GROWING TOGETHER

Patient centred strategies for the development of LTV care

Fisher & Paykel HEALTHCARE

Resmed

BREAS

East of England Paediatric Critical Care Operational Delivery Network

Collaborative working to deliver high quality care to our children and their families

South West Paediatric Critical Care Operational Delivery Network

The Yorkshire and Humber Paediatric Critical Care Operational Delivery Network

Thames Valley and Wessex Paediatric Critical Care Operational Delivery Network

Pan Thames Paediatric LTV Programme

North Thames Paediatric Network
Connecting paediatric services

South Thames Paediatric Network
Transforming Healthcare for Children and Young People

ODN NORTHWEST SiC LTV PCC

East Midlands Paediatric Critical Care ODN

West Midlands Children's Network

Rapid Response Service

LAURA LOWNDES

CLINICAL SPECIALIST PAEDIATRIC RESPIRATORY PHYSIOTHERAPIST

Why are we doing this

Respiratory issues common cause of death in CYP with learning disabilities (14x higher than no disabilities)

Not changed since the 1970's despite vast improvements in medical care and technology

Recurrent illnesses and hospital admissions have major impact on quality of life

Hospital stays are 2.5 times longer for children with CP as for other children

Re-admission rate high as well (41% readmitted within 2 years)

Why are we doing this

Respiratory issues common cause of death in CYP with learning disabilities (14x higher than no disabilities)

Not changed since the 1970's despite vast improvements in medical care and technology

Recurrent i quality of life

Hospital sta r children

Re-admission rate high as well (41% readmitted within 2 years)

Prevention, early detection, intervention and management is vital to improve these outcomes

Version for Consumers and Families

Version for Professionals

Risk factors for respiratory hospital admissions for young people (1-26 years) with cerebral palsy

Risk checklist: https:www.abilitycentre.com.au/resources/cpchecklist/

Perth Children's Hospital

Ability Centre

TELETHON KIDS INSTITUTE

Red Flags

Gross Motor Function Classification System (GMFCS) Level V

IRR* = 23.25 (95% CI: 10.46 to 51.70)

At least one respiratory hospital admission in the last year

IRR* = 11.8 (95% CI: 5.6 to 24.7)

At least 2 courses of antibiotics for respiratory illness in the last year

IRR* = 5.9 (95% CI: 3.0 to 11.6)

Potentially Modifiable Risk Factors

Oropharyngeal dysphagia
(requires foods or drinks with modified texture OR uses a tube OR coughs or chokes on saliva)

IRR* = 12.7 (95% CI: 7.3 to 22.1)

Frequent respiratory symptoms
(daily cough or weekly sounding sound chesty or phlegmy or wheezy)

IRR* = 9.4 (95% CI: 3.5 to 25.8)

Current seizures

IRR* = 7.6 (95% CI: 4.2 to 13.8)

Gastro-oesophageal reflux disease
(now or previously)

IRR* = 3.4 (95% CI: 1.8 to 6.3)

Mealtime respiratory symptoms when well
(gurgly voice, wheezing, coughing, sneezing, choking)

IRR = 3.8 (95% CI: 2.1 to 7.1)

Snoring every night

IRR* = 2.8 (95% CI: 1.3 to 6.1)

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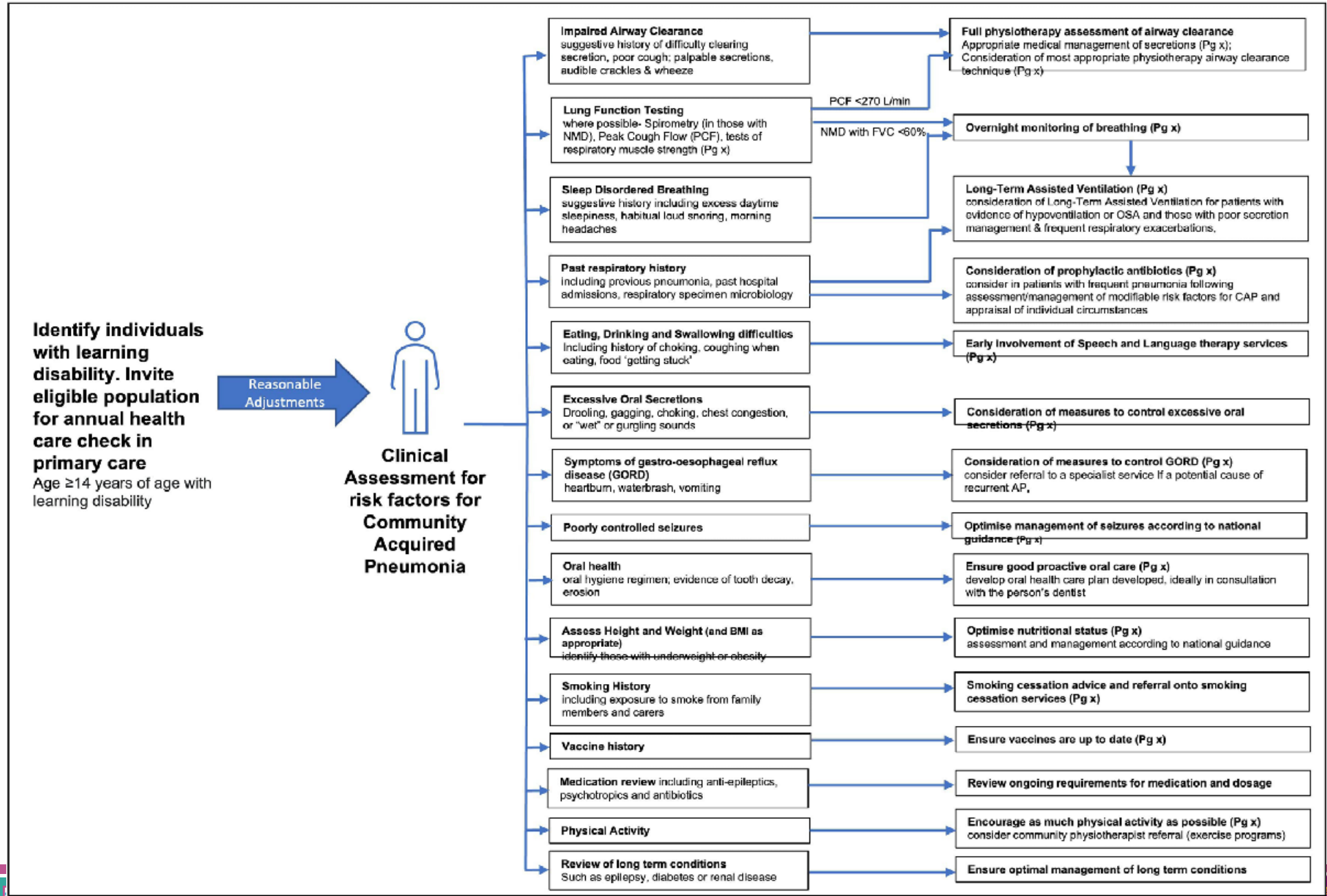
BTS Clinical Statement (2022)



INTRODUCTION

This risk identification matrix is intended to aid health professionals to identify people at risk of respiratory compromise and to guide actions to prevent or reduce this.

It may be used in a variety of settings, for example; during a routine therapy review, alongside Cerebral Palsy Integrated Pathway (CPIP) assessment, following a hospital admission.

The items have been selected based upon risks identified in the two key documents referenced below: Gibson et al. 2021 (Items 1,2,4,5,8,9,10,12,13), Legg et al. 2023 (Items 11,14,16,17) and on those used by existing community respiratory physiotherapy services (Items 3,6,7,15).

It is primarily designed for use with children and young people aged 0-25 but users may choose to adapt for use with older people. It has not been validated. The identification matrix may be adapted for local use, and in particular the 'actions' column may need amendment depending upon your setting and services.

We acknowledge the Glasgow Paediatric Respiratory Team, Zoe Johnstone and Lesley Harper (NHS Lothian) who kindly shared their matrix which we adapted with their permission.

The Association of Paediatric Chartered Physiotherapists
Respiratory Risk Identification Matrix for Children and Young People with Neurological Impairment

Consultation History

DATE	PROGRESS
September 2023	First draft compiled using template from NHS Lothian Paediatric respiratory (RHC Glasgow) team alongside recommendations from Gibson et al (2021) and Legg et al (2023)
October 2023	Draft circulated for comments (Feedback via Microsoft Forms): - Members of 'Cons - Paediatric Physiot Conference
November 2023	Amendments from membe health
January 2024	Amendments - removed 'li
May 2024	Final consultation with cor

References:

1) Gibson, N., Blackmore, A.M., Chang, A Wilson, A.C. (2020). Prevention and n statement. Developmental Medicine

2) Legg, J., Allen, J.-L., Andrew, M., Anne Tavare, A., Tedd, H. and Simpson, A.J. acquired pneumonia in people with l doi:https://doi.org/10.1136/thorax-2

Acknowledgements:

The 'Consensus to Action' Multidisciplinary gro Childhood Disability (BACD) Toni Wolff, Morag Dysphagia Clinical Excellence Network (PDCEN

Item	Risk	Low	Medium	High	R/A/G	Actions if medium or high
1	**Gross Motor Function Classification Scale level 5 equivalent** (difficulty controlling head and body posture in most positions)/ **neurodegenerative diagnosis**	No	Yes	n/a		Ensure 24-hour postural care optimised
2	**Frequent respiratory symptoms** (e.g. daily cough or weekly wheeze, phlegm or gurgly chest)	No regular respiratory symptoms	Intermittent symptoms	Frequent		Respiratory physiotherapy review to optimise routine airways clearance - if no local service may require tertiary referral
3	**Respiratory Intensive Care Unit (ICU) admission in the last 5 years**	None				
4	**Hospital admissions with respiratory infection/year**	None				
5	**Courses of oral antibiotics for respiratory infections/year**	<2/year				

Item	Risk	Low	Medium	High	R/A/G	Actions if medium or high
6	**Home oxygen**	None	n/a	Yes		Ensure has regular respiratory review with appropriately trained clinician, clear prescription and monitoring of trends Ensure target oxygen saturations (wake and sleeping) agreed and clearly documented
7	**Non-Invasive Ventilation (NIV) / Tracheostomy / mechanical cough assist / high flow oxygen**	None	n/a	Yes		Ensure on active tertiary respiratory consultant caseload - refer if not on active caseload
8	**Current seizures**	None				
9	**Upper airway obstruction/ Snoring every night**	None/				
10	**Gastro-oesophageal reflux disease (GORD)**	None contro				

Item	Risk	Low	Medium	High	R/A/G	Actions if medium or high
11	**Scoliosis**	None or postural only	Mild to moderate	Severe		Ensure 24-hour postural management is optimised Ensure on active orthopaedic caseload for monitoring and appropriate intervention If bracing used, ensure respiratory comfort and efficiency is assessed with bracing
12	**Mealtime respiratory symptoms when well** (e.g. gurgly voice, coughing, wheezing, sneezing, choking with feeding)	No symptoms evident and no history of frequent chest infections	Infrequent symptoms present with oral intake or combination of oral intake and gastrostomy			
13	**Dysphagia** (e.g. needs food or drink with modified texture or has feeding tube or coughs or chokes with saliva)	No concerns or swallow concerns are effectively managed	Requires modified texture, supported posture, specific feeding techniques and supplementary tube feeding to reduce risk of aspiration and dependence on other people to eat / drink safely			
14	**Nutritional status**	No concerns	Underweight but maintaining current growth trajectory			

Item	Risk	Low	Medium	High	R/A/G	Actions if medium or high
15	**Using/prescribed nebulisers**	None	Bronchodilators or normal saline	Mucolytics or nebulised antibiotics		Respiratory specialist (nurse/physio/paediatrician) to ensure optimal nebuliser timing and administration - if stable prescription may not require review
16	**Secretion management**	No concerns in ability to manage own secretions	Difficulties managing oral secretions; may be using oral suction, be on medication, Botox or surgical intervention for saliva management	NBM but coughs on saliva or needs frequent oral care / oropharyngeal or nasopharangeal suction for saliva management		Speech and language therapy dysphagia assessment If difficulty with saliva, Paediatrician to review management of drooling, including oral medications, Botulinum toxin and salivary gland surgery Therapy team to review positioning to optimise head control for optimal airway management, including consideration of night time positioning
17	**Oral Health / mouth care**	No concerns	Dry mouth, some tooth decay, sticky secretions and difficulty brushing teeth. No oral intake	Ulceration, infection, bleeding or red sites within oral cavity, decayed teeth, limited / no saliva, no daily mouth care routine in place.		Emphasis of routine oral hygiene. Review of medications contributing to dry mouth. Consider referral to specialist dentist to optimise mouth care

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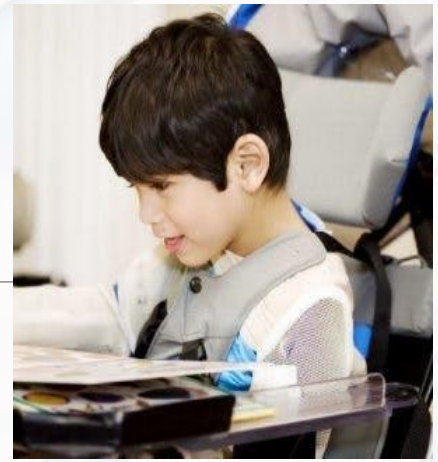


Item	Risk	Low	Medium	High	R/A/G	Actions if medium or high
1	**Gross Motor Function Classification Scale level 5 equivalent** (difficulty controlling head and body posture in most positions)**/ neurodegenerative diagnosis**	No	Yes	n/a		Ensure 24-hour postural care optimised
2	**Frequent respiratory symptoms** (e.g. daily cough or weekly wheeze, phlegm or gurgly chest)	No regular respiratory symptoms	Intermittent symptoms but with periods of more than one month with no symptoms	Frequent respiratory symptoms		Respiratory physiotherapy review to optimise routine airways clearance - if no local service may require tertiary referral Respiratory review with paediatrician - optimisation of modifiable risk factors, consideration of prophylactic antibiotics if frequent respiratory tract infections
3	**Respiratory Intensive Care Unit (ICU) admission in the last 5 years**	None	1	>1		(NB. Actions may not be necessary if isolated incident without a background of, or subsequent respiratory morbidity) Respiratory physiotherapy review to optimise routine airways clearance – if no local service may require tertiary referral Full respiratory review by appropriately skilled consultant – if no local service may require tertiary referral
4	**Hospital admissions with respiratory infection/year**	None	1	>1		Respiratory physiotherapy review to optimise routine airways clearance - if no local service may require tertiary referral Full respiratory review by appropriately skilled consultant - optimisation of modifiable risk factors, consideration of prophylactic antibiotics - If no local service may require tertiary referral
5	**Courses of oral antibiotics for respiratory infections/year**	<2/year	2-3/year	>4/year		Respiratory physiotherapy review to optimise routine airways clearance - if no local service may require tertiary referral Respiratory review with paediatrician - optimisation of modifiable risk factors, consideration of prophylactic antibiotics

Role of RRT

Early respiratory home visits

Appropriate physiotherapy and medical management in the community

Training for all involved in the care of that CYP at home, school or in hospice care.

Communication with different members of the multi-disciplinary team (MDT) across primary, secondary and tertiary care as well as the education and charity sectors to ensure the CYP and their carers are well supported and can get access to rapid, appropriate respiratory care

Avoid hospital admissions/ GP appointments where appropriate

Early supported discharge from hospital

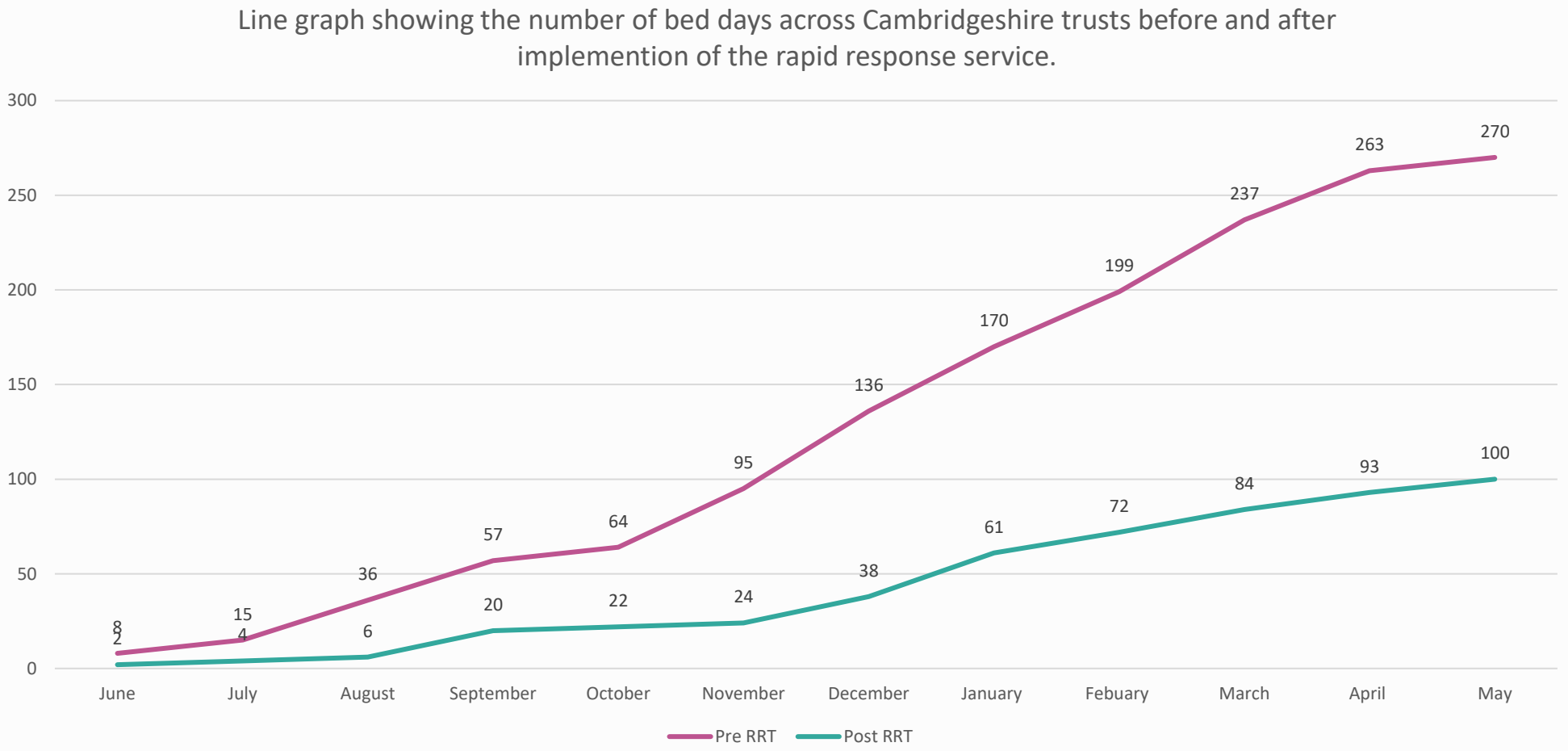
Referrals and prioritisation

1. CYP with a history of respiratory-related hospital admissions;
2. CYP with multiple courses of oral antibiotics for respiratory infections;
3. CYP at risk of respiratory deterioration due to underlying condition(s), but currently stable.

Outcomes

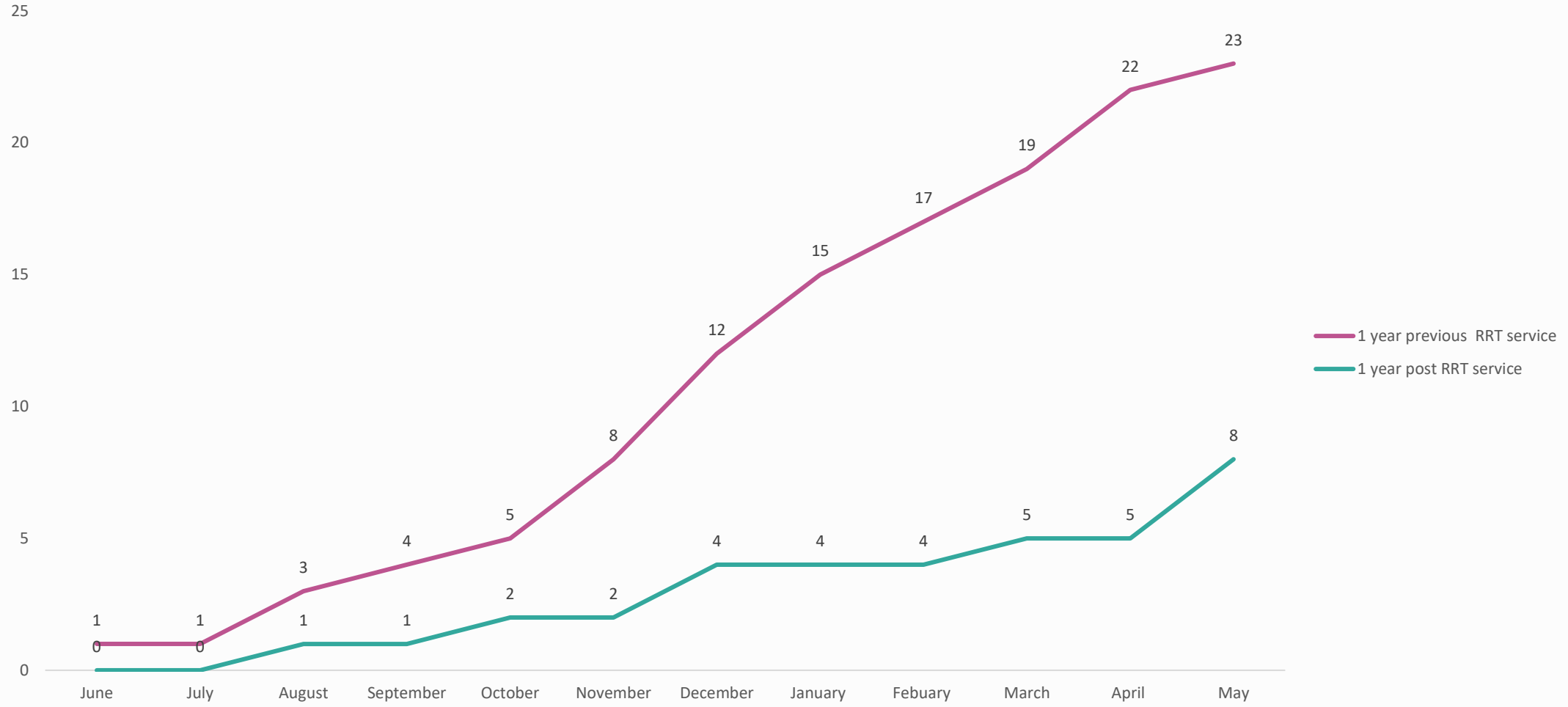
Category	June 2022-May 2023 cost	June 2023-May 2024 cost	Cost Saving
Bed day (ward and ICU) based on HRG codes and spell income	£244512.16	£85181.37	£159,330.29
ED attendances (£419)	£9637	£3352	£6285
GP attendances (£39.23)	£3,687.62	£313.84	£3,373.78
Total estimated saving			£168,989.07

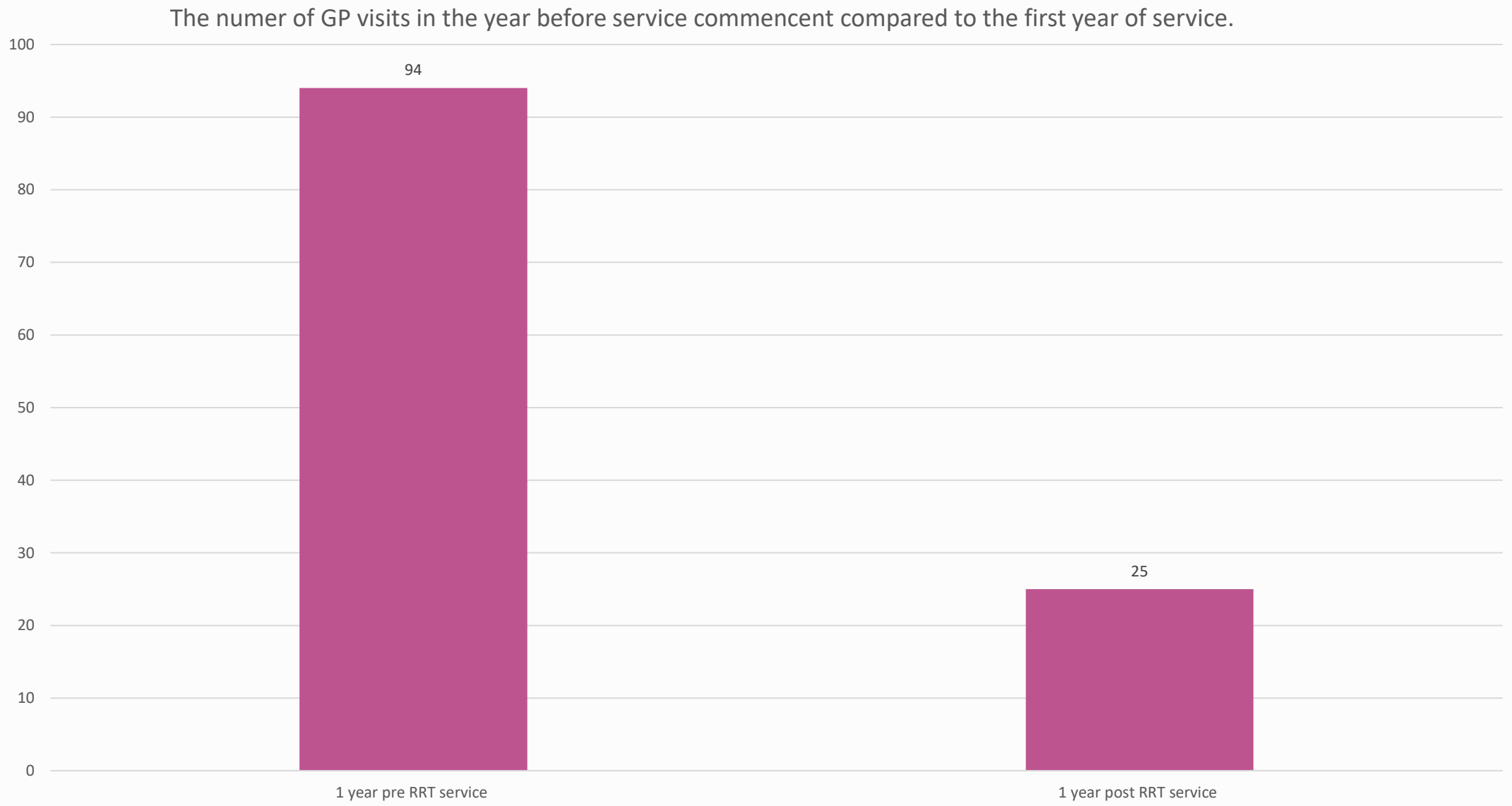
Extrapolating this data to the current RRT caseload of 70 CYP, estimated cost savings (bed days, ED attendances, GP reviews) is approximately **£454,970.57.**

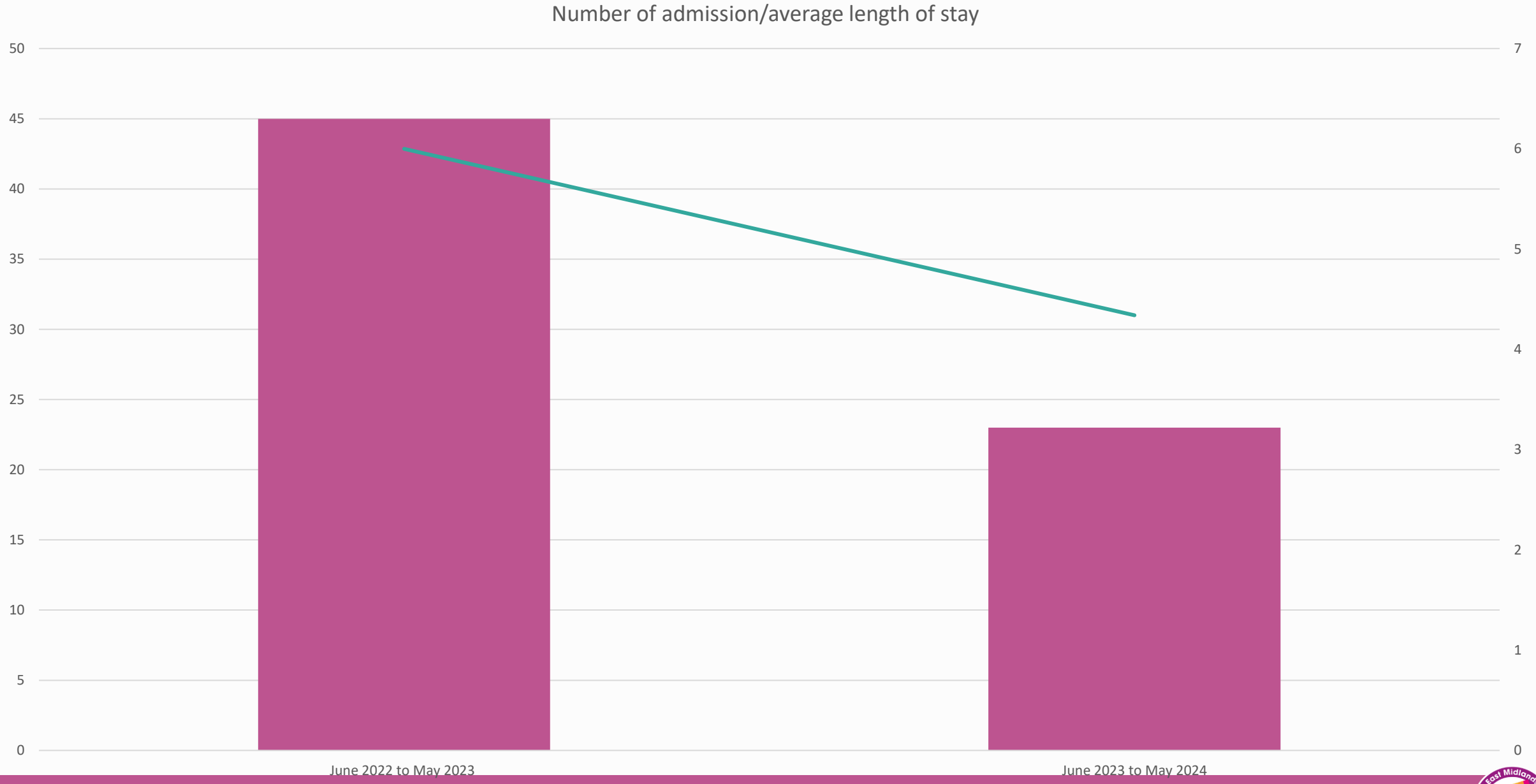


Data based on the 26 patients that were onboarded onto the service within the first six weeks

Number of Emergency department attendances across Cambridgeshire for RRT patients 1 year before service compared to 1 year after service commencement




The numer of GP visits in the year before service commencent compared to the first year of service.
100
90
80
70
60
50
40
30
20
10
0
94
25
1 year pre RRT service
1 year post RRT service


Number of admission/average length of stay
50
45
40
35
30
25
20
15
10
5
0
7
6
5
4
3
2
1
0
June 2022 to May 2023
June 2023 to May 2024
Number of admssions
Average length of stay

Successes

-Agreed permanent funding for 4 physios
-You made a difference award nomination
-3 x PALS compliments received (two from a parents; one from teacher in a school we have been supporting).
- 9 nominations for CUH annual awards

‘I'd say that your team has made a huge impact in our patients. Families feel more confident in managing their children at home and I'd say that we had avoided some unnecessary hospital admissions for several children. For those who have been admitted to hospital, we had been able to send them home earlier thanks to your team.’

They have already provided me and my daughter with exceptional care. Because of this we have avoided my daughter becoming too unwell and avoided a hospital admission.’
‘Laura offers a wealth of knowledge something that my community team and local hospital aren’t always able to offer the best advice on.’ It’s a massive gap that has been missing over the past 7 years in my daughter’s care.’

‘They are proving to be an essential team for these children and the education/support for all involved, including the CCN team. This is a service that will be pivotal to the care of Complex children in Peterborough’

Laura trained the school on how to use the cough assist machine. S now takes the cough assist machine to school when she is recovering from infections. Consequently, her attendance has gone up by 20-25% (from 60-65% to around 80-85%)

Challenges

Electronic notes (different systems)

Trying to co-locate service in different areas

Wide area

Only have 2 members of staff

Current age of transition is 19 however no service to transition to therefore 2x 19 year old patients will be discharged this summer with no service to pick up.

No weekend service

Any Questions????

Contact: l.lowndes@nhs.net
07871108206

www.future.nhs.uk/neurodisabilityrespiratorycare