University of Essex

EAST OF ENGLAND TRAUMA NETWORK

East of England Rehabilitation and Trauma Networks Report 2024

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Publication date: 25 Oct 2024

Version: 3.3

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Abstract

Introduction

Rehabilitation coverage in the East of England (EoE) was outlined as “variable, inequitable and under-resourced 20 years ago. Despite progress in some rehabilitation domains, there remains much need for improvement in coordination and equity. This is pertinent and challenging considering the ever-growing need for rehabilitation in the context of NHS budget strain. This study offers a current picture of rehabilitation over the EoE, to investigate change and offer targeted service development initiatives.

Methodology

An update to the Directory of Services (DoS) was undertaken, involving the contact of every service listed. Responses were recorded and qualitative information on service provision over the EoE was later collected from service leads. Data were analysed and compared against population data for each area to highlight areas of low and high need. One-to-one conversations with individuals working within EoE rehabilitation were held to provide further detailed perspectives on service provision.

Results

Results presented indicate that the EoE is heavily underserved for L1 care, operating at 19.96% of UK ROC recommendations. EoE service distribution is still “inequitable”, with disparity of services placing Cambridgeshire as having the highest coverage and Essex and Suffolk as having the lowest coverage. The update to the DoS revealed that service leads and phone numbers for services were the pieces of information that changed the most. Analysis of thoughts presented by service leads produced themes of coordination, system architecture, specialism and dynamics. During the period of this study one service experienced a withdrawal of funding from a locality, illustrating that precarity of funding is a further problem for service planning.

Discussion

The uneven spread of services across the EoE is worsened by the inaccessibility into a Level 1 facility. As there is only one available for the EoE, Level 2 services are having to make up Level 1 demand and are becoming over-stretched as a result. Collaboration and communication between services should be promoted, though it should be noted that communication will be hindered by the changing DoS information. A regularly updated DoS is proposed to counteract this and include information on new areas. Regular meetings between rehabilitation services should be encouraged to facilitate networking and sustain contact with regional leadership. There is a need for more systematic and formalised research using a wider range of data and greater stakeholder engagement that includes patients and more service providers.

Introduction

The ‘patchy’ nature of rehabilitative care over the East of England has been reported on for the last 20 years (Pickard et al., 2004), with numerous official reports campaigning for increased integration of services to reduce deficiencies in organisation and communication (Seeley & Hutchinson, 2006). With the ever-growing need for rehabilitative care (Cieza et al., 2020) occurring with budget strain within the NHS (Vize, 2022; Robertson et al., 2017), services are increasingly stretched. Consequently, it appears that little progress has been made in the last 20 years, when rehabilitation services in the East of England were characterised as “variable, inequitable and under-resourced” (Seeley & Hutchinson, 2006). The fact that the same issues are still being grappled with two decades later emphasises the need for improvement.

The same report detailed the need for rehabilitative responses to coincide with increased awareness of the “economic efficiency of healthcare provision” (McGregor & Pentland, 1997; Seeley & Hutchinson, 2006). Progress has been made in this area, with the UK Rehabilitation Outcomes Collaborative’s (UK ROC) analysis of rehabilitation’s quantitative data demonstrating total cost savings exceeding £4 billion for a population requiring specialist rehabilitation (Turner-Stokes et al., 2022; UK ROC, 2022). This posits rehabilitation as one of the most cost-effective treatments available within NHS healthcare, further demonstrating the need for development in service provision- to optimise care provided, therefore optimising cost-savings for the NHS, at a time when it is desperately needed (Menon, 2018).

Building on this research, this study seeks to offer an updated summary of rehabilitation provision across the East of England. The Eastern Head Injury Study showcased the challenges of rehabilitation 20 years ago, including “organisation and clinical management” and “a lack of, or disjointed, untimely or inappropriate rehabilitation care and ongoing support for many patients” (Seeley & Hutchinson, 2006; Pickard et al., 2004). This was due to the heterogeneity of injuries requiring rehabilitation meaning many professionals of different specialisms need to be involved. Through this study, we aimed to determine whether these challenges persist, and to highlight further challenges currently being faced by rehabilitative services across the East of England. Therefore, this report provides evidence to facilitate targeted service development initiatives. We present the report in two parts, the first based around the update of the service directory and the second some preliminary findings from interviews with services.

Part One

Methods

The existing Trauma Network Directory of Services was last updated in March 2023. Every service in the directory was contacted by phone. Where necessary, email communication was used as an alternative. Responses to all questions needed to update the Directory of Services, as well as enquiries around number of beds, service commissioners, service communication, capacity, and number of staff were recorded on a spreadsheet. Email addresses were provided during phone contact with services, enabling a google form to be sent out to collect additional qualitative information around service provision across the East of England.

Following the 4-week data collection period, responses were collated to provide a picture of what service provision looks like over the East of England. This information was further analysed through comparison against population data from the 2021 census for each region of the East of England. Population figures were compared against number of beds and number of different service types to determine service coverage of different areas, highlighting areas of low and high need. UK ROC service suggestions (Turner-Stokes, 2022) were then consulted to determine East of England performance against recommendations for provision. East of England performance against UK ROC requirements was further evaluated through comparison against neighbouring regions.

Results

Directory of Services Update

In updating the Directory of Services (DoS), it became apparent how much information had changed in the span of a year. In 42.8% of services included in the DoS (30/70), the contact number or service lead information had changed since the last update.

Descriptive Analysis of Services

Each service included on the East of England Directory of Services was mapped below to visualise the distribution of services. Level 1 services are in green, level 2 in red and level 3 in blue.

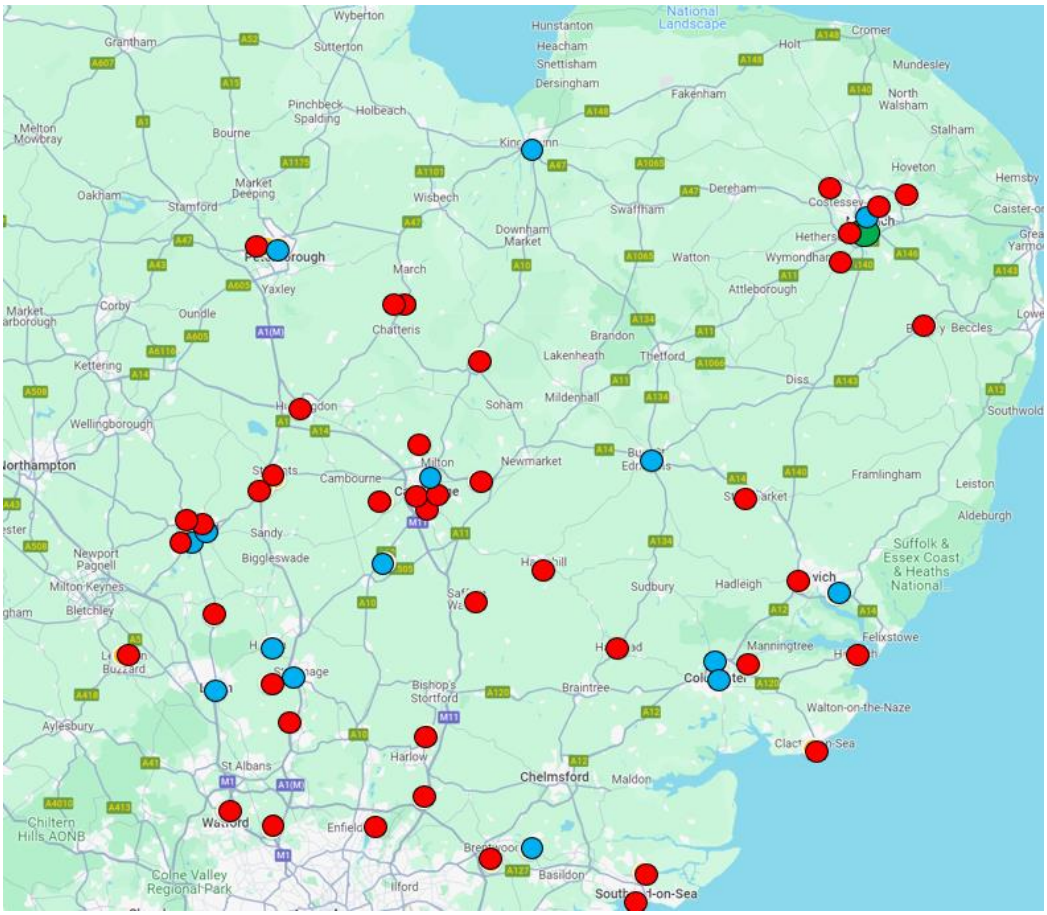

Figure 1: Distribution of services (recorded in the DoS) across the East of England.

Detailed in the Directory of Services, there are 9 services in Bedfordshire, 20 services in Cambridgeshire, 15 services in Essex, 9 services in Hertfordshire, 11 services in Norfolk and 6 services in Suffolk. Services were asked about the type of rehabilitation that they provide, and encouraged to select all areas that apply to their care. Their responses are detailed in the tables below.

Area/ Service type	Adult	Paediatric	Amputee	Brain Injury	Physical Disability	Spinal Cord Injury	Trache-ostomy
Bedfordshire	9	1	1	6	5	1	0
Cambridgeshire	18	2	4	19	15	12	6
Essex	15	0	1	10	13	1	2
Hertfordshire	8	0	1	9	7	6	1
Norfolk	11	1	1	10	5	4	1
Suffolk	6	1	1	5	1	2	0

Figure 2: Table displaying service type by area. See Appendix 1 for graphs.

Area/ Service type	Day centre	Long-term stay/ other inpatient	6-24 week stay	Short stay (</=6 weeks)	Locked hospital	Home visit/ out-patient comm-unity	Other/ misc support
Bedfordshire	2	2	5	4	0	0	1
Cambridgeshire	1	13	6	1	0	7	0
Essex	1	4	5	5	1	3	1
Hertfordshire	0	3	2	3	0	3	2
Norfolk	1	5	2	0	0	5	1
Suffolk	3	2	0	0	0	2	1

Figure 3: Table displaying service type by area. See Appendix 1 for graphs.

The number of beds in services is detailed below:

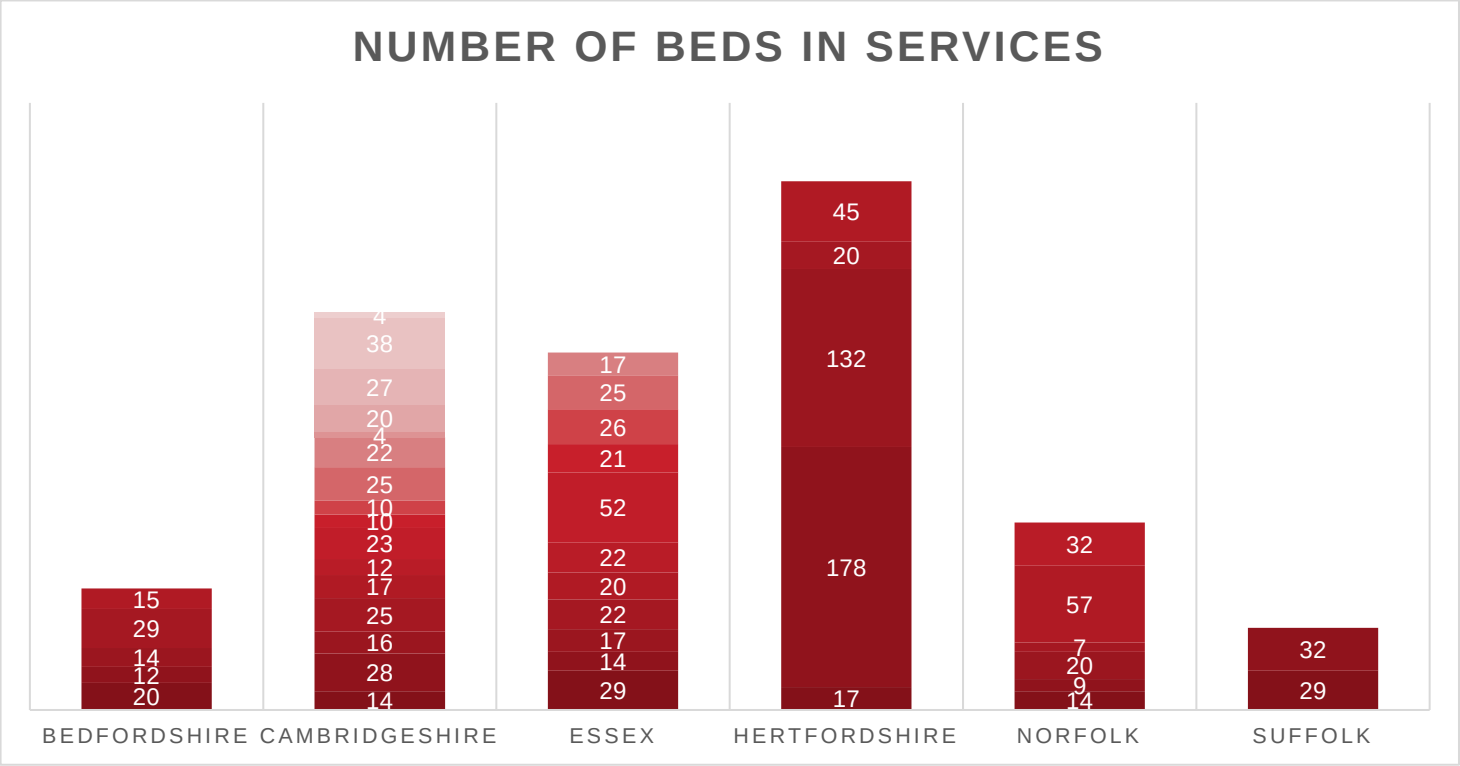

Figure 4: Number of beds in services in East of England areas

It is important to note that the catchment areas and populations for different services vary. Fig 4 simply displays the number of beds in services in these areas across the East of England (for example, Bedfordshire has five services ranging between 12 and 29 beds)..

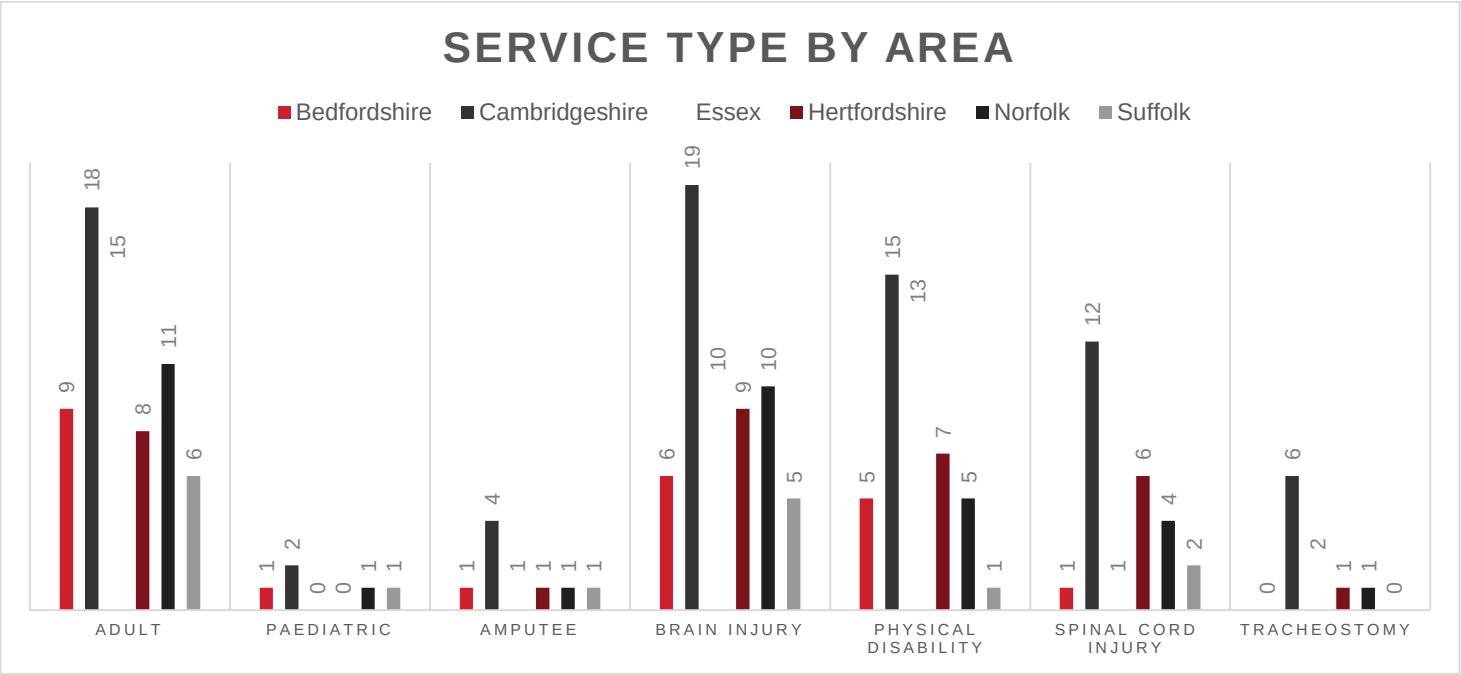

Figure 5: Number of different types of services in areas across the East of England

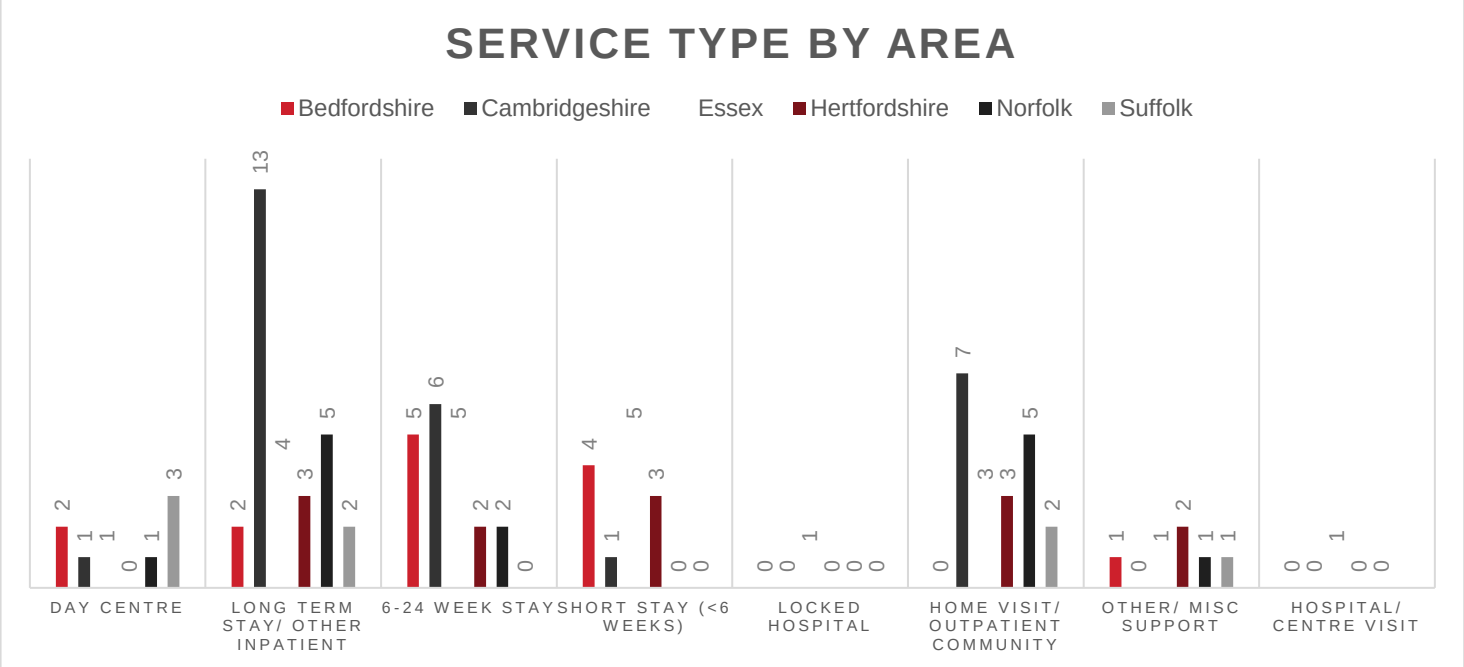

Figure 6: Number of different types of services in areas across the East of England

Gap Analysis of Service Provision

Cambridge consistently emerged as the area of the East of England that had the best service coverage, with the only areas it was not top for being day centres, and short stays (</=6 weeks). Bedfordshire, Hertfordshire and Norfolk were evenly matched in their service provision, with Essex and Suffolk emerging very low for service coverage, highlighting them as the most probable areas of high need. Graphs included in Appendix 1 (figures 7-18) detail service coverage for different service types, with the most coverage on the right (lowest number of people per service) and the least coverage on the left (highest number of people per service. Where there were no services, the bar is marked as 0.

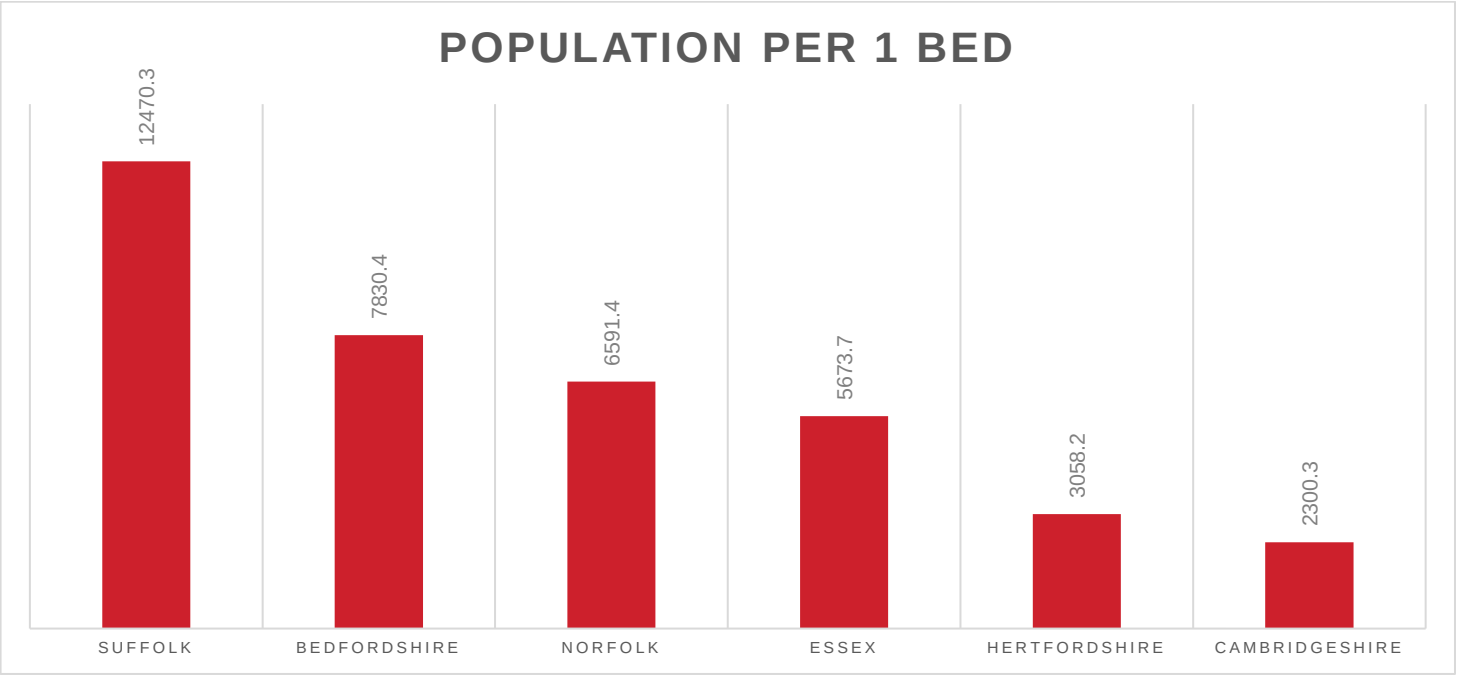

Figure 19: Bed coverage per area

This graph details the number of individuals that each bed accounts for based on 2021 census population information for different areas across the East of England. Therefore, bed provision is best in Cambridgeshire, with each rehabilitation bed serving 2300 people and worst in Suffolk, with each rehabilitation bed serving 12,470 people.

UK ROC Recommendations for Service Provision

The UK ROC Six-year report (Turner-Stokes et al., 2022) outlines the population figures that services are designed to serve. Level 1 services are planned for a population of between 1-5 million people, catered towards those with highly complex rehabilitation needs that extend beyond the scope of district and local specialist services. UKROC outlines that for every million people, approximately 20 rehabilitation beds are required. Level 2 services are planned over a district-level population of 350,000 to 500,000, with possible extension to support a supradistrict catchment of 750,000 to 1 million people. Considering 2021 census data that reported the population of the East of England as 5,762,545, the East of England would need between 2-5 Level 1 services (containing a total of 115.25 beds) and 11-17 Level 2 services to meet UK ROC requirements.

As outlined by the UK ROC, there is one Level 1 services that provides for the East of England, containing 23 Level 1 beds. This places the East of England significantly below the required provision for Level 1 care. Reflecting on the number of beds in comparison to UK ROC requirements, the East of England is operating at 19.96% of what it should be, considering that only 23 Level 1 beds are available, in comparison to the recommended 115+. Conversely there are 37 Level 2 services providing care across the East of England, above the recommended minimum requirements of care for Level 2 provision.

Level 1 provision in neighbours to the East of England

North East London

North East London ICB serves the areas: Barking & Dagenham, City of London, Hackney, Havering, Newham, Redbridge, Tower Hamlets and Waltham Forest. Considering 2021 census data that reported the population of North East London as 1,997,700, North East London would need between 1-2 Level 1 services (containing a total of 39.95 beds). As outlined by UK ROC, there are 2 Level 1 services in North East London, containing a total of 31 beds. This places North East London below the required provision for Level 1 care. Reflecting on the number of beds in comparison to UK ROC requirements, North East London is operating at 77.60% of what it should be, considering that only 31 Level 1 beds are available, in comparison to the recommended 39+.

Midlands

The Midlands contains 11 ICBs: Birmingham and Solihull ICB, Black Country ICB, Coventry and Warwickshire ICB, Derby and Derbyshire ICB, Herefordshire and Worcestershire ICB, Leicester, Leicestershire and Rutland ICB, Lincolnshire ICB, Northamptonshire ICB, Nottingham and Nottinghamshire ICB, Shropshire, Telford and Wrekin ICB and Staffordshire and Stoke-on-Trent ICB. Considering 2021 census data that reported the population of the Midlands as 10,831,000, the Midlands would need between 3-11 Level 1 services (containing a total of 216.62 beds). As outlined by UK ROC, there are 4 Level 1 services that provide for the Midlands, containing a total of 83 beds. This places the Midlands below the required provision for Level 1 care. Reflecting on the number of beds in comparison to UK ROC requirements, the Midlands is operating at 38.32% of what it should be, considering that only 83 Level 1 beds are available, in comparison to the recommended 216+.

Taken together the observations from two neighbouring regions illustrate the challenges facing rehabilitation nationally. However, we have not discussed this analysis with colleagues in these regions and acknowledge local contextual information would be required to draw firm conclusions about these two comparisons. As such, a national study may be required.

Discussion

Directory of Services Update

As only a year had passed between updates to the DoS, it was surprising that such a high percentage of vital information had changed. Both contact numbers and service lead details are key items of information, instrumental for inter-service communication. In facilitating rehabilitation, movement between different services is expected, so it is extremely important that these pieces of information remain up to date, to allow services to communicate with each-other, therefore preventing ‘blockages’ throughout the system. Frequent change of contact numbers and service leads therefore may provide a barrier to smoother inter-service communication.

Descriptive Analysis of Services

The varied number of different services in the different areas of the East of England highlight that there is a vast spread of provision of care, with different aspects of care better represented in certain areas. Though different areas seem to be ‘hotspots’ or ‘areas of need’ for different aspects of rehabilitative care, the trend remains evident that there are some areas of the East of England that have better provision than others. It should be noted that this is not intended to imply that care provision in ‘hotspots’ such as Cambridgeshire is excessive. Instead, highlighting areas as ‘hotspots’ and ‘areas of need’ serves to highlight the disparity in care provision between the different areas of the East of England, thereby identifying areas that may require prioritised intervention.

Gap Analysis of Service Provision

When considering service provision across the different regions of the East of England, both variation in service types available and number of beds overall must be considered. As included in Appendix 1, figures (7-18) portraying coverage of different service types, Essex and Suffolk were presented as having the lowest service coverage, highlighting them as the most probable areas of need. Notably, Essex had no paediatric coverage, and Suffolk had no 6-24 week stay or short stay coverage. In contrast, Cambridgeshire emerged as having the best coverage in all but two areas. Regarding the number of beds available, Cambridgeshire also emerged as having the best coverage, with the population of Cambridgeshire represented by one bed to 2300.3. Conversely, Suffolk presented the worst coverage, with its population represented by one bed to 12,470.3. This implies that if there was an immediate need to allocate rehabilitation beds to the whole population of Cambridgeshire and Suffolk, there would be a competition for one bed amongst 2300.3 in Cambridgeshire and 12,470.3 in Suffolk.

By comparing the number of beds available to the population of the different areas, the true “inequitable” nature of care can be seen. There is simply not the same level of provision over the different areas, meaning that where one is can affect access to necessary rehabilitative care. This has been termed a postcode lottery. The disparity in care may mean that patients residing outside of ‘hotspots’ would need to travel to obtain the same level of care that is more readily accessible to patients within ‘hotspot’ areas. This would place patients farther away from their community and family, therefore reducing their access to their support network throughout the duration of their placement in rehabilitative care. The results indicate that patients residing in Suffolk would be less likely to have access to a bed within their area, and it is therefore more probable that they would be transported out of area to receive the care that they require.

UK ROC Recommendations for Service Provision

Firstly, it is imperative to underscore the considerable pressure under which services in the East of England are currently operating. At 19.96% of UK ROC recommendation for Level 1 provision, the East of England has less than a fifth of the infrastructure that it should do, to be serving the population that it does. Also, Level 1 demand is not negated by above requirement Level 2 provision, as the specialism

needed in Level 1 provision cannot be provided at a Level 2 level. The ‘highly complex rehabilitation needs’ displayed by those requiring Level 1 care are stated by the UK ROC to ‘extend beyond the scope of district and local specialist services’, placing the rehabilitative needs above what Level 2 services should be expected to provide.

This causes an issue with system flow, as Level 1 patients cannot access the care that matches their complex rehabilitative needs due to a lack of Level 1 beds. Patients therefore are placed on an interim basis in Level 2, which causes further problems as ‘true’ Level 2 patients are therefore less able to access the care that they need as their place is being held by someone with more complex needs than the service is designed to accommodate. Where Level 2 care would be more helpful in the case of a ‘true’ Level 2 patient, as their needs would match what the service is designed to accommodate, they are being held up and are unable to access this care.

Issues with system flow therefore end up not just affecting the Level 1 patients who cannot access care to accommodate their complex rehabilitative needs, but cause blockages further down the system, stretching Level 2 demand and preventing patients needing less complex care, access to the care they need. This does not only impact the patients, but also the services themselves. Coping with Level 1 demand does not only mean an increase in number of patients but an increase in complexity of needs displayed within patients. The primary rationale for stratifying care into distinct levels was to mitigate issues of this nature and to ensure that individuals with diverse and complex needs are directed to the appropriate care setting corresponding to their level of complexity (Turner-Stokes et al., 2022). Therefore, system blockages undermine the levelled system and create exactly the issues that the system was designed to prevent.

Level 1 provision in neighbours to the East of England

The comparison of the East of England’s performance to its geographic neighbours (North East London and the Midlands) revealed that none of these areas meet UK ROC requirements for Level 1 service provision, operating under the baseline recommendation. Despite that, the direct comparison served to demonstrate that other regions have more services and beds available compared to their respective populations. This demonstrates larger inequity than just between regions of the East of England, that the region as a whole is underserved in comparison to its neighbouring regions. Operating at 19.96% of what it should be is extremely low compared to 77.60% and 38.32%, further presenting a ‘postcode lottery’ of rehabilitative care. However, it is imperative to recognise that none of the regions are operating at the baseline recommended level of provision.

This underscores the need for a significant push for growth and development of Level 1 rehabilitation services, nationally, but especially in the East of England. With only 23 Level 1 beds, as opposed to the recommended 115+, the East of England has a stark shortfall in Level 1 provision. Therefore, we concluded that there is urgent need for substantial investment in Level 1 services, providing more Level 1 beds, to bring the East of England closer to what is recommended as a baseline figure. Such efforts are crucial for improving the landscape of rehabilitation within the East of England and addressing the broader national shortage of Level 1 provision.

Part Two

Methods

Findings detailed in Part One were discussed in one-to-one conversations with service leaders and presented to regional team meetings within the East of England rehabilitation network. This gave opportunity to verify findings and provide more contextual information about service provision over the East of England.

Points made in conversations and focus groups were noted down and analysed with google form responses taken in Part One. Our analysis was influenced by the method know as “thematic analysis” although it is important to note that this study was not established as a formal full research study. We were able to review the records of conversations and themes from the dataset were identified, outlining the key opinions and viewpoints from some service leads within the East of England.

Results

A google form, sent to services in Part One was utilised to capture additional ‘qualitative’ information. 45 services that provided email information were sent the google form, and 11 completed the form, providing further information. Fields and questions within the google form are contained within Appendix 2.

We highlight two independent themes identified from the responses. These were:

I. Staffing
II. Impact

Focus group sessions, held with service leads on the 4th and the 19th of April with a total of 51 invited guests, provided additional ‘qualitative’ information, contributing to this report. These supplemented smaller conversations held with service leads on the 1st February, 28th February and the 12th April with a total of 4 guests.

We highlight four independent themes that emerged from the discussions. These are:

I. Training
II. Directory of Services
III. Effect of COVID
IV. Effect of stroke

There are four larger themes that emerged within both the qualitative data of the google form responses and the focus group conversations. These are:

I. Coordination
    a. Capacity

    b. Referrals
II. System architecture
    a. Pathway navigation
    b. Levelled system
    c. System organisation
    d. Funding
III. Specialist services and provision
    a. Complexity
    b. Specialist knowledge
    c. Service development
IV. Dynamics
    a. Communication and collaboration
    b. Leadership
    c. Competition and tension

Staffing

The google form responses highlighted positive and negative aspects to staffing within East of England rehabilitation. Services stated that they were having issues with staff recruitment- specifically nurses and support workers. Adjustments to team structures was also raised as a current issue within services, as fewer higher banded staff present meant that weighting of care was being inappropriately distributed. Recovery from COVID within staffing patterns was stated to still be an issue, even four years after the pandemic began, as post-COVID working has changed the landscape of staffing significantly meaning that staff are more frequently working from home and in isolation from a team. Coupled with increased staff sickness, the structure of NHS staffing was overall seen as an issue due to the changes it has undergone in the last four years.

However, positive aspects related to an ‘invigorating’ changeover of staff were highlighted also. Services reflected that a positive aspect of the services themselves was having a ‘great’ team of people and being surrounded by skilled individuals. Having a skilled therapy team was highlighted as a positive of services, demonstrating that there remains positive outlook to staffing within current rehabilitation provision.

Impact

Services highlighted that an understanding of the impact of their work would be extremely welcome, bolstering positive perception that the work being done for rehabilitation over the East of England is making a difference. Having a ‘clear view of impact’ of the services at the frontline of rehabilitative care would not just raise morale but would also allow services to reflect on possible improvements.

Services highlighted many positives relating to impact when asked about positives of the services they are working in. Clients were said to be ‘enjoying the changes and new enthusiasm and ideas’, and services reflected that they were making a ‘real impact on the recovery progress’ of their clients. The feeling of positive impact still provided in services lacking resources is underscored by this services reflection that they are ‘managing rehabilitation well’ given the circumstances and have ‘moved clients into the community who had been told they would always remain in care’.

Training

Focus group participants discussed the necessity of having regular training opportunities provided as part of routine rehabilitative work, allowing professionals to progress in their knowledge of rehabilitative processes and equipping them with the necessary understanding to progress in their careers. The want for ‘regular CPD training sessions’ was discussed in context of other networks being able to access such training, as participants outlined that ‘training like this is readily available for stroke’, which is not the case for ‘neuro’. Related to training, the need for a place to provide training opportunities was discussed.

Directory of Services

Developments to the Directory of Services were brought up in many focus groups due to the nature of this project in updating the directory as one of its aims. Participants highlighted the need for the directory to remain up to date, allowing for patients and services to access information on all relevant services within the area. In this, a rehabilitation coordinator post was presented as needing to be filled following its year-long vacancy. Without someone in this role, the directory falls out of date ‘extremely quickly’- presenting the need for continuous updates due to the quick-changing nature of services. Furthermore, many ideas for future development and inclusions were raised. The inclusion of neuro-palliative care, a bigger audit on outpatient community care and better descriptions of specialist neuro facilities were all raised as developments needed within the DoS. Finally, it was noted that it would be helpful to ‘view the distribution of services by ICB rather than by region’, to clear understanding of pathways. The importance of understanding the genesis of the DoS and its use by professionals was also raised as essential for this report.

Effect of COVID

As briefly touched upon when discussing staffing, the effect of COVID has been monumental on the whole healthcare industry and trauma and rehabilitation are no different. The loss of beds to the wider system was raised by professionals as extremely detrimental to what could have been a great development to the system. Not only did COVID halt future development of rehabilitative services, but the loss of beds that have been unable to be recovered halted already planned developments. One participant highlighted that within the pandemic, there was a loss of 20 beds that were meant to be solely dedicated to neuro.

Effect of stroke

The comparison of neuro to stroke was one that was made frequently over the course of the focus groups. Participants highlighted that stroke patients have ‘dedicated spaces’ that people with other neurological conditions are not afforded. The persistent want for these specialist spaces is demonstrative of the need to provide quality care to the highest standard. This is presented as extremely difficult when patients are ‘dotted around’. Participants further highlighted the effect of stroke on service provision, stating that ‘where stroke units are ends up affecting the configuration of rehabilitation services’. Furthermore, discussion around bed capacity presented further influence from

stroke as participants detailed that where bed capacity is being influenced by stroke patients, this is not being monitored through ABI pathways as independent ABI providers do not have to provide that data.

Coordination

Participants discussed the wider theme of coordination in reference to the capacity of services and the referrals they were receiving.

Capacity

The word ‘full’ emerged frequently in the qualitative data collected, with participants reflecting that they ‘are full’ and had ‘full occupancy’. This ‘lack of capacity’ as a result of being full had implications such as struggling to ‘cover caseload in a timely manner’ as services are only ‘just coping with demand’. This underscores the issues in the distribution of care described through the quantitative results, as it is apparent that services are struggling, after being pushed to the limits of their capacity. With this, services reflected that the strain on capacity resulted in them having no time for ‘extra stuff’, such as filling out forms or providing feedback on the system that is useful to inform studies such as this one. They presented that they are already ‘burning out at 100mph’ leading then to have no time for discussions about the fact that they are working to such an extreme capacity, which could aid in understanding and preventing the very issue.

Referrals

Services highlighted issues with referrals, reflecting that they are not ‘on a consistent intake’, that they came in the pattern of peaks and troughs. This is difficult for service management, affecting provision and capacity and as a result, staffing and overall care. The knock-on effect of inconsistent referral patterns is only worsened by ‘inappropriate’ referrals being made, where patients are moved away from where they would be ‘better placed’. This was said to accentuate the fact that ‘NHS ABI services are in crisis’. Some services reported a ‘lack of referrals’, demonstrating the inequitable distribution of care as where some services are at the point of strained capacity, some are not meeting capacity at all.

System architecture

Participants discussed the nature of pathway navigation through a levelled system, the overall organisation of the system and the role that funding plays within system architecture.

Pathway navigation

Discussions illuminated that service leaders have issues in understanding the ‘clarity’ of the pathways. They highlighted that there is the need for ‘clearer pathways and links to commissioners for better support’. Issues in understanding how to navigate pathways was discussed as a contributory factor to maintaining blockages in the system, as the ‘confusing’ organisation of the pathways means that service users are unsure how to move patients through the system. One participant detailed that it felt like services were just ‘moving blockages around the system’ instead of getting people to care that they need. Services highlighted that the funding aspect of the pathways, including access to commissioners was ‘confusing’, which contributed to the feeling of ‘moving blockages’, as the lack of understanding of

the different commissioning and funding systems halts the ability to successfully move patients throughout the system. In order to understand this, service providers highlighted the 'importance of discussing pathways and decision processes with neuro-navigators. This was highlighted as neuro-navigators have a better understanding of the different pathways and processes and so are better-equipped to contribute the necessary knowledge that service providers may lack.

Levelled system

Participants discussed pathway issues within the levelled system of rehabilitation, where care is split into levels 1, 2 and 3 to outline level of need and type of care. Issues presented were not with the levels themselves, rather issues that are existing and persisting within the levelled system. Alike pathway navigation, the idea of blockages was brought up in discussion of the levelled system. Specifically, within the East of England, the lack of Level 1 provision was highlighted as the cause of these blockages, with participants detailing that Level 1 'restriction puts pressure onto' Level 2. This is not the extent of the issue, as further affect was presented to arise from this, including that if Level 1 patients are in Level 2 beds, this causes 'blockages' as 'true' Level 2's cannot access their care if Level 1 patients are in Level 2 beds. This causes issues even further down the chain as 'pressure' is put onto Level 3 as a result of all of these blockages. This was said to be the source of the 'delays' that participants presented they were hearing about 'all the time'. Furthermore, the overwhelming repetition of the words 'pressure' and 'blockages' serves to demonstrate the feelings of those working in rehabilitation services across the East of England due to these persisting issues within the levelled system.

More specific issues persisting within the levelled system across the East of England were presented as contributing to the broader themes of pressure and blockages. Interim placements in Level 2 were discussed to be becoming increasingly common in the wait for Level 1 beds. This was highlighted as a particular issue in Norfolk as this is where the interim placements started. Also, discussions presented that 'there is not enough money' to create the necessary beds, making the tough situation hold permanence, with no future sight of blockages being removed. Participants raised that due to the length of these blockages, 'by the time that' patients receive the level of care that they were referred for, they may not be suited to that level anymore and may require different care. Finally, a further issue persisting within the levelled system was that patients may become 'suspended' in Level 1 services where there are no other services closer to home. Step-down processes therefore can result in patients being moved further away, in contrast to what is expected of the step-down process. This was presented as an issue in Essex, but highlights a bigger issue of distribution of care, that there is not an appropriate spread of services to ensure that people living in a certain area can receive step-down care from Level 1 in a place closer to their home.

System organisation

The feeling that 'gaps and hotspots of care produce a feeling of luck rather than strategy' was raised as a major issue in the organisation and provision of healthcare, both across the East of England and nationwide. Participants raised that you have to get 'lucky' to live in a place of 'good' rehabilitation provision, and the fact that that is not guaranteed immediately outlines the flaws of the system. This

was discussed as a ‘postcode lottery’, with that phrase employed to outline the luck necessary to obtain a certain level of rehabilitation provision. The distribution of care was discussed as being ‘determined by community configurations’ which was presented as a possible cause for the present gaps and hotpots. Furthermore, the effect of COVID on the ‘postcode lottery’ of care was spotlighted, as a loss of beds to stroke and COVID patients throughout the pandemic was discussed as only worsening the present inequitable distribution by removing beds from areas that need them.

The issues of distribution of care were also presented as a problem regarding transport provision to access care. This issue was raised regarding patients accessing an ambulance for scans that travels from Peterborough, as there is not one closer, to move a patient ‘two minutes down the road’. With more even distribution of care there would not be the need for an ambulance to travel the initial distance, as there would those placed closer.

Another broad issue raised within system organisation was issues with patient placement. Discussions underlined that due to a ‘lack of integration with providers’, placements became ‘complicated cases’. This is exacerbated by different ICBs having different ‘placement scheme[s]’ as it makes it difficult to move patients through the system without knowledge of each scheme. The idea of a ‘system’ allowing ‘consistent updates’ on bed availability to help navigate the logistics of different placements was raised as a necessary future development within rehabilitation. In the meantime however, communication between services is necessary to plug this gap. As many services reflected that they did not consider themselves part of a network, better integration with groups and networks is essential.

Funding

Discussions surrounding funding were characterised by the word ‘lack’, both in a lack of clarity on the funding systems in place, and a lack of funding itself. Regarding the lack of clarity about the funding systems, participants presented that ICB’s may not have full understanding of their spending at Level 1 and 2, particularly regarding ‘how many people’ are being paid for. Services also highlighted a lack of understanding of the different pricing models between them, with the idea of a ‘single pricing model’ brought up to solve this issue. This would ‘display the care costs for different services’, therefore allowing for open access to understanding of the funding patterns and pricing structures of services within the East of England and wider.

A lack of funding available was discussed as a resented but accepted fact of working within healthcare. Services presented that there is a ‘lack of funding’ for securing services ‘to support clients and carers’ and that funding was intrinsically linked to issues with capacity. When asked about issues within the rehabilitation system, ‘funding and capacity’ came up together frequently. This was presented as not a recently occurring issue, rather that there has been ’systematic underfunding of brain injury’ and rehabilitative care for ’20 years’. This contributed to a discussion where participants presented that they felt ‘the need to communicate’ firstly the extent of the underfunding within a platform such as this report, but also the ‘cost-effectiveness of rehabilitation’. They discussed how funding rehabilitation should be more of a ‘government priority’, not just for the people that need the help, but also because of the money that can be saved for the NHS as a result of funding rehabilitation.

Specialist services and provision

Participants discussed the rising complexity of cases within the rehabilitation network, the requirement for specialist knowledge within the discipline and the need for service development.

Complexity

The feeling that there has been ‘increasing complexity of patients’ was reflected frequently, with participants presenting that they have seen increasing numbers of patients with more complex needs, including those with motor-neurone disease, neuromuscular disorders, functional neurological disease and Huntington’s. Participants revealed that there are ‘really sick people coming through the door’, and this ‘rising’ ‘complexity of patients’ increases the pressure felt on services. In addition, participants disclosed that there was specific pressure from acute to ‘diagnose quickly’ meaning that patient medical stability is ‘questionable’ due to the rushed process. It was said that ‘every part of the system has increasing complexity’, not just the services themselves. Neuro-navigators were also discussed to have rising complexity within their role as they ‘used to mainly deal with trauma patients’ but their job roles have since expanded. On the other hand, an increase in complexity was not always reflected on negatively as one service highlighted the positive aspects of service development that came with rising complexity.

Specialist knowledge

One of the main issues that surrounded specialist knowledge is the ‘lack of’ and ‘issues accessing’ specially trained individuals who can offer ‘specialist support’ and knowledge through their training. Services highlighted that there is a ‘lack of support’ from ‘psychologist and psychiatrists for complex cases’, ‘areas such as SALT’ and ‘issues accessing AHP clinicians and psychotherapy’. The specialist supported needed for the complexity of rehabilitative and trauma care is clearly lacking, with one participant positing that this is ‘due to funding’. Issues accessing other domains within rehabilitative care were also raised, such as NHS dentistry and social work. Participants highlighted that there is ‘no social work involvement once a client has been transferred’, leaving them with nobody to ‘discuss issues with’. Overall, it was raised that there is a lack of ‘support to optimise recovery’, as without the ‘development of additional provisions’, services are struggling to gain access to the specialist knowledge that they need.

The specialist knowledge required specifically for neuro care was discussed as not always being adhered to, as participants disclosed that ‘non-neuro specific OTs [occupational therapists] and other professionals’ are being ‘brought on to work on neuro cases’ without having the ‘specialist knowledge required’. This was specifically presented as an issue within ‘primary care teams’ by another participant. This same lack of knowledge was discussed for tracheostomy care and neuro-palliative care also, as both require specialist knowledge and therefore are difficult to place, meaning there may be errors in placement. The loss of Sue Ryder to the system was also mentioned by one participant as a loss to specialist knowledge as they ‘did tracheostomy care extremely well’.

Finally, an issue in specialist knowledge brought up within discussion is the ‘increased demand for private’ care including private physiotherapists and other professionals. Though this is not an issue

within itself, however, participants detailed cases where ‘private and NHS practitioners have given conflicting advice’. One participant discussed a case where a private physio brought in by a case management team advises a splint where NHS practitioners working with the patient do not believe a splint is necessary.

Service development

The need for increased service development was discussed explicitly with discussions detailing that an issue within the network was a lack of ‘places for young people’, and a great ‘shortage for paediatric trauma’. The lack of provision for under-18s was said to be demonstrative of a need for service development, to increase provision. In addition, service development was proposed to prevent issues accessing ‘participation in work, social, leisure, sport, physical activity’ and other necessary domains of care. As highlighted above, services are struggling to access specialist knowledge, and so the need for service development is apparent. Participants highlighted that there were issues within their specific services such as threats ‘to clinic and gym’ spaces, hindering development. In contrast, there was some positive reflection on service development, where a service reflected on their ‘continued growth’ as they have had an addition of some rooms recently.

Dynamics

Participants discussed the dynamics of communication and collaboration against those of competition and tension. Leadership dynamics were also discussed.

Communication and collaboration

Communication and collaboration as a whole were raised as an issue between services in the East of England, particularly as networks in the area were labelled as ‘confusing’ and difficult to integrate with. This has left some services feeling as if there is ‘no link between services’ and ‘nobody to turn to for advice in a crisis’. In addition, communication and collaboration were detailed as lacking as participants discussed ‘a lack of insight’ into what services can offer to differentiate themselves, and a lack of ‘regular information on services and new developments’. This has spotlighted a need for ‘more support and links between services’. Despite the issues with communication and collaboration, participants discussed that within the networks of communication in the East of England there was good opportunity for ‘information sharing’ including sharing of ‘lessons learned’, ‘clinical knowledge and initiatives’ and ‘ideas’. This contributed to the positive feelings around the network, that services can be ‘really supportive’.

Communication and ‘networking’ were described as ‘vital’ for sharing insight into ‘treatment pathways’ and ‘what is needed within the speciality’, allowing services to expand based on need. One service discussed how vital networking was as it allowed them to ‘find resources and capacity to provide excellent services’. Networking was also discussed as allowing for sharing of specialist knowledge as participants discussed ‘building links with specialist centres’. In order to allow better collaboration within services through networking, the idea of contacting ‘regional groups that are doing really well in certain areas’ was raised, in order to share ideas between services.

Leadership

In discussing leadership, services reflected on it as a ‘real issue’, saying that ‘no one wants to lead’ and that ICBs ‘cannot get their heads together’. There was the suggestion of a ‘neuro-rehab steering group’, pulling together ICB leads, to engage with commissioners and ‘keep up to date on issues. A clinical lead within ISDN was discussed as a positive move forward in rehabilitation, but participants reflected that stroke ICSs need a clinical lead also. Issues such as community neuro care integration and communication, as well as enforcing a common pricing model, were discussed as only solvable with a better leadership presence, making the NHS less ‘isolated individuals’, and bringing together rehabilitative care over the East of England.

Competition and tension

The feelings of competition and tension were said to arise from a ‘lack or respect for each other’s specialism and knowledge’ and ‘perceived superiority’. The dynamics of the placement system were discussed as a facilitator of this tension as ‘all ICBs have equal grab on the independent’ placements within the East of England, and rehab cases encounter the situation of ‘buying from a pool of providers from individual patient’s prices’. This creates a feeling of competition between services as they all are vying for the same patients, rather than having a ‘queuing system’ and a common ‘pricing model’ to navigate this issue and prevent the ‘bidding war’. Feelings of tension were also produced due to ‘turnover within the private sector’, as where a ’few corporate entities’ are ‘buying out smaller practices’ the regional provision of rehabilitation changes. Finally, tension was said to be held within the network as there are ‘politics’ between the East of England and ICBs within it, as ‘ICBs don’t like’ the East of England contacting their staff. Though tension and competition exist, one participant neatly highlighted that what the network needs is ‘greater collaboration rather than perception of threat’.

Discussion

Discussions with service leads provided key context to the findings detailed in Part One, offering region-specific perspectives on rehabilitation service provision across the East of England. The principal conclusion to be drawn is that that services are in ‘crisis’ and are under ‘pressure’, underscoring the need for rehabilitation to become both a government priority, and a priority for region-specific MPs and ICBs.

The most immediate point of need relates to the coordination of the levelled systems within the East of England. Validating the findings of Part One, conversations with service leads illuminated the dire need for better Level 1 provision within the region. The lack of Level 1 services was presented as a big contributing factor to the ‘pressure’ felt within the region, as it strained Level 2 services. The inappropriate placement of Level 1 patients within a Level 2 facility causes loss of beds, preventing *true* Level 2 patients the placements they need. Additionally, further stress is put on Level 2 services due to the higher level of complexity that Level 1 patients present with. This will ultimately contribute to the vocalised sentiment that patients are getting ‘sicker’, as patients with higher complexities are being placed within a Level 2 setting due to the Level 1 demand.

In addressing this situation, more Level 1 beds are needed in the East of England. Furthermore, better step-down pathways should be established, preventing patients from being stuck within Level 1, when they are no longer in need of care of that complexity. It should be ensured that the new step-down pathways prioritise stepping down into care that is closer to home, and Level 2 providers should be appropriately distributed in order to facilitate this. This would also serve to aid the issue of 'blockages' within the system. With more Level 1 beds available, and a better step-down strategy, patients would not be stuck with inappropriate Level 2 placements. Where services are currently functioning at full capacity, the best referrals cannot always be made. Therefore, appropriate funding and commissioning to increase the capacity of Level 1 care within the East of England is necessary.

Particular areas needing attention, regarding specific groups of patients were raised within discussions, as reported within the results. There is a need for neuro specific beds, grouped together rather than 'dotted around', as service leads reported, to enable the best possible care delivery for neuro patients. Also, there is the need for development of paediatric care offerings over the East of England, as that was reported on as underserved. Overall, better distribution of care is required across the region as discussions validated the findings that there are 'gaps' and 'hotspots' of care over the East of England.

The need for regularly updated knowledge within rehabilitation and trauma networks was highlighted through the conversations had. Firstly, the value of the Directory of Services for allowing inter-service communication was highlighted, furthering the point of its importance in being maintained and kept up to date. It must be guaranteed that the directory is kept up to date so that services can communicate, facilitating referrals and networking across the region. Therefore, it is important to have an individual appointed to assume responsibility for the task of updating this necessary document. In addition, regularly updated knowledge was sought for in the form of appropriate training sessions. The set-up and maintenance of CPD-accredited training opportunities would serve to foster collaboration through networking, developing the skills and knowledge of those working within rehabilitation and trauma over the East of England. This would also work in demonstrating the need for neuro-specific knowledge to work within that discipline, something that was raised within discussions.

Limitations and next steps

We acknowledge the limitations to this report, particularly the pressure in the system meant that comprehensive and systematic sampling was not achieved. It was out of scope for us to include patient and carer voices. Further and ongoing structured research that enables a wider range of participant interviews would be warranted. A health systems framework approach that examines service delivery, resource generation, financing, and governance is recommended (e.g., WHO 2010). We need to investigate intersectional perspectives (Veladhir et al 2023). To help us understand underlying factors contributing to differences across the region a deeper analysis, using a well-established framework like the one from the European Observatory on Health Systems and Policies used for evaluating Universal Health Coverage (UHC) is proposed. This will provide a more thorough and standardized evaluation of service gaps. Nonetheless, we consider that our perspective has highlighted some key areas for development that are situated within a wider national narrative of challenges experienced by rehabilitation service providers. Where we have focused on Level 1 and 2 capacity; charity, specialist

community and outpatient services are recognised as crucial contributors that enable the system to operate effectively and continue to experience variable and precarious funding.

Finally, the concept of maintaining positive dynamics across the trauma and rehabilitation network within the region was raised repeatedly. The importance of communication and **being part of a network** is celebrated, and this should be extended to all those within the region. Communication and discussion on an inter-regional basis could serve to provide missing knowledge into the different pricing systems and placement schemes between areas of the region, ultimately aiding referrals and placements. Though, there remains a need for clearer **leadership** from the ICBs as a whole, a need for this discussion to be supported **regionally and nationally,** and there is opportunity to **strengthen training and networking**. To conclude, the idea of promoting collaboration over competition between the region, and nationally, should be maintained earnestly. The ongoing underservice of rehabilitation in the East of England and nationally, underscores the critical need for fostering collaboration within this sector, partnering together to enhance rehabilitation.

Recommendations for the rehabilitation system:

1. Improve financial analysis: Conduct a detailed assessment of funding gaps and develop strategies to optimize resource allocation for equitable service provision.
2. Update directory regularly:
   Implement a process for frequent updates to the Directory of Services to ensure accurate information and better coordination between services.
3. Develop more robust governance: Create a unified strategic vision and clearer governance structures to reduce service fragmentation and ensure equitable access across all regions.

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Appendix 1

Explanation of graphs

These graphs display provision of services or beds in different areas of the East of England through the comparison of population statistics to the number of beds available. Population statistics are divided by number of relevant services/beds within that region. Where there are no services/beds, the bar is left blank and marked with a 0. The higher the number above the bar/the bigger the size of the bar, the more people each service/bed has to serve. Better provision = lower number of people to be served by each service/bed.

Therefore, to explain the graph below, Cambridgeshire would have the most service provision for adult services, as each of its services only has to serve 37,700 people, as opposed to Hertfordshire which has the least, with each service having to serve 149,850 people.

Graphs (figures 7-18)

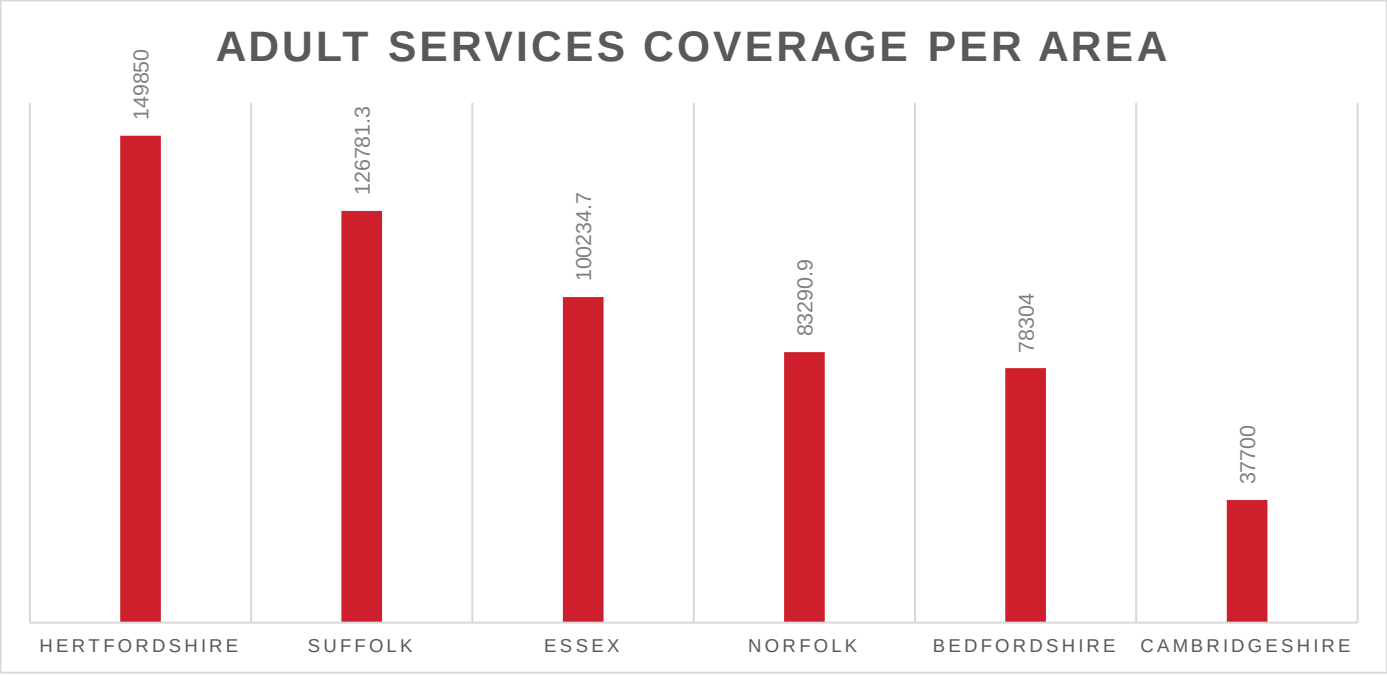


Figure 7: Number of patients served by 1 adult service in areas across the East of England

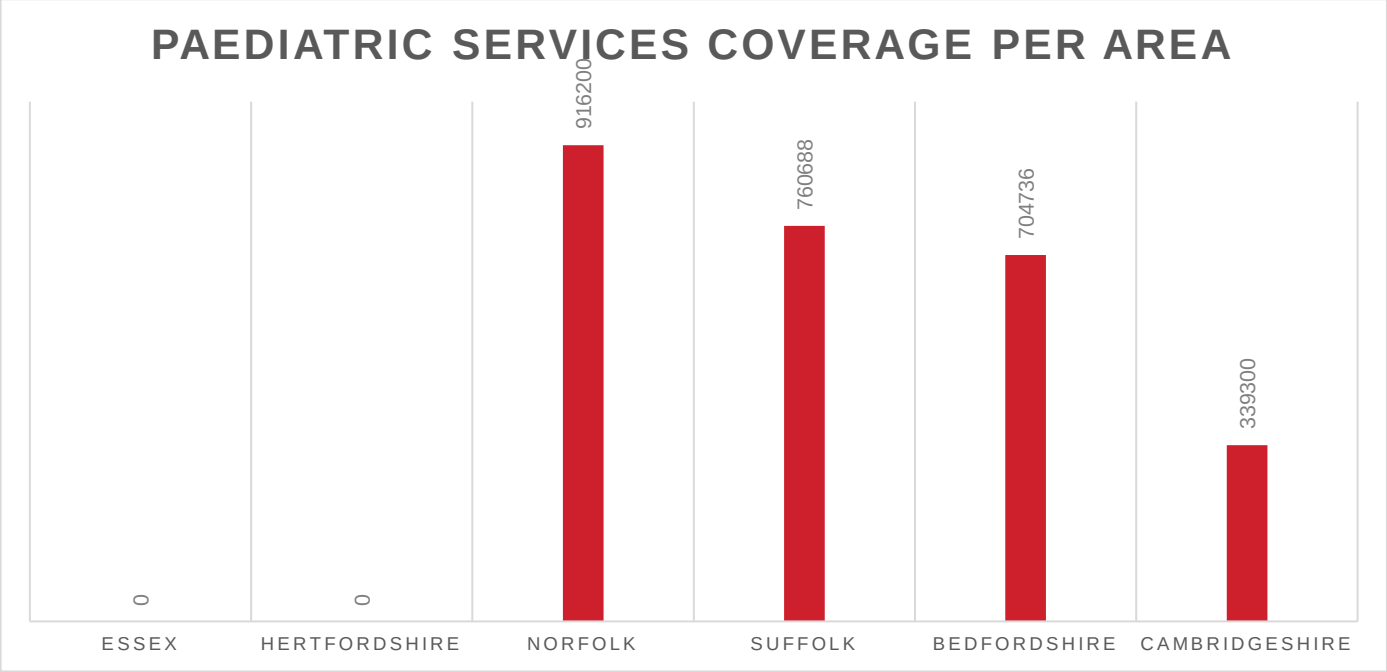


Figure 8: Number of patients served by 1 paediatric service in areas across the East of England

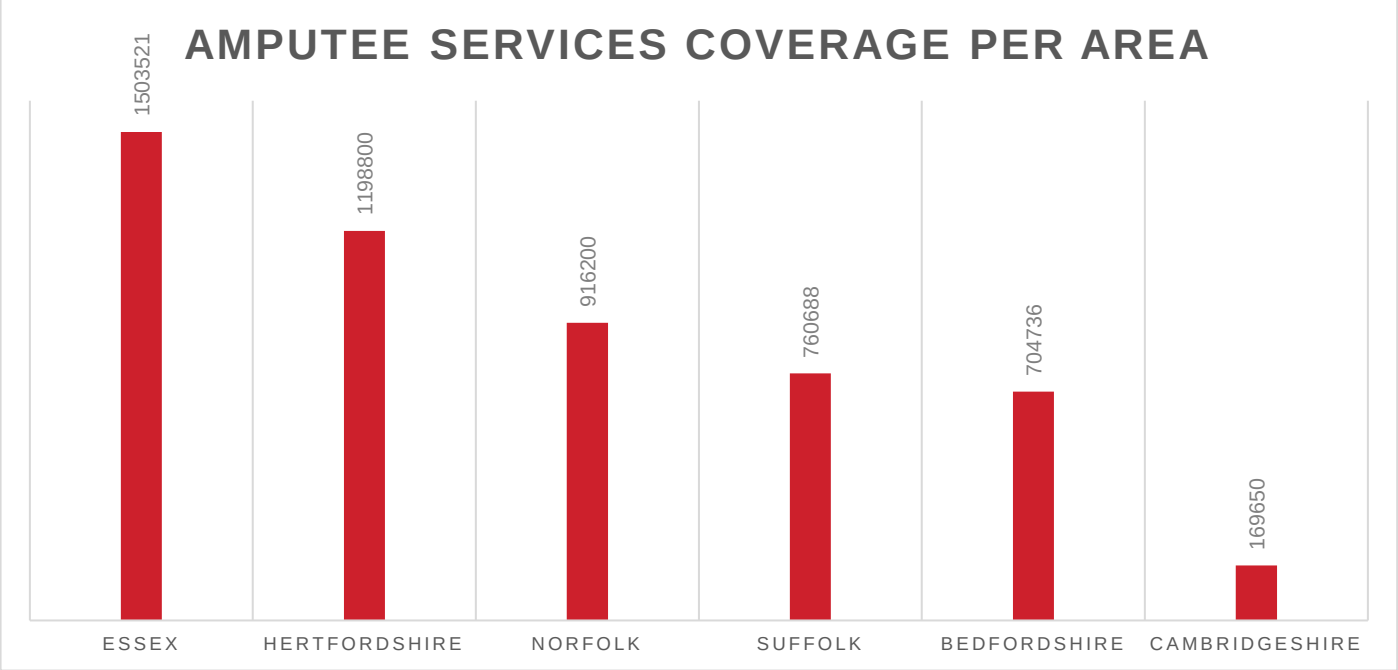


Figure 9: Number of patients served by 1 amputee service in areas across the East of England

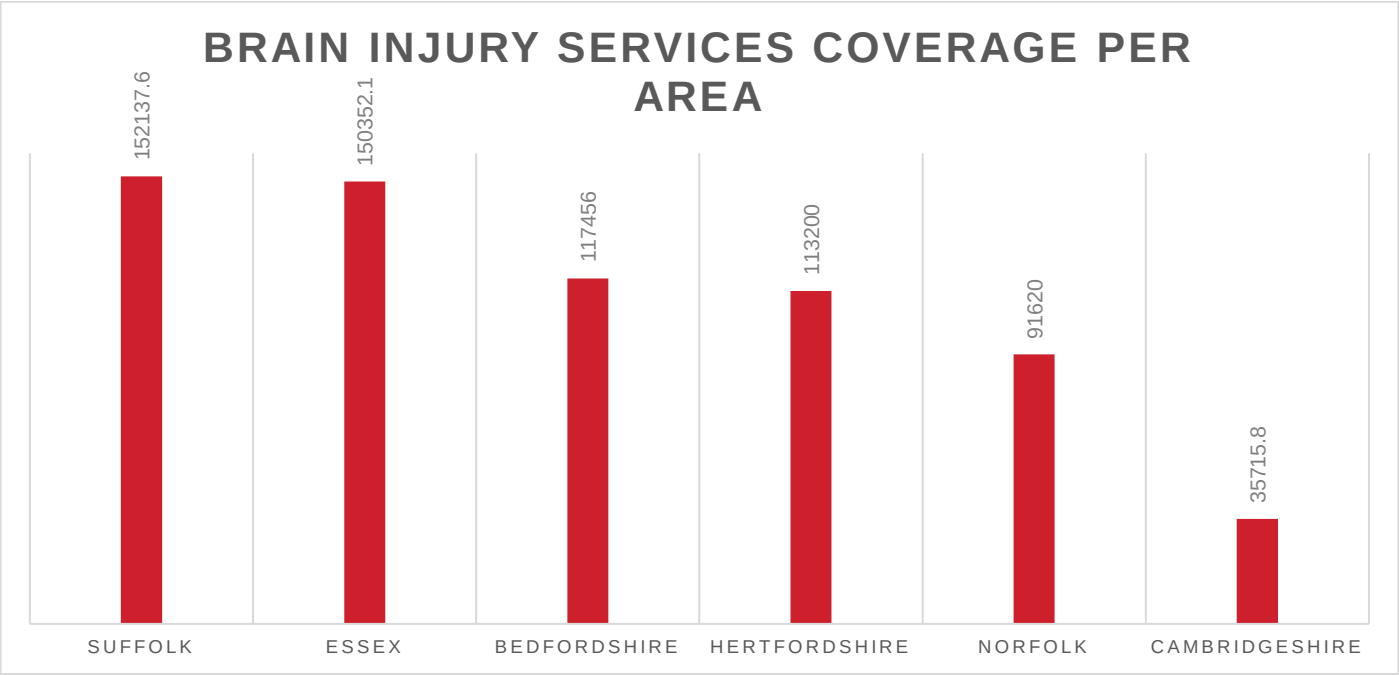


Figure 10: Number of patients served by 1 brain injury service in areas across the East of England

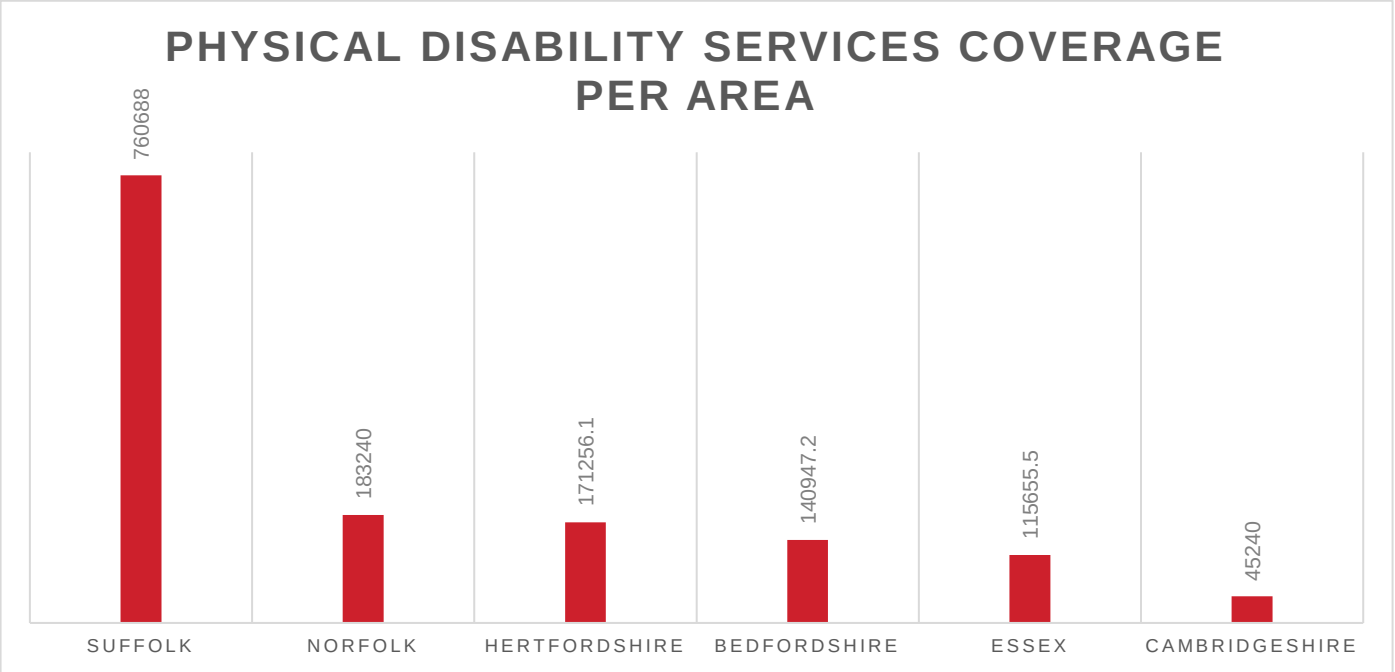


Figure 11: Number of patients served by 1 physical disability service in areas across the East of England

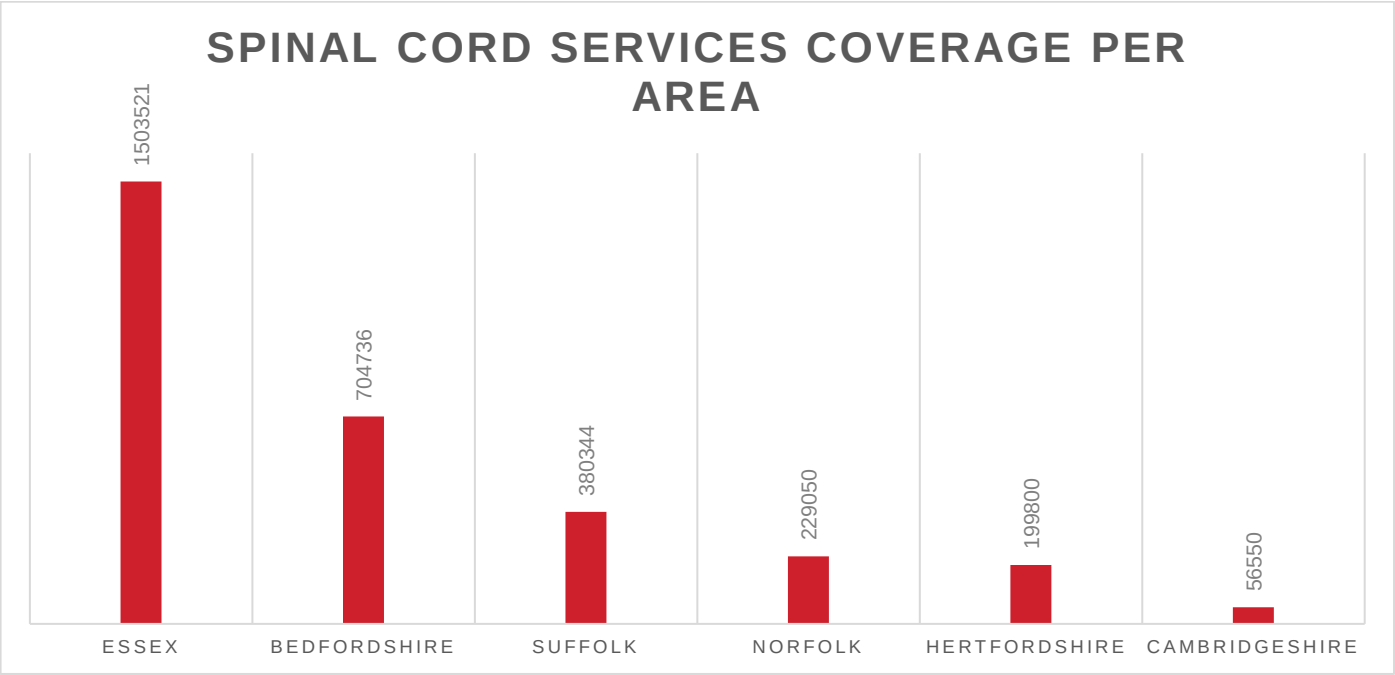


Figure 12: Number patients served by 1 spinal cord service in areas across the East of England

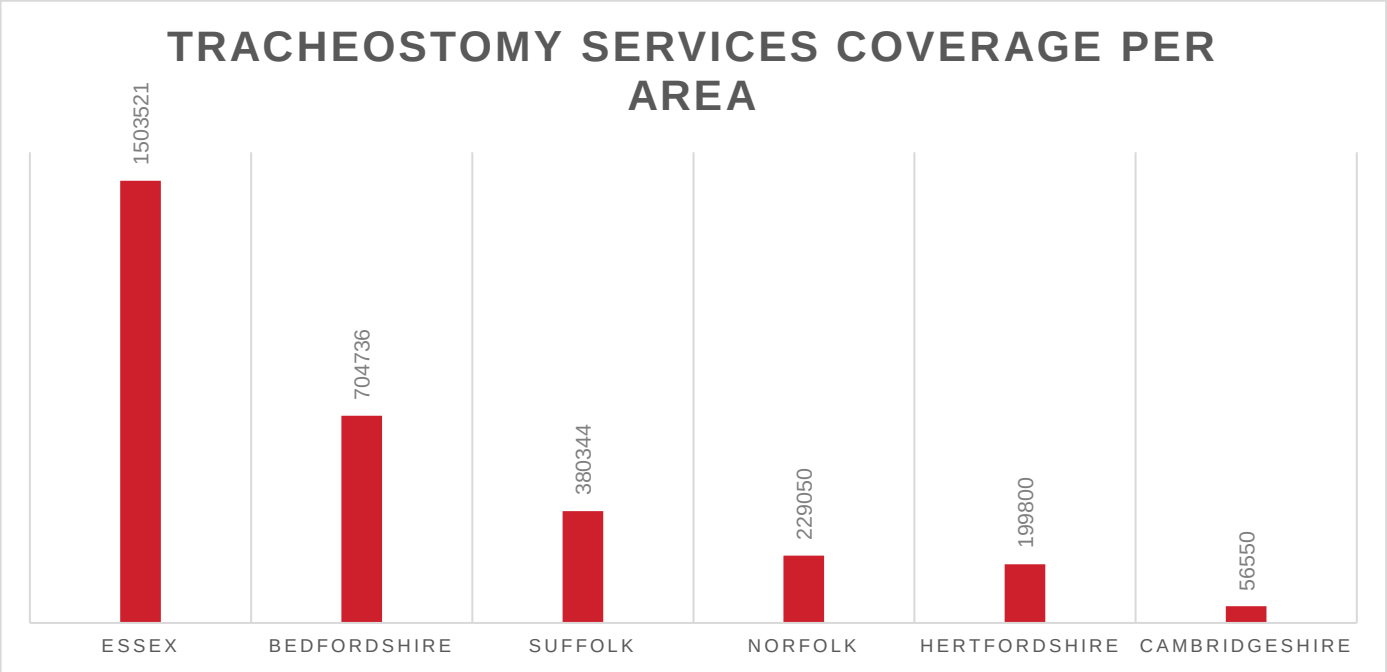


Figure 13: Number of patients served by 1 tracheostomy service in areas across the East of England

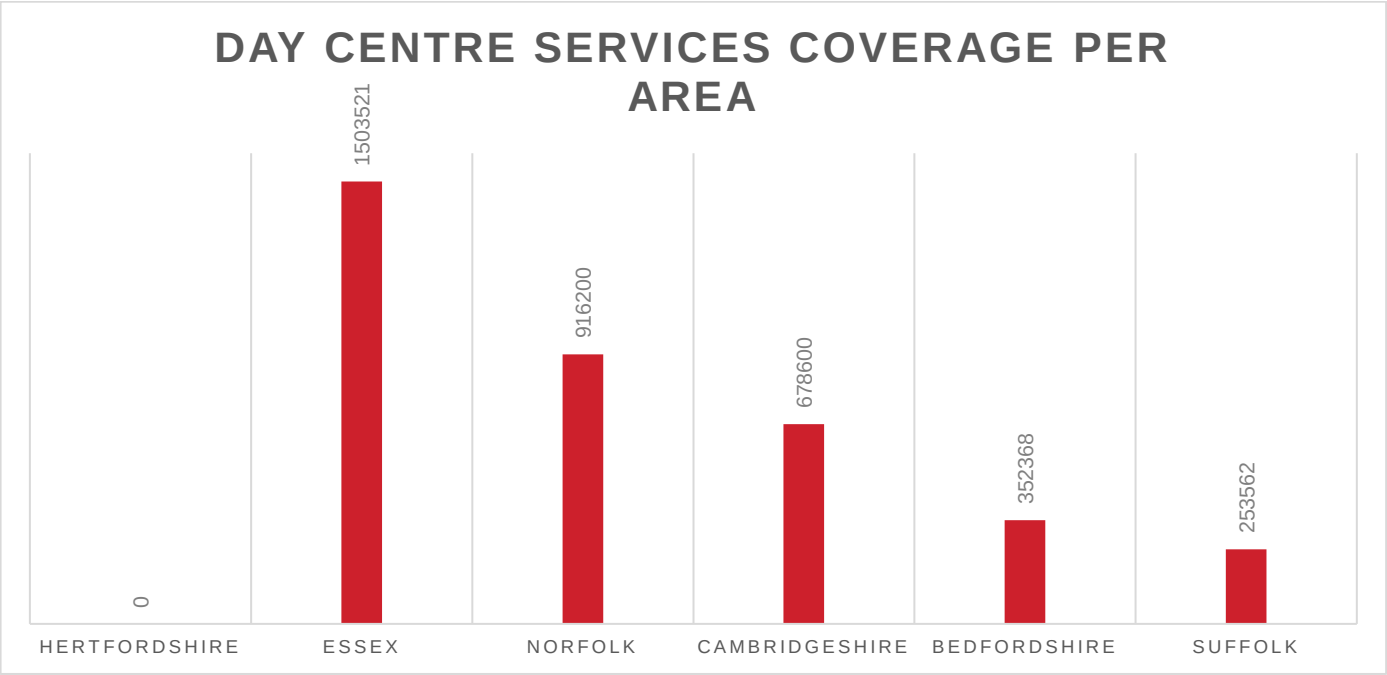


Figure 14: Number patients served by 1 day centre service in areas across the East of England

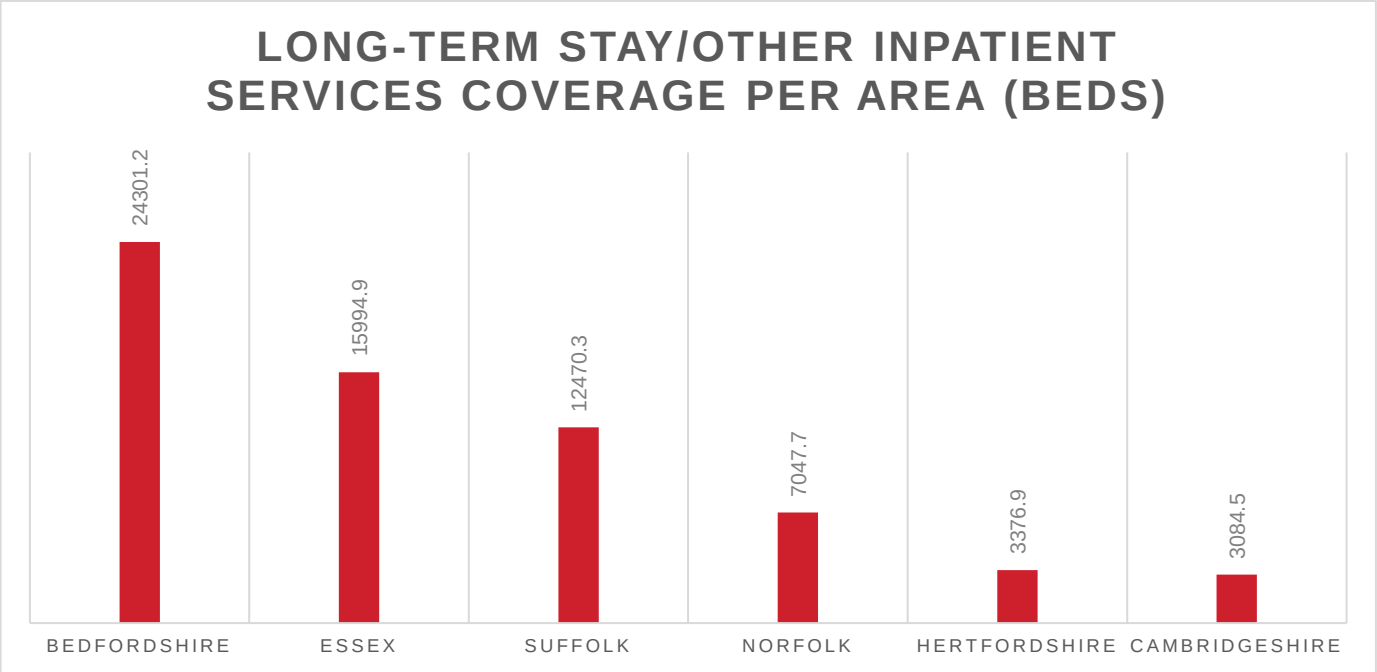


Figure 15: Number patients served by 1 long-term stay/other inpatient service in areas across the East of England

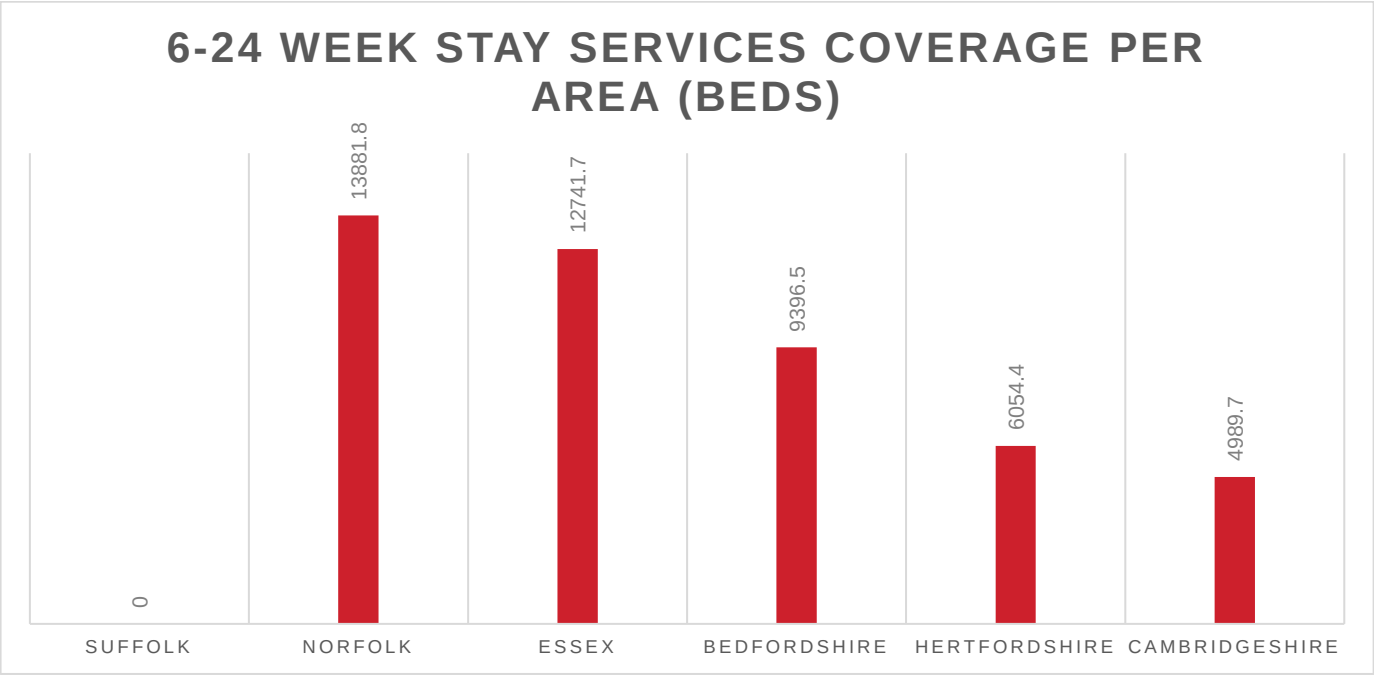


Figure 16: Number patients served by 1 6-24 week stay service in areas across the East of England

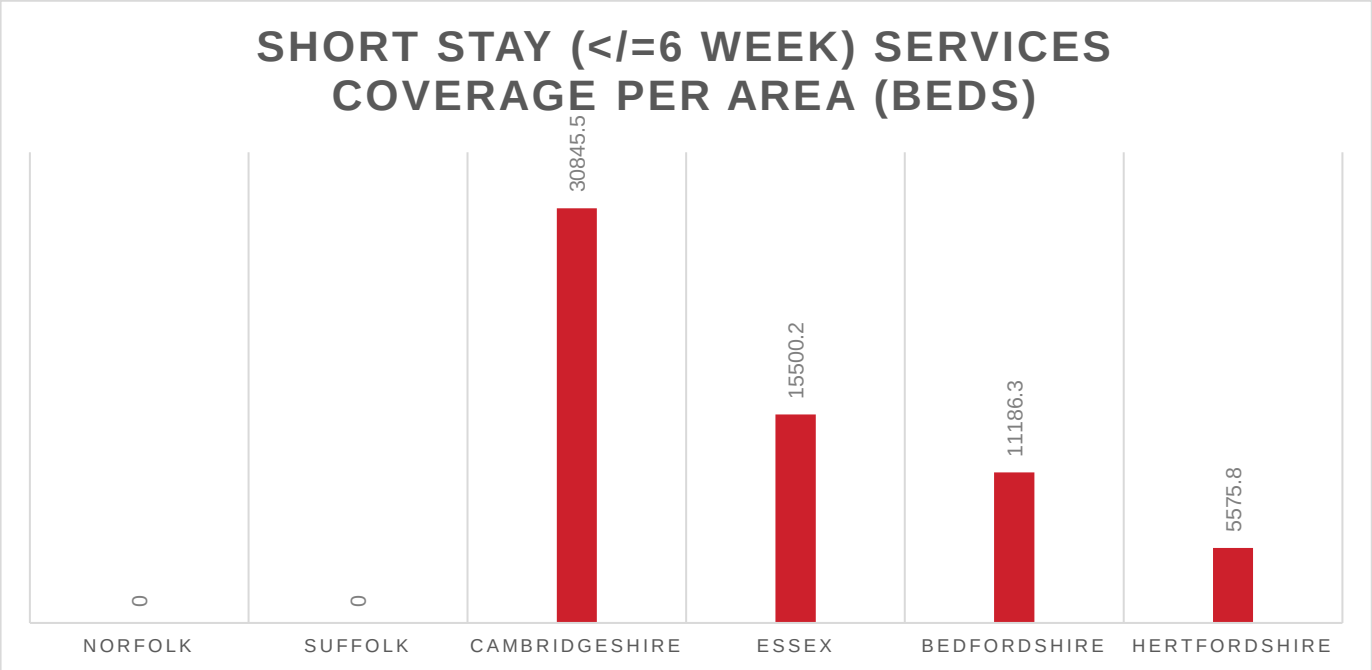


Figure 17: Number patients served by 1 short stay (</=6 week) service in areas across the East of England

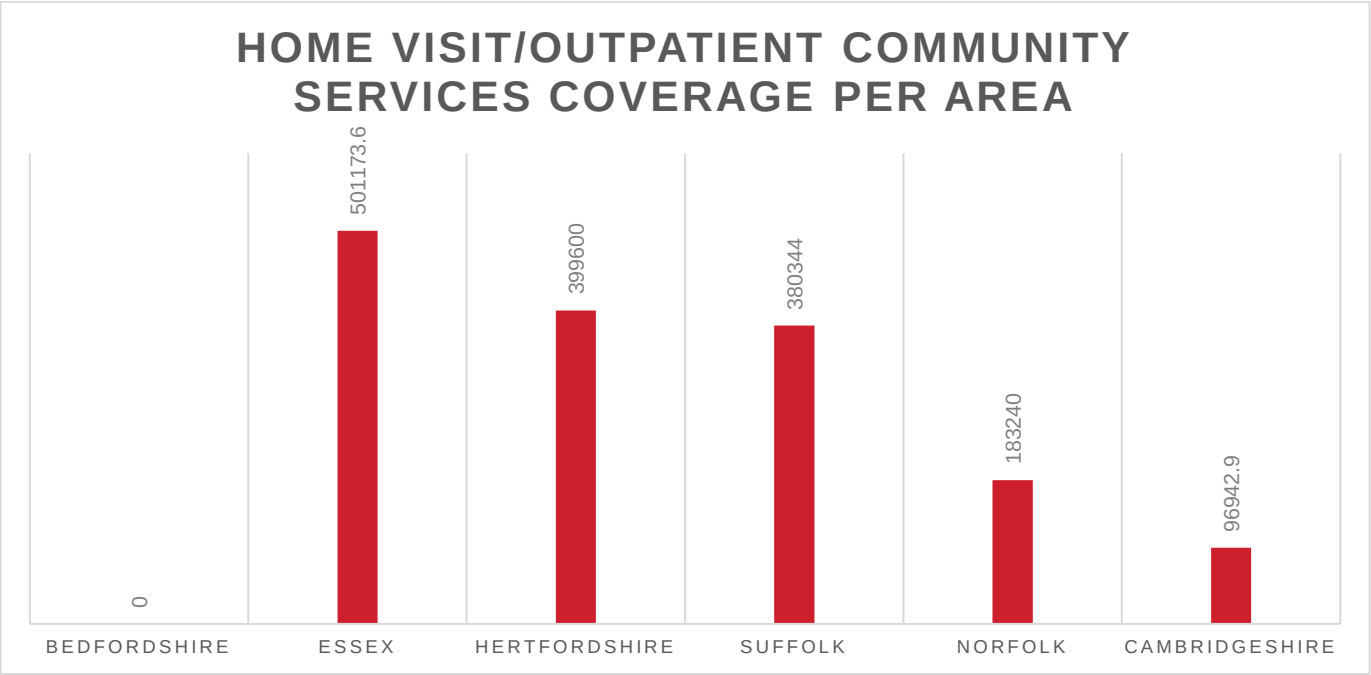
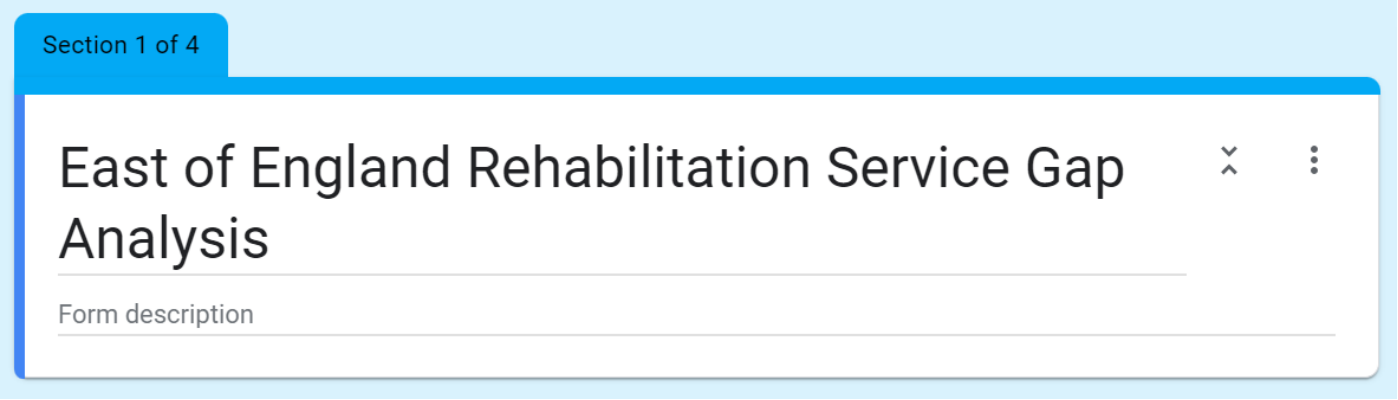
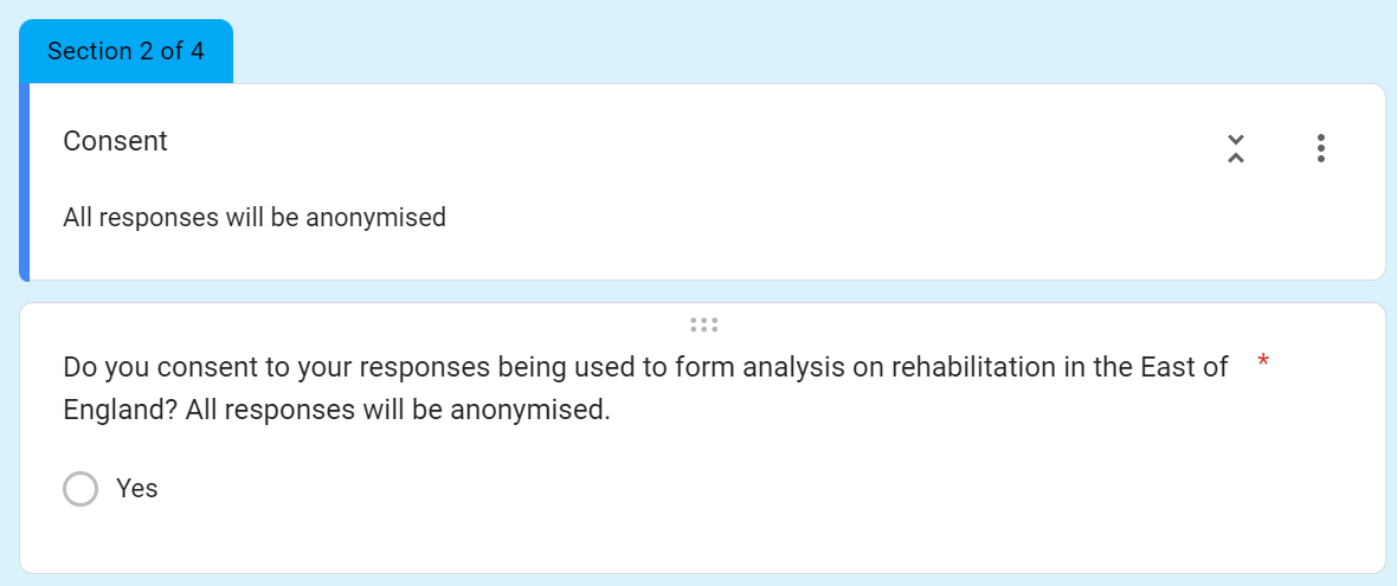


Figure 18: Number patients served by 1 home visit/outpatient community service in areas across the East of England

Appendix 2

Google Form fields and questions





Section 3 of 4

Service information

This information will not be published, but will be used to inform the gap analysis.

What area is your service based in?

- ○ Bedfordshire
- ○ Cambridgeshire
- ○ Essex
- ○ Hertfordshire
- ○ Norfolk
- ○ Suffolk
- ○ Other...

What is the name of your service?

Short answer text

Section 4 of 4

Qualitative understanding of East of England care

Description (optional)

What issues are you currently experiencing within your service?

Long answer text

What do you perceive as the biggest issue in the wider rehabilitation network?

Short answer text

What issues are you currently experiencing with the wider rehabilitation network?

Long answer text

In what ways is the wider rehabilitation network useful?

Long answer text

Are you part of any groups based around the wider rehabilitation network? (Ex: East of England Trauma Network)

- ○ Yes
- ○ No
- ○ Other...

What is currently going well for your service?

Long answer text

How often do you reach out to/contact the wider rehabilitation network on a typical work day?

- ○ Multiple times a day
- ○ Every day
- ○ Few times a week
- ○ Few times a month
- ○ Rarely
- ○ Never

Describe any additional aspects you would like to see within the wider rehabilitation network.

Long answer text

Are there any aspects of the wider rehabilitation network that are unclear/confusing?

Long answer text

What do you think your service lacks?

Long answer text

What do you think the wider rehabilitation network lacks?

Long answer text

Is there anything else you want to comment on that you think we may have missed?

Long answer text