodies campaigning for equal access to high-quality community rehabilitation services for all patients in the UK. This report summarises the findings of the Community Rehabilitation Alliance (CRA) Data and Evidence Task and Finish group. The group undertook a needs analysis using two surveys and a roundtable discussion with stakeholders. The first survey analysed current practices and needs concerning data collection and the second asked what should constitute a common universal data collection framework.

The responses suggest the current data collection was simply not good enough. The surveyed organisations, however, strongly aspire to routinely collect service-level data for various reasons ranging from clinical service delivery to measuring impact and research. Data needs to be collected on clinical outcomes, patient experience, individual goals, onward referral and workforce numbers and skill mix. There is a need for improvement in consistent data collection, submission to established databases, in-built analysis and feedback to inform services performance and benchmarking. There is an agreed consensus on developing a community rehabilitation core dataset that services must collect.



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Implementing the recommendations in this report will require both top-down and bottom-up approaches. There will be barriers to overcome, such as making data collection routine, agreeing on a core data set amidst the diversity of specialties, and securing the funding for the systems that allow effective data collection to happen. NHS England, Integrated Care Boards (ICBs), member organisations, and most importantly individuals with long-term conditions have a key role in planning the next implementation stage and discussion with funding authorities and stakeholders.

I wish to congratulate all members of the working group and those who participated in the surveys and expert panels. Their time, hard work and dedication will be invaluable to bringing quality rehabilitation care to the doorstep of every individual with a long-term condition.

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Executive summary

Acute, specialised and community rehabilitation services are historically under-resourced and over-subscribed. The Community Rehabilitation Alliance (CRA) brings together organisations across England to improve access to high quality, person-centred rehabilitation. Rehabilitation service data and analysis is critical in the delivery of high quality community rehabilitation.

The CRA Data and Evidence Task and Finish Group was set up in 2021 to explore the challenges and opportunities around data use for community rehabilitation and to support service improvement and commissioning.

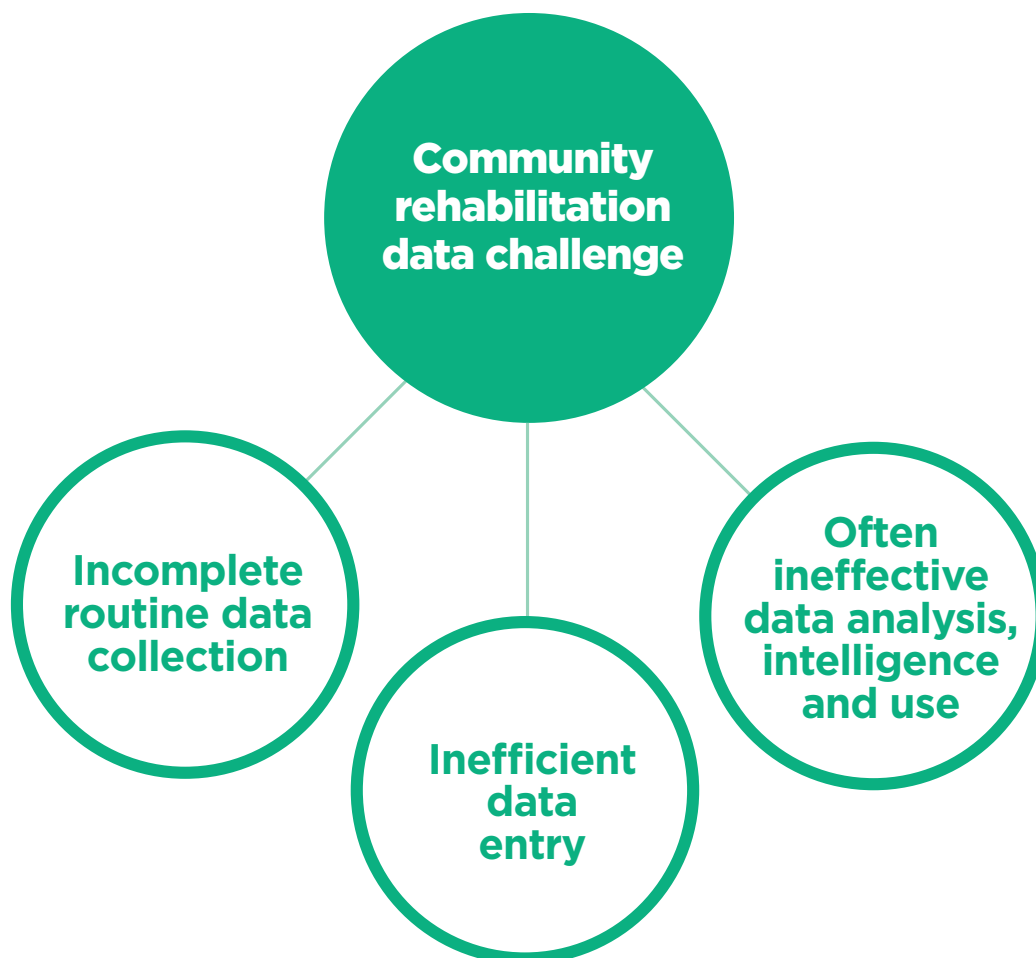
This group used a multi-methods approach to gather insight from CRA member organisations and community rehabilitation providers to:

- explore how and why community rehabilitation services currently use databases and identify gaps in data use (survey 1)
- explore the characteristics and types of data that could be included in an 'ideal core dataset' to identify needs and inform solutions (survey 2 and Roundtable discussion).



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Key findings



- Community rehabilitation organisations want service level data for multiple purposes including, clinical delivery, research, quality improvement, benchmarking, showcasing best practice, making business cases and workforce planning.
- With incomplete data, it is not currently possible to know how effective many community rehabilitation services are; of 206 community rehabilitation organisation survey respondents, 83 (40%) are not submitting data to databases.



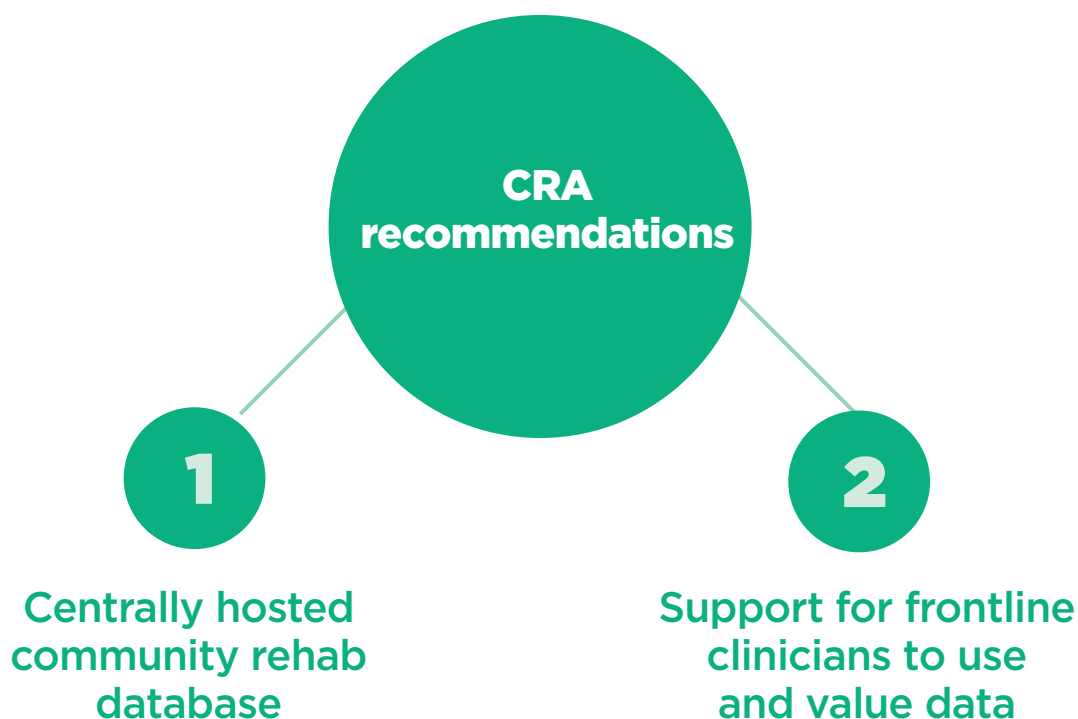
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- Current data collection and submission processes are inefficient; 45% of survey respondents reported duplicating data entry when submitting data to databases.
- Data is not collected consistently, and is not stored in one place. This makes it very difficult for services to access data and use it to benchmark and improve their services.
- Many community rehabilitation organisations, services and clinicians do not routinely receive analysis on data collected, limiting its value; less than half (45%) of organisations who submit data to databases always receive data analysis.
- There is widespread support for improvement in data collection and use, however, service diversity and clinical complexity is an inherent challenge to this goal.
- There is broad agreement regarding items for inclusion in an ‘ideal core dataset’ for community rehabilitation.



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Recommendations



For NHS England and NHS Digital

A community rehabilitation database must be simple to use, safe, efficient and hosted centrally. Such a database should be co-designed with stakeholders to reduce data entry duplication and foster data sharing. This, in turn, could help map service need and outcomes, support audit, service evaluation and research and improve integration of community services (including partnership working between acute, specialised rehabilitation, long-term and social care).

NHS England and NHS Digital have a key role in supporting, funding and delivering a community rehabilitation central database including associated hardware and software. Without coordinated support, a national data collection system is unrealistic and indeed might be detrimental to service delivery given the unsupported clinical and managerial time costs required.



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For NHS England, Integrated Care Boards, Place boards, Rehabilitation leaders and Clinicians

There is an important need to support frontline clinicians and leaders through training, involvement and feedback about data uses, benefits and analysis of findings. This is necessary to ensure data capture and upload include relevant fields, is valued, valuable and prioritised at an individual and system level.

Data collection should reflect the 2022 Community Rehabilitation Alliance Best Practice Standards and be part of the solution to tackle health inequity.⁽¹⁾

Appropriate involvement of other sectors outside the NHS is essential to reflect the breadth of community rehabilitation services.



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Background

The community rehabilitation challenge

Person-centred community rehabilitation is the provision of assessment, advice, and tailored rehabilitation to improve (or maintain) people's health and wellbeing, outside of acute hospital wards⁽²⁾. It is primarily provided by Allied Health Professionals (AHPs) and is vital to support people to live well for longer⁽³⁾. Community rehabilitation can include support to help people manage long-term conditions (such as stroke, heart diseases or chronic obstructive pulmonary diseases, cancer and frailty), recover following an injury or fall, and be in the best possible shape for a medical intervention (like surgery)⁽²⁾. As well as the wide-reaching benefits to the individual, community rehabilitation also has a key role to play in improving population health and reduces demand on the most expensive parts of the NHS, like emergency admissions⁽⁴⁾. Community rehabilitation can both prevent hospital admissions and support timely discharge from acute care.

National challenges in the provision of community rehabilitation include unwarranted variation in the commissioning of services, insufficient workforce and inadequate skill mix⁽⁴⁾. Community rehabilitation services have traditionally been commissioned for single conditions, rather than on a person-centred, needs-led basis which can result in lack of care for some, fragmented care for others and services that are not well coordinated and integrated. These challenges are compounded by a dearth of data from community rehabilitation services⁽⁴⁾.

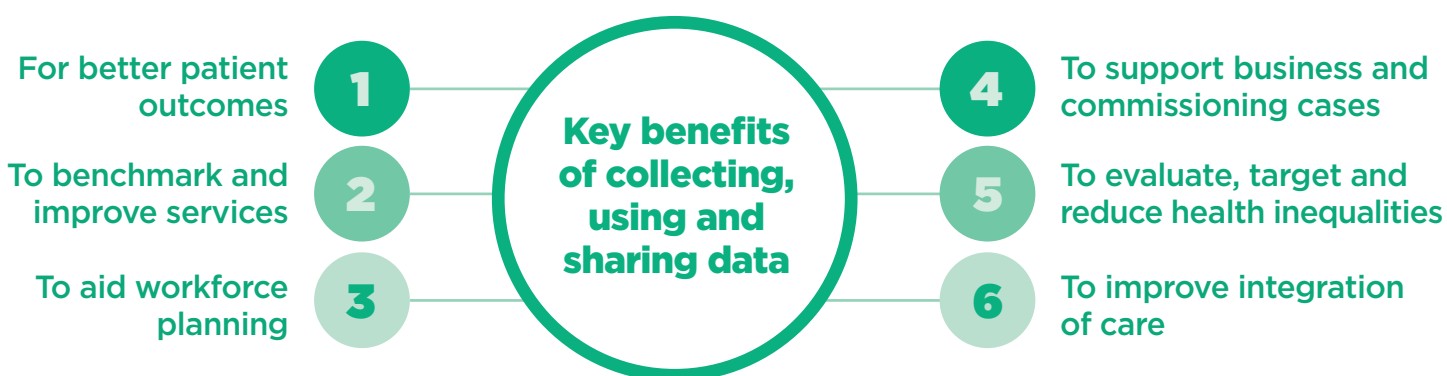
Without shared data these services, which are historically under-resourced and over-subscribed, struggle to define their role, demonstrate their impact, showcase improvement and make a robust commissioning case⁽⁵⁾. To deliver efficient integrated care, effective data sharing must become the norm across health, adult social care and public health⁽⁶⁾. Service data, including protected characteristics of the population served, is also key to understanding equity of access and outcomes in community rehabilitation.



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Without such data there are community rehabilitation health inequity blind spots and it is not possible to identify where culturally competent service improvement is necessary⁽⁷⁾. Hence, high quality data collection, analysis and use is integral to delivering best care community rehabilitation⁽¹⁾.

“The NHS has some of the most powerful health data in the world... This raw information has phenomenal potential... But raw data is not powerful on its own. It must be shaped, checked, and curated into shape. It must be housed, and managed securely. It must be analysed. And then it must be communicated, and acted upon”⁽⁸⁾



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The Community Rehabilitation Alliance Data and Evidence Task and Finish Group

The Community Rehabilitation Alliance (CRA) is made up from a group of organisations across England and some UK-wide organisations who work together to improve access to rehabilitation services. The CRA includes over 50 charities and professional bodies committed to improving delivery of rehabilitation through political commitment and improving quality of services with new models, better data collection, planning, commissioning and delivery of services. In 2021, to further investigate the challenges and opportunities around data for community rehabilitation, the 'CRA Data and Evidence Task and Finish Group' was set up (co-chaired and led by volunteers from CR organisations). This report summarises their work and recommendations to date and is intended as intelligence for Community Rehabilitation Alliance stakeholders such as member organisations, NHS England, NHS Digital, care providers and researchers.

CRA Data and Evidence Task and Finish Group objectives

- 1** To map current data use by CRA member organisations
- 2** To identify data needs and inform potential community rehabilitation database solutions
- 3** To explore the characteristics and types of data that could be included in an 'ideal core dataset'



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Methods

Current data practice and needs - survey 1:

In August 2021, the Data and Evidence Task and Finish Group (TaFG) formed a working group (representing different healthcare professions and specialist rehabilitation areas) to iteratively develop and test an online survey with wider feedback from the CRA. The survey was purposively sent to CRA member organisations and their wider community rehabilitation service provider networks. A request was made for those 'who were responsible for data entry' from these organisations to complete the survey. Categorical data was collected on: the participant organisation's country of work; whether the organisation collected data for local, regional or national databases; names of specific databases where data was submitted to; care setting (acute/primary/community/secondary); clinical specialty; nature of the data submitted (activity, patient outcome, workforce); how data was collected and entered; whether data collection was mandated; how data analysis was undertaken and funded; whether data analysis was returned to the data enterer; and data uses. Options for free text comments were also available for many questions. The findings were presented as a poster at the 'Rehab 2021- British Society of Rehabilitation Medicine conference'.

Exploring the characteristics & types of data to include in an ideal 'core dataset' - survey 2:

In January 2022, the Data and Evidence TaFG formed a working group to iteratively develop a second online survey. Survey content topics and individual question items were initially created and tested by the working group. The survey was then circulated through the wider CRA Data and Evidence TaFG for comment before final agreement by the working group. The survey was purposively sent to CRA member organisations along with some selected individuals acting on behalf of clinical trusts, professional bodies, research societies and social enterprises. Representatives of those organisations with



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responsibility for data and evidence were invited to submit data. Categorical data were captured about the proposed content of an 'ideal dataset'. For example, responding to a question on whether service user date of birth would be included participants could answer 'must not include', 'should not include', 'not sure', 'should include', 'must include'. The survey was also designed to capture free text responses. The survey respondents were subsequently invited to attend a virtual roundtable event in March 2022 to understand more about their survey responses.

Elaborating on the survey findings, database solutions and refining the 'core dataset' - roundtable discussion:

Responders to survey 2 were invited to take part in a roundtable discussion, which was hosted virtually on Zoom on 2nd March 2022. Topics and questions for the discussion were generated following discussions with the wider CRA and the Data and Evidence TaFG. 16 attendees were split in to 2 groups. Each group conversation was hosted by a member of the Data and Evidence TaFG with notes taken by another member. All conversations were recorded with the permission of those attending.



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Findings

Current data practice and needs - survey 1

206 respondents completed the survey. The majority were from England (80%) with fewer participants from Wales (12%), Northern Ireland (5%) and Scotland (3%).

Only 123 (60%) of the total respondents collected data for at least one database highlighting that many community rehabilitation organisations and services do not routinely use databases to collate data.

83 respondents completed the survey indicating they used a single database, 30 respondents used 2 databases, 7 respondents used 3 databases and 3 used 4 databases (a total of 176 databases).

40%

of community rehabilitation organisation services surveyed report not currently collecting data for databases

Of the 83 (40%) of total respondents who were not collecting data for any databases, the most common reasons for this were: 'Did not think we had to' (n=37, 45%), 'lack of time' (n=25, 30%), 'lack of human resource to collect and submit data' (n=17, 20%), 'not got the right equipment (hardware or software)' (n=16, 19%), 'don't have the headspace to think about it right now' (n=14, 17%).



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The survey responders contributed to a variety of databases including condition-specific databases (e.g. The Sentinel Stroke National Audit Programme- SSNAP, the UK Rehabilitation Outcomes Collaborative) and general clinical databases (e.g. the Community Services Dataset- CSDS, AHP Operational Measures dataset). The most common databases submitted to by respondents were the Sentinel Stroke National Audit Programme (SSNAP) (n= 36, 17%) miscellaneous local databases (n= 31, 15 %), followed by the UK Rehabilitation Outcomes Collaborative- UKROC (n= 11, 5%) and CSDS (n= 8, 4%).

When asked what 'type' of data they submit to each database 'activity data' was most common (submitted to 83% of the reported databases), followed by 'outcome data' (64%), 'workforce data' (25%), 'experience data' (18%) and 'impact data' (10%). The common reasons given for submitting data to each database were: 'Quality improvement' (72%); 'performance management' (60%); 'benchmarking' and 'regular reporting' (59% each) and, 'business cases' (48%).

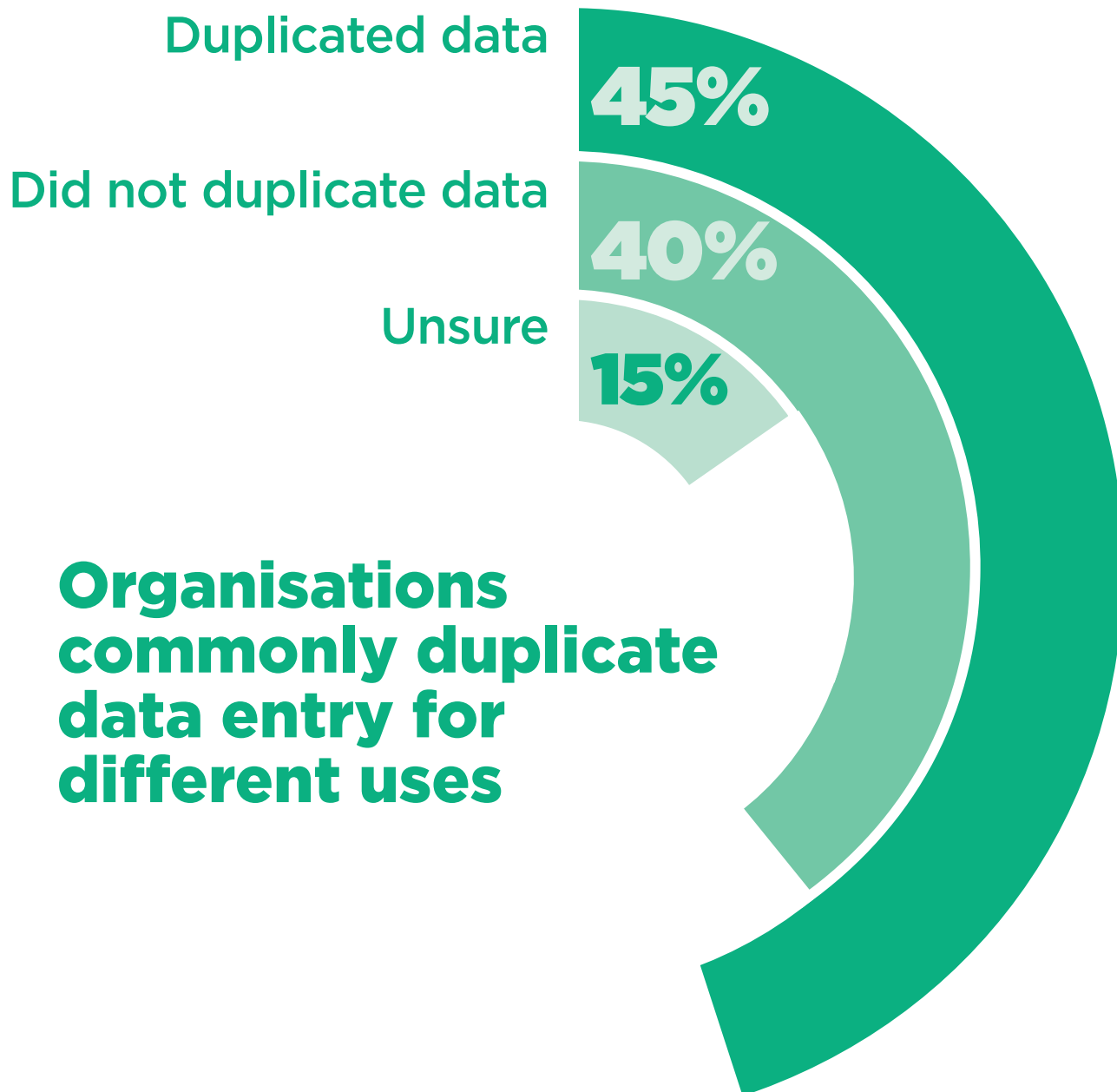
Methods of collecting data

Survey responders were asked how they collected and submitted data. Of those who reported collecting data for at least one database, the most common ways were: through a local database (26%); via a website (23%); on a central database (16%) and by file upload (15%). The person/people submitting the data varied by organisation and by the specific database being contributed to and was most commonly: a clinician 41%; a service/team administrator 27%; business intelligence/informatics team member 18%; or, service lead 11%. The remaining responses were 'unsure', 'other' or a combination of team members.

Duplication of data entry for different purposes was common with 45% of organisations who submit data to at least one database reporting this.



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Data analysis and sharing

This paragraph describes the information gathered at the database-level (from the 176 databases submitted to by the 123 respondents who reported submitting data to at least one database). Responding organisations reported they ‘always’ received data analysis on 45% of the datasets; ‘sometimes’ received data analysis on 30%; and, ‘very rarely’ received data analysis on 6%.



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Data analysis was 'never' received on approximately 1 in 5 datasets (19%). A third (34%) didn't know how the data analysis was undertaken and funded. 31% reported that it was locally undertaken and funded by the local care provider, 15% and 11% reported analysis was centrally undertaken and funded by another organization (e.g. specialist society) or commissioner respectively. The remaining gave other miscellaneous answers.

Data analysis intelligence was never received back from

1 in 5

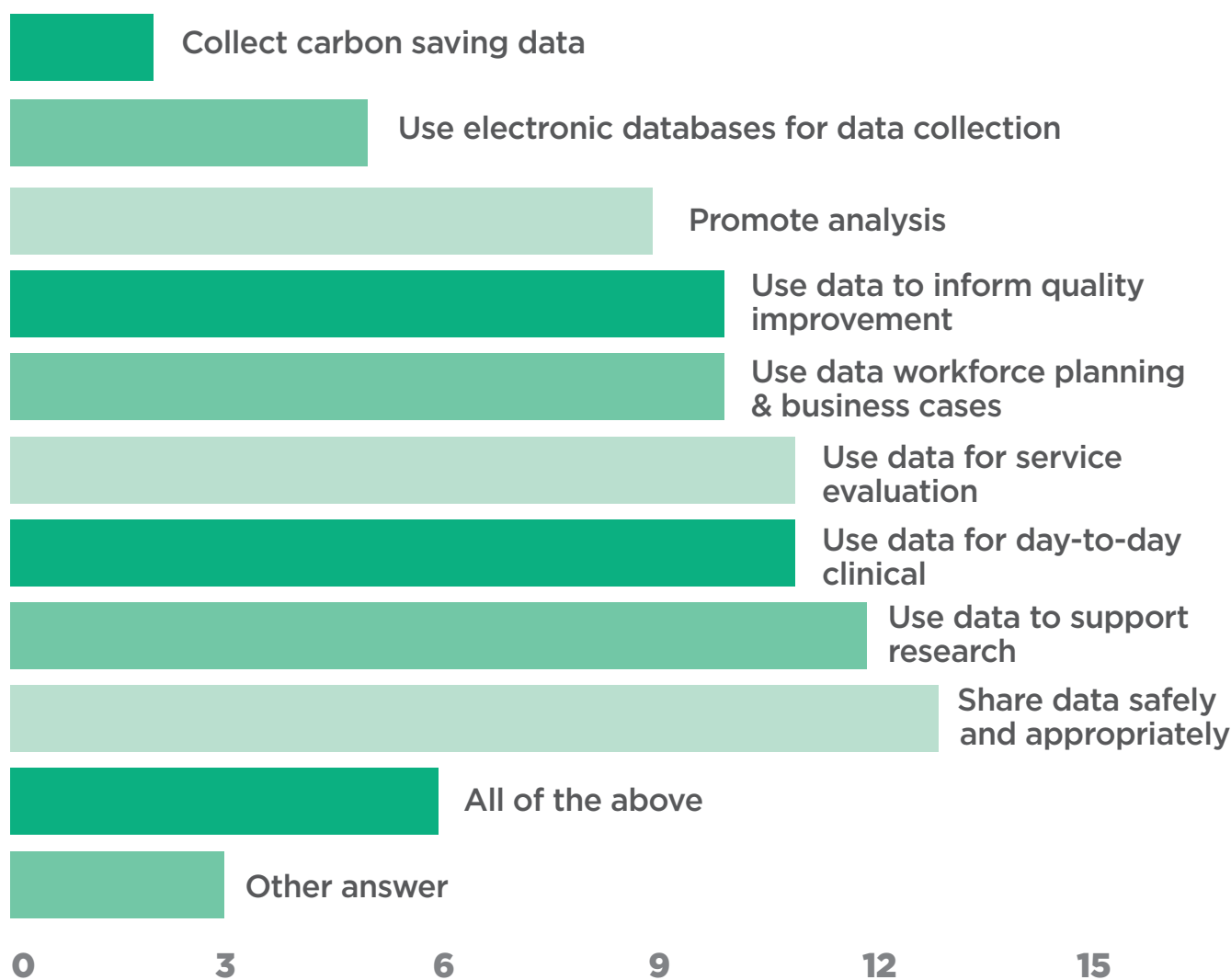
databases submitted to

Data analysis from each database was regularly shared with management (81%), and other team members (77%), but was infrequently shared with directors (33%), the public (6%) and commissioners (3%).



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Figure 1: Bar chart of organisations' messages to members around data (n=20)



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Exploring characteristics & types of data to include in a ideal 'core dataset' – survey 2

Most responses (n=9, 45%) were from professional bodies/societies, with some from the charity sector (n=5, 25%) and healthcare trusts (n=4, 20%). There were individual responses from a research society and a social enterprise.

Organisation data messages

Organisations were asked what messages they promoted to their members around data use. The most common responses (by 65% of participants) were 'to promote safe and appropriate sharing of data', 'routine use of data to support research' and to 'promote routine collection'. Multiple answers were allowed in this question with 30% of responders saying they would recommend all of the above. Individual free text responses included 'for governance', to 'inform commissioners' and 'population need'.

Organisation uses of data

Organisations were asked what they would expect their members to be doing with the data they gathered about their community rehabilitation services. The most common expectation was for 'research' followed by 'quality improvement', 'business cases' and 'showcasing best practice', and 'campaigning/lobbying/influencing', 'celebrating success' and 'benchmarking'.

Preferences for data types to include as part of standardised community rehabilitation dataset

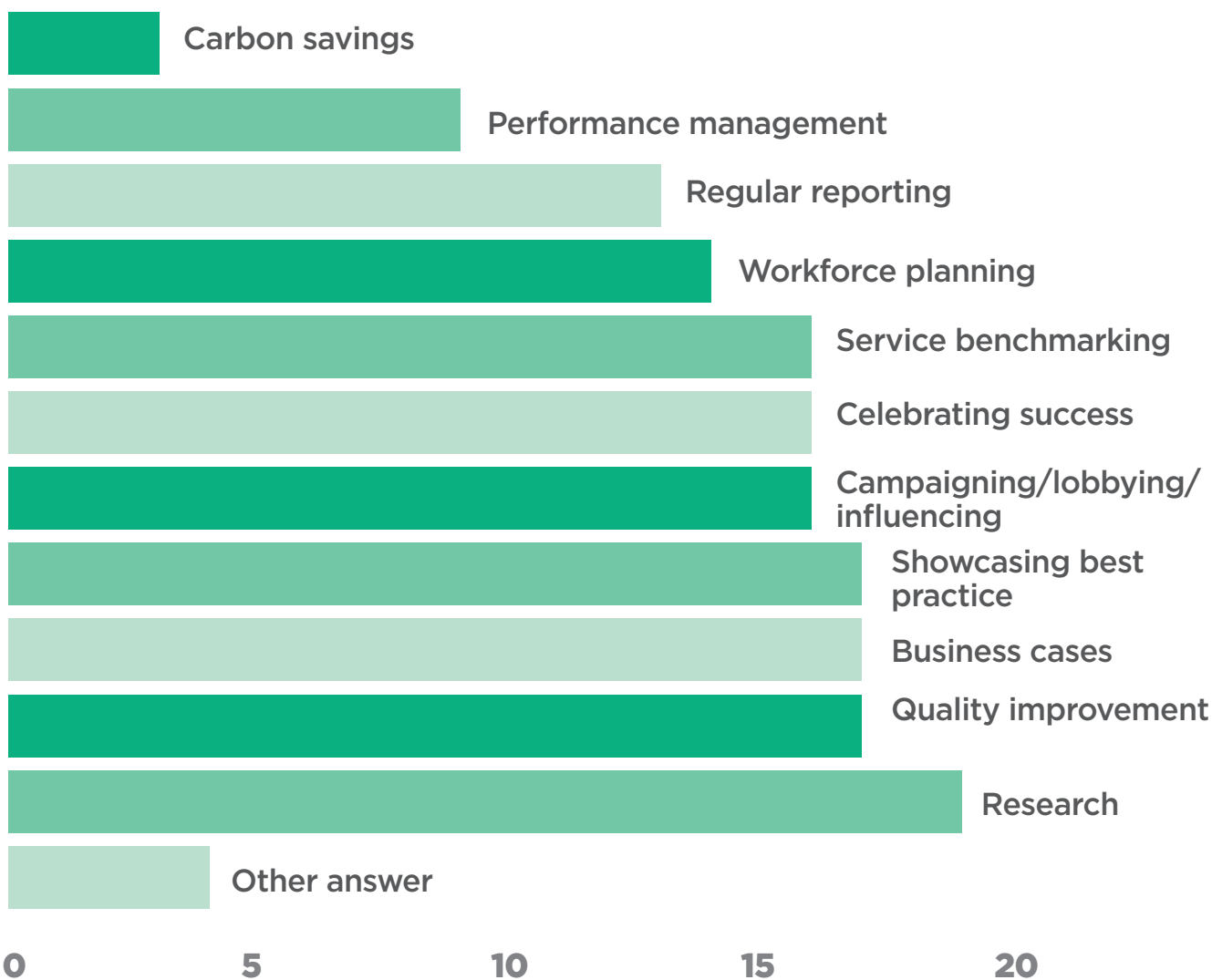
Organisations were asked what data types they would like to be included in a standardised dataset for community rehabilitation services (as recommended by the CRA Data and Evidence TaFG survey of August 2021). Again multiple



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answers were allowed to this question. All but one of the organisations wished to include 'individual outcome data' (n=19, 95%) closely followed by 'experience data' (n=17, 85%). 70% wanted to include 'service outcome data' and 'workforce data' while 60% wanted to include 'onward referral data'.

Figure 2: Bar chart showing the purposes for which organisations want community rehabilitation services to be using data (n=20)



Elaborating on the survey findings, database solutions and refining the ‘core dataset’ - roundtable discussion

16 people took part in the roundtable discussion from which four main themes emerged:

1) Collection of data

“Routine collection of data” means different things to individuals in different services. Clinicians are extremely busy so often find it hard to find the time to prioritise data collection. There is variation in the data that is mandated for collection between services and the drivers for data collection. For many clinicians in routine practice, their main reason to collect data is to plan and modify treatment.

At a system level, there are pockets of excellent practice with respect to data collection, though there is wide variation. This leaves us with potentially lots of data available but little integrated intelligence. Therefore, we need systems, processes and the correct infrastructure in place to support efficient and valuable routine collection. Central support, rewards for good practice, and making it everyone’s business to be involved in data for community rehabilitation services can help drive the culture change needed to improve data collection and use in community rehabilitation services. There was a suggestion of a Kitemark or similar to be explored to demonstrate organisational excellence in community rehabilitation service data collection and use.



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2) Value of data

System level support is urgently required to drive up the value of data in community rehabilitation. Attendees reported that data is not valued highly by all clinicians and that this would be unlikely to change without a clear rationale for collecting data, and mandating of data collection and submission. This lack of value is seen across multiple professions, specialties and settings and is often correlated with system constraints and lack of skills/knowledge/training but may reflect real poor data value in a fragmented and inefficient system. A culture of improvement driven by systems to collect and submit good quality data is required to improve the real and perceived value of data amongst clinicians and this has to be driven by leadership. Expectations of data value must be set appropriately as most impact will come through longitudinal collection, meaning that instant value demonstration should not be expected. Investment is required now to improve the collection, submission and analysis of data to drive up clinician's perceptions of value and support service quality improvement.

3) Generic core dataset for community rehabilitation

Creating a single core dataset for all community rehabilitation is desirable and would make a huge contribution to the perceived and realised value of community rehabilitation services. Standardisation of data items could facilitate exploration of appropriate quality benchmarking and other comparisons. However, creating such a dataset is challenging because of the diversity and complexity of the specialties, professions, settings and populations covered. In addition to the core dataset, additional data will likely be needed in unique specialties.

Understanding the key stakeholders and what community rehabilitation data consumers need, should contribute to the process of designing a generic dataset for community rehabilitation with co-production at its core. A generic dataset should be kept as simple as possible with enough fields to demonstrate value but not so much as to overload the clinicians and staff who will be responsible for collecting it. Supplementing the core dataset, specific specialities may also require additional speciality-specific data sections. The UKROC database was suggested as a potential blueprint in terms of the data management processes and some data items.



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A generic community rehabilitation dataset should include

(but not be limited to):

- **Operational/transactional data** (for example, workforce staffing levels, disciplines and banding)
- **Patient reported outcome measures** (PROMs) (difficult to narrow down to a few to use)
- **Patient reported experience measure** (PREMs)
- **Demand/capacity data**
- **Data capturing non-patient facing activity, when appropriate**
- **Diversity/inclusion data**
- **Complexity/condition acuity data**

Furthermore, such a dataset should be able to support analysis of care quality and areas for improvement, service forecasting and cost effectiveness modelling.

4) Data administration

Community rehabilitation data should be collected locally with the data processing and analysis hosted centrally (as with SSNAP and UKROC) and should have registry status to allow the health status of patients and the care they receive to be tracked over time and between services. This would also allow the possibility of broad linkage to other datasets across all sectors and professions. The infrastructure must be in place to collect and share data efficiently, and with necessary data quality assurance processes in place, with analyses shared back with the supplying organisations. Acute care, specialised rehabilitation and long-term continuing care services should all be involved. There must also be appropriate data flows between services at different points on the care path and to third, social and independent sectors. SSNAP is a good example of how this can work.



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Summary and Discussion

The Community Rehabilitation Alliance Data and Evidence TaFG has identified key findings that help map how community rehabilitation services currently use data and have added understanding to what an ‘ideal core dataset’ may comprise for community rehabilitation. These findings are important in identifying the required steps to optimise data collection, submission and analysis in community rehabilitation which, in turn, can aid in showcasing, planning, maintaining and reviewing service provision.

Organisations want service level data for multiple purposes including, clinical delivery, research, quality improvement, benchmarking, showcasing best practice, making business cases and workforce planning, whilst clinicians primarily collect data to plan and modify their treatment for the individual patient. This represents a “clinician-organisation data use gap”. Hence, improving community rehabilitation data culture and use will require solutions that speak to the needs of both clinicians and organisations.

Only an incomplete picture of community rehabilitation services is currently possible due to limitations in data collection, submission and analysis. We found that although the majority of community rehabilitation organisations and services surveyed currently utilise databases, four in every ten do not- highlighting the need for improvement in data use. Current data use is a barrier to population health approaches and to patient data flow that would allow individuals to be tracked through health and social care services over time. We uncovered a wide variety of local, regional and national databases used. This could contribute to fragmented care if data is not optimally shared across different services on the care pathway. Having multiple individual, and often locally housed, databases contributes to the high levels of data submission duplication, system inefficiency, and makes it a challenge to compare services. Another key finding was that fewer than half of the organisations who submit data to databases consistently receive data analysis intelligence back and, concerningly, no data analysis is received from approximately one in five databases submitted to.



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Furthermore, when it is received, intelligence from data is often not shared with key stakeholders, such as the public and commissioners. This may contribute to lower perceived value of the whole process of data collection, submission and analysis, and fails to make the best use of collected data.

There were different opinions on what a generic ‘ideal core dataset’ might look like for community rehabilitation due to the diversity and complexity of the specialties, professions, settings and populations covered. Characteristic core data types of an ideal dataset agreed by over 70% of survey respondents included: individual outcome data (e.g. patient reported outcome measures – PROMs); experience data (e.g. patient reported experience measures -PREMs and staff wellbeing); service outcome data (e.g. impact on other services) and workforce data (e.g. staffing levels and skill mix).

Although we identified support to mandate community rehabilitation data collection and sharing, our roundtable discussions highlighted additional resource support, training and capacity to input, analyse and share data is required to optimise the use of community rehabilitation data. Although data is “everyone’s business”, it is unrealistic to expect the busy clinician to drive improvements in data collection, analysis and use alone. Central support for training in data use is essential and needed. However, without system improvements, such as a centrally housed efficient community rehabilitation database, and additional resource support and capacity to input, analyse and share data, we will not have the necessary system level infrastructure to realise the major potential benefits of community rehabilitation data.

Finally, we make the case for a coherent strategy for data that both aligns with the new Community Rehabilitation Alliance Best Practice Standards⁽¹⁾ and also helps us to understand and tackle health inequity⁽⁷⁾. Data is a fundamental part of the community rehabilitation agenda and necessary to optimise, integrate services and drive up the quality of person-centred care.



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Recommendations

For NHS England and NHS Digital

A community rehabilitation database must be simple to use, safe, efficient and hosted centrally. Such a database should be co-designed with stakeholders to reduce data entry duplication and foster data sharing. This, in turn, could help map service need and outcomes, support audit and service evaluation and improve integration of community services (including partnership working between acute, specialised rehabilitation, long-term and social care).

NHS England and NHS Digital have a key role in supporting, funding and delivering a centralised community rehabilitation database, including associated hardware and software. Without coordinated support, a national data collection system is unrealistic and indeed might be detrimental to service delivery given the unsupported clinical and managerial time costs that would be required.

For NHS England, Integrated Care Boards, Place boards, Rehab leaders and Clinicians

There is an important need to support frontline clinicians and leaders through training, involvement and feedback about data uses, benefits and analysis of findings.

This is necessary to ensure data capture and upload includes relevant fields, is valued, valuable and prioritised at an individual and system level.

Data collection should reflect the Community Rehabilitation Alliance Best Practice Standards 2022 and be part of the solution to tackle health inequity.

Appropriate involvement of other sectors outside the NHS is essential to reflect the breadth of community rehabilitation services.



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Conclusions

At the current time, only an incomplete picture is possible from fragmented community rehabilitation data collection, submission and analysis. Unifying data collection in rehabilitation is long overdue and the lack of high-quality data disenfranchises service users and disempowers rehabilitation clinicians, leaders and commissioners. The time to act is now as there is a combination of motivation to change throughout the system, technology availability and a focus on improving access to rehabilitation. Condition specific central data submission and support (such as in stroke) has been shown to change and improve care and is an exemplar of how data use can be improved in community rehabilitation. Full cross-system accountability for service outcomes, optimal service quality and adequate commissioning is impossible without such data.

This report contributes to the evidence supporting an integrated rehabilitation data collection strategy that is developed swiftly, supported centrally and implemented without delay. Good high quality data collection, submission and analysis underpins greater access to excellent community rehabilitation for all.



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Endorsements



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If you would like to get in touch or find out more about the Community Rehabilitation Alliance Making Community Rehabilitation Data Count report or the Data and Evidence Group you can contact us by email at: **communityrehab@csp.org.uk**

You can access the PDF and easy read versions of the report online at: **www.csp.org.uk/CRAdatareport**

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