The Post-ICU Presentation Screen – Community version (PICUPS-Community)

A brief functional screening tool to inform the rehabilitation and support needs of patients following treatment in intensive care – or indeed any acute severe illness or injury.

Self-complete version for follow-up in the community: Version 5 31.8.20

The original **Post-ICU Presentation Screening tool (PICUPS)** was developed as a functional screening tool to support triage and handover of patients stepping down from ITU into the acute wards, and onwards into rehabilitation. It is designed to:

- Inform the immediate plan for care on the acute ward
- Identify problems that are likely to require further, more detailed assessment / evaluation by members of the multi-disciplinary team and
- Inform development of the **Rehabilitation Prescription** as patients leave the acute care setting (which will include the Rehabilitation Complexity Scale) to indicate the patient's needs for rehabilitation at their next stage of care as they move into the community.

The **PICUPs-community** follow-up tool is a version of the PICUPs monitor going functional change as patients recover from severe illness and injury in the community. It is written for self-report by patients or their families, but the content is designed to mirror the hospital version and to guide referral to the different disciplines that may need to be involved in the individual's rehabilitation.

Together with the **Needs and Provision Complexity Scale** it can be used to monitor the needs for, and provision of, rehabilitation and support services for patients in the community

It can also inform the extent to which the recommendations in the **Rehabilitation Prescription** are being met, and provides a basis on which to formulate the ongoing plans for care and provision of services as the patient's need change during recovery.

Developed in the aftermath of Covid-19, it complements symptom-screening tools such as the Covid -19 Yorkshire Rehabilitation Screening tool, but is suitable for use with any patient recovering from acute severe illness or injury, whether or not they were admitted to hospital or intensive care. **Appendix 1** sets out the various complementary components of these three tools.

As well as helping to guide decision-making for individual patients, this information will help to identify where their needs are and are not being met. Used at population level, the information will enable us to quantify shortfalls in service provision and to estimate the gap between capacity and demand for future planning.

For further information please contact:

Professor Lynne Turner-Stokes DM FRCP, The UK Rehabilitation Outcomes Collaborative (UKROC)

Regional Hyperacute Rehabilitation Unit, Northwick Park Hospital, Harrow, Middlesex. HA1 3UJ

Tel: +44 (0) 7889046699. Email: lynne.turner-stokes@nhs.net

Part 1: The PICUPs-Community

Please complete this tool to describe your condition over the last week.

If your condition varies or falls between different levels, please record the **worst level** you experience.

A. Breathing, upper airway and nutrition

	1. Breathing
We want to know if you experience breathlessness	
❒	**I do not suffer from breathlessness**
❒	**I have mild breathlessness** (eg only with strenuous or heavy exercise)
❒	**I have moderate breathlessness** (eg when hurrying or walking up a slight hill)
❒	**I have marked breathlessness** (eg I have to walk more slowly, or stop after a mile or so)
❒	**I have severe breathlessness** (eg I have to stop and rest after about 100 yards or a few minutes of walking even on level ground)
❒	I *have* **extremely severe breathlessness** (eg I am breathless on minimal exertion such as dressing or I am too breathless to leave the house)

	2. Voice
We want to know if you experience problems with your voice, such as hoarseness or loudness	
❒	**I have no problems with my voice**
❒	I have **mild problems with my voice** (eg I have difficulty being heard in loud environments or when I am tired)
❒	I have **moderate problems with my voice** (eg occasionally my voice sounds abnormal, or it is an effort to make myself heard in conversation or on the telephone)
❒	I have **marked problems with my voice** (eg my voice sounds very abnormal, or it is hard to make myself heard)
❒	I have **severe problems with my voice** (eg I can only produce a whisper – or sometimes no voice at all)
❒	I have **extremely severe problems with my voice** (I have no audible voice)

	3. Swallowing
We want to know if you experience problems with swallowing	
❒	**I have no problems with swallowing – I can eat or drink anything, whatever the texture** (eg soft, hard, crunchy foods etc)
❒	I have **mild problems with swallowing** (eg I take longer to eat a meal, or I cough if I drink too quickly, but I can manage any consistency of food and liquids with some extra time and care)
❒	I have **moderate problems with swallowing** (eg I can only take food that is soft and easy to chew, or that is cut up small. I use strategies to swallow safely and I may need assistance or supervision in case I choke)
❒	I have **marked problems with swallowing** (eg I can only take minced or pureed, or thickened liquid, or I get tired when swallowing, which limits the amount of food and drink I can take by mouth)
❒	I have **severe problems with swallowing** (eg I can only manage small amounts of food and drink by mouth, and I have to supplement my diet with tube feeding)
❒	I have **extremely severe problems with swallowing** (I cannot take any food or fluid by mouth - I take all my nutrition by tube-feeding)

	4. Nutrition
We want to know if you experience problems with appetite or nutrition	
❒	**I have no problems with appetite or nutrition – I am my usual weight**
❒	I have **mild problems with nutrition** (eg my appetite has changed, but I maintain my usual weight, albeit with some effort)
❒	I have **moderate problems with nutrition** (eg my appetite / eating habit has changed and I have lost/gained a few pounds weight, which I want to correct)
❒	I have **marked problems with nutrition** (eg I have lost /gained a large amount of weight and I require advice from a dietitian to help me get back to my usual weight)
❒	I have **severe problems with nutrition** (eg I require ongoing dietetic monitoring and intervention)
❒	I have **extremely severe problems with nutrition** (eg my weight is out of control despite support from a dietitian)

B. Physical activities of every-day living

	5. Moving around indoors
We want to know if you experience problems with moving around indoors	
❒	**I walk independently (by myself) and safely indoors, including stairs**
❒	**I walk independently indoors but with some risk of falling** (eg I manage by myself but I am unsteady on my feet – or I use a stick or other walking aid for support)
❒	I can walk indoors, but **I need someone with me** (eg to guide or support me)
❒	**I move around independently indoors, but in a wheelchair that I propel and manoeuvre myself**
❒	I move around indoors **in a wheelchair that is pushed by someone else**
❒	**I am unable to move around indoors at all** (eg I stay in bed or in a chair all day)

	6. Moving around outdoors
We want to know if you experience problems with moving around outdoors	
❒	**I walk independently (by myself) and safely outdoors**, including managing steps and rough ground
❒	I can walk independently out-doors **but with some risk of falling.** (eg I manage by myself but I am unsteady on my feet – or I use a stick or other walking aid for support)
❒	I can walk outdoors, but **I need someone with me** (eg to guide or support me)
❒	I move around **independently outdoors, but in a wheelchair that I propel and manoeuvre myself**
❒	I move around outdoors in a **wheelchair that is pushed by someone else**
❒	**I am unable to move around outdoors at all** (eg I stay in indoors all the time)

	7. Arm and hand function
We want to know if you experience problems with using your arms or hands	
❒	**I have no problems with using my arms and hands,** including fine hand movements (dexterity)
❒	**I can use both my hands quite well**, but I have some **problems with arm strength or reaching** for things, or with **fine hand movements** (eg difficulty with writing or manipulating small objects such as doing up buttons etc).
❒	I have **good use of one hand,** but have difficulty doing things that require both hands
❒	I have **some use of one hand,** but difficulty with fine movements even in my good hand
❒	I have **limited use of both my hands** (which affects nearly all activities)
❒	**I am completely unable to use either of my hands**

	8. Personal hygiene
We want to know if you experience difficulties with maintaining personal hygiene (eg washing, bathing, dressing, toileting)	
❒	**I can manage all my own personal hygiene needs by myself, without any help**
❒	I need **minimal help to maintain my personal hygiene** (eg just with setting things up for me or reminding me to wash)
❒	I need **moderate help** (eg I am **able to manage more than half of the tasks** myself but I need some hands-on help from another person to maintain my personal hygiene)
❒	I need **substantial help** (eg I am able to manage **some of the tasks myself**, but I need help from another person for more than half the tasks of maintaining personal hygiene)
❒	I need **maximal help** (I am able to **contribute in a very small way**, but nearly all hygiene maintenance is done for me)
❒	**Unable** (I am unable to contribute in any way to maintaining my personal hygiene – all tasks are done for me)

	9. Maintaining a household
We want to know if you experience difficulties with maintaining a household (eg shopping, cooking cleaning, laundry, shopping, finances, do-it-yourself (DIY), gardening etc, that you would usually do yourself)	
❒	**I can manage all my usual household activities by myself, without any help**
❒	I have **mild difficulties** (eg I need **occasional help with higher-level tasks** (such as gardening, DIY, or managing my finances) that I would have done before my illness/injury)
❒	I have **moderate difficulties** (eg **I am able to manage more than half of my usual household activities** myself, but I need some help from another person)
❒	I require **substantial help** (eg I am able to manage **some of my usual household activities myself**, but I need help from another person for more than half the tasks)
❒	I have **maximal help** (I am able to **contribute in a very small way to usual household activities**, but nearly all of them are done for me)
❒	**Unable** (I am unable to contribute in any way to maintaining a household – all the tasks are done for me)

	10. Vocational - Work, study or leisure activities
We want to know if you experience problems with your usual work, study (or leisure activities if you are retired / unemployed)	
❒	**I can do all my usual job / study / activities in my normal way**
❒	I have **mild problems** (eg I am still able to work / study as before, **but with extra effort**)
❒	I have **moderate problems** (eg **I am able to do more than half of previous job / study / activities**, but with reduced hours and my productivity is moderately affected)
❒	I have **marked problems** (eg I am able to do **less than half of my previous job / study / activities**. I work less than half time and my productivity is substantially affected)
❒	I have **severe problems** (I am able to **work / study in a very small way** (eg a few hours a week) but not really in any meaningful capacity)
❒	**Unable** (I am unable to work or study at all, or to undertake any of my previous leisure activities)

C. Symptoms and interference with activities

	11. Fatigue
We want to know if you experience problems with fatigue	
❒	**I have no problems with fatigue**
❒	I have **mild fatigue** (eg I am able to carry out my normal activities (including work) but I am tired at the end of the day)
❒	I have **moderate fatigue** (eg I have had to modify my activities (eg part-time working, limited exercise) but I am able to manage my basic daily activities)
❒	I have **marked fatigue** (eg Fatigue impacts significantly on my daily activities – **I take a rest during the day**)
❒	I have **severe fatigue** (eg Fatigue impacts severely on my daily activities – I take **several rests during the day**)
❒	I have **extreme fatigue** (eg **I am only able to get up for very short periods** – I spend most of the day in bed or in a chair due to fatigue)

	12. Pain / discomfort
We want to know if you experience problems with pain or discomfort	
❒	**I have no problems with pain or discomfort**
❒	I have **mild pain** (But it is well-controlled and **does not interfere with my activities**, or stop me from doing things)
❒	I have **moderate pain** (But it is helped by medication or other pain-relieving interventions and it **only occasionally interferes with my activities)**
❒	I have **marked pain** (eg Medication/pain interventions offer some relief, but **pain interferes with some activities** and stops me from doing something most days)
❒	I have **severe pain** (It is not controlled by medication/pain interventions and **pain interferes with basic daily activities every day**)
❒	I have extreme pain (**It interferes with my sleep and almost all activities**. Medication/pain interventions have little or no effect)

D. Communication, cognition and psychosocial

	13. Communication
We want to know if you experience problems with communication	
❒	**I have no problems with communication** (eg I can understand and express complex information, and I can communicate with anyone)
❒	I have **mild problems with communication** (eg some people may find it a little hard to understand me, but **I can communicate with unfamiliar people** even if they did not already know the context of the conversation)
❒	I have **moderate problems with communication** (eg it is often hard to understand me, but **I can communicate with people who are familiar with me**, or if they know the context of the conversation)
❒	I have **marked problems with communication** (eg but I can attract people's attention and **I am generally able to make my needs understood** and to express basic information)
❒	I have **severe problems with communication** (eg I cannot attract people's attention, but **I can respond to direct questions about my basic needs** using Yes/No or gestures, if someone asks me.)
❒	**Unable – I have no consistent functional communication**

	14. Thinking – attention, memory etc.
We want to know if you experience problems with thinking eg concentrating or remembering things	
❒	I have **no problems with thinking** (eg I can concentrate and remember things as normal for me)
❒	I have **mild problems with thinking** (eg I cannot concentrate for as long as normal and I have to use strategies, such as writing things down or noting them in my phone or diary)
❒	I have **moderate problems with thinking** (eg I am more distracted than usual and I sometimes forget appointments)
❒	I have **marked problems with thinking** (eg I cannot concentrate for more than a few minutes. I find it hard to remember things and have to rely on other people to remind me)
❒	I have **severe problems with thinking** (eg I sometimes feel confused and disorientated - I may even forget where I am or what day it is)
❒	I have **extremely severe problems with thinking** (eg I am constantly confused and disorientated. I have no day-to-day memory of events)

	15. Mental health – mood issues (such as anxiety, depression or stress)
We want to know if you experience problems with depression, anxiety or stress	
❒	I have **no problems - my mood is normal for me and I do not suffer from any symptoms of stress**
❒	I have **mild problems** (eg I experience **mild anxiety / depression or stress, which do not impact on my daily function or rehabilitation**, but which require further exploration by a psychologist)
❒	I have **moderate problems** (with some impact on my daily function or rehabilitation, and for which **I require active psychological support / monitoring**)
❒	I have **marked problems** (that impact significantly on my daily activities and on my ability to engage in rehabilitation, **requiring frequent psychological intervention**)
❒	I have **severe new problems with my mental health** (eg stress/ depression /psychosis) that effectively prevent me from engaging in daily activities, for which **I require psychiatric treatment**)
❒	I have **extremely severe problems with mental health** (eg I have a known active mental health disorder (which may also be a pre-existing condition) that requires **on-going formal psychiatric treatment** (eg bipolar disorder, schizophrenia, other psychosis)

	16. Family distress / support requirements
Severe illness does not just affect the patient, it can impact on family members / close friends who may experience distress or difficulty for which they require support in their own right. We want to know about any support needs your family members may have. **Please complete this item with their input.**	
❒	**My family members are adjusting well to my situation** (eg they do not need any additional support, other than the usual information that is given to families)
❒	My family members are **experiencing mild difficulties** (eg they need additional information / explanation, but are coping well without formal support)
❒	My family members are **experiencing moderate difficulties** (eg they need additional support / counselling from my treating team)
❒	My family members are experiencing **substantial difficulty and distress** (eg they need formal psychological support in their own right)
❒	My family members are **experiencing severe difficulties and distress** (eg they are finding it hard to cope and need very active support and management)
❒	My family members are **experiencing extreme difficulties and distress** with imminent risk of breakdown (eg needing referral to the emergency support services)

Part 2: Complete this section ONLY if you are a wheelchair user

	1. Postural management and seating
We want to know if you experience problems with seating or maintaining your posture in a chair	
❒	**I have no problems - I do not require any support and am able to sit in an ordinary armchair**
❒	I have **mild problems maintaining my posture while sitting** (but I am able to maintain good sitting position in an **ordinary standard wheelchair with no modifications**)
❒	I have **moderate problems** (but I am able to sit out in a **standard wheelchair with minor modifications**, such as a pressure relief cushion)
❒	I have **marked problems** (I am unable to control fully my head and/or trunk and I require a special wheelchair (prescribed and adapted for me by an occupational therapist) that supports me in the right places)
❒	I have **severe problems that limit seating** (I am only able to sit out in customised seating system that has been especially built and moulded to the shape of my body)
❒	**I am unable to sit out in any type of wheelchair or seating system** (eg due to contractures or pressure ulcers)

	2. Transfers from bed to chair (or wheelchair) and back
We want to know if you experience problems moving from your bed to a chair (or wheelchair) and back	
❒	**I have no problems – I can move between my bed and chair by myself and without equipment**
❒	I can move between my bed and chair (with or without an aid), but **with someone standing close by to supervise me**
❒	I require **physical help from one person** to move between my bed and chair (ie someone to support me)
❒	I **require physical help from two people** to move between my bed and chair (ie to support me or lift me)
❒	I am moved between my bed and chair **with the aid of a mechanical hoist**
❒	**I am unable to move between my bed and chair at all** (ie I stay in bed all the time)

	3. Changing position in bed / chair to maintain pressure relief
We want to know if you experience problems changing position to relieve pressure on your skin	
❒	**I have no problems – I can change position by myself**
❒	I require **minimal help from one person** to change position or just to remind me to do so
❒	I require **hands-on help from one person** to change position, but I have no pressure sores (eg I need help to change position about every 4 hours)
❒	I require **hands-on help from one person** to change position, and I have pressure sores or am at high risk of developing them (eg I need help to change position every 2 hours or more frequently)
❒	I require **hands-on help from two people** to change position, but I have no pressure sores (eg I need help to change position about every 4 hours)
❒	I require **hands-on help from two people** to change position, and I have pressure sores or am at high risk of developing them (eg I need help to change position every 2 hours or more frequently)

Summary scores and triggers for referral

Domain	Item	Score	Score Triggers referral to:	
Breathing, Upper Airway and nutrition	Dyspnoea	(0-5)	2, 3	P/T, SLT
	Voice	0-5)	≤ 4	SLT, ENT
	Swallowing	0-5)	≤ 4	SLT, Dietitian
	Nutrition	0-5)	≤ 2	Dietitian
Physical and Activities of daily living	Moving around indoors	0-5)	≤ 4	P/T, O/T
	Moving around outdoors	0-5)	≤ 4	P/T, O/T
	Arm and hand function	0-5)	≤ 4	P/T, O/T
	Maintaining hygiene	0-5)	≤ 4	P/T, O/T
	Maintaining a household	0-5)	≤ 4	O/T
	Vocational activities	0-5)	≤ 3	O/T, vocational psychologist Consultant in rehab medicine
Symptoms that interfere with daily activities	Fatigue	0-5)	≤ 3	P/T, O/T, Psychologist
	Pain	0-5)	≤ 3 ≤ 1	P/T, O/T, Psychologist, Consultant in rehab medicine Pain specialist
Communication, cognition, psychosocial	Communication	0-5)	≤ 4	SLT, O/T
	Cognition	0-5)	≤ 4	Psychologist, O/T
	Mental Health	0-5)	≤ 4 ≤ 1	Psychologist/, O/T Psychiatrist
	Family distress	0-5)	≤ 4 ≤ 3	Consultant in rehab medicine Psychologist
Wheelchair users only	Postural management/ seating	0-5)	≤ 4	P/T, O/T
	Transfers	0-5)	≤ 4	P/T, O/T
	Changing position in bed/chair	0-5)	≤ 4	P/T, O/T, nurse

Complex disability (as reflected by a score of ≤ 3 in any item of three or more domains) triggers referral to a consultant in RM

Appendix 1: Content compared: C19-YRS tool vs PICUPS vs Needs and Provision scale

Symptoms	Functional level		Support needs	Community tool
C19-YRS	**PICUPS**	**Version**		**PAIR-ACS**
	Acute Medical stability	Basic		**If Pt is in nursing home – record original PICUPS, rather than the self-complete version**
	Care - Risk / Safety monitoring	Basic		
	Respiratory Support	Basic		
	Tracheostomy nursing	Basic		
	Tracheostomy weaning	Basic		
2. Laryngeal/airway	Cough / secretion clearance	Basic		
	Cognition/ delirium	Basic		
	Behaviour	Basic		
	Transfers	Basic		**Record in the community only if the patient us a wheelchair user**
	Repositioning in bed	Basic		
	Postural management / seating	Plus		
1. Breathlessness	Breathing	Plus		From PICUPS-plus
3. Voice	Voice	Plus		From PICUPS-plus
4. Swallowing	Swallowing	Plus		From PICUPS-plus
5. Nutrition	Nutrition feeding	Basic		From PICUPS-basic
6. Mobility	Moving around (indoors)	Plus		From PICUPS-plus Moving around outdoors*
	Arm and hand function	Plus		From PICUPS-plus
7. Fatigue	Fatigue	Plus		From PICUPS-plus
8. Personal-Care 9. Continence	Personal hygiene	Plus		From PICUPS-plus
10. Usual Activities				Maintaining a household*
11. Pain/ discomfort	Pain	Plus		From PICUPS-plus
12. Cognition	Cognition			Attention/memory*
13. Cog-Communication	Communication	Basic		From PICUPS-basic
14. Anxiety	Mental health	Basic		From PICUPS-basic
15. Depression				
16. PTSD screen				
17. Global Perceived Health				
18. Vocation				Work/study/leisure*
19. Family/carers views	Family/friends support	Basic		From PICUPS
			NPCS	
			Medical needs	From NPCS
			Nursing needs	From NPCS
			Basic care needs	From NPCS
			Personal assistant	From NPCS
			Therapy needs	From NPCS
			Vocational needs	From NPCS
			Social support	From NPCS
			Advocacy	From NPCS
			Equipment	From NPCS
			Accommodation	From NPCS

*New items for community PICUPS

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References

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2. Adapted from the Chelsea Critical Care Physical Assessment (CPAX) Tool © Chelsea and Westminster. Corner EJ, et al. Physiotherapy (2012),doi:10.1016/j.physio.2012.01.003
3. Adapted from the NHSE Standard Contract D02 supplement Levels of nursing care and supervision for tracheostomised patients ©Lynne Turner-Stokes 2015.
4. Adapted from the Therapy Outcome Measures (TOMS). Enderby, P., John, A. (2019) Therapy Outcome Measure User Guide. Croydon: J & R Press Ltd
5. Adapted from the Modified Medical Research Council Dyspnoea Scale
6. Adapted from Airway-Dyspnoea-Voice-Swallow (ADVS) scale (Nouraei, S., et al Clin Otolaryngol. 2017;42(2):283-294) and Grade, Roughness, Breathiness, Asthenia, Strain (GRBAS) Perceptual Voice Rating Scale
7. Adapted from ADVS and International Dysphagia Diet Standardisation Initiative (IDDSI)