



# **Model of Care for Specialised Weaning Units**

## **APPENDICES**

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BTS/ICS Model of Care for Specialised Weaning Units - Appendices**

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## **Appendices**

The following are the appendices that accompany the main Model of Care Document.

1. Patient Story 1
2. Patient Story 2
3. QI Tool
4. NIV/CPAP Safety checklist
5. Whole body rehabilitation care strategy
6. Pathway flowcharts
7. Referral criteria
8. Referral flow diagram
9. Whole body rehabilitation pathway
10. Equipment list
11. Product/consumables list

## **Appendix One – Story from parents of adult patient with deteriorating neuromuscular condition**

What do you see as important elements of patient-centred and family-centred care that should be present in all weaning centres?

From our perspective as parents of a young man with a deteriorating neuro muscular condition being able to stay with him throughout his hospital stay was for us non negotiable .

He needed help will all daily activities which became second nature to us over the years and meant that the care he received was predictable comfortable and stress free. To place him in a hospital ward which is stressful enough and to have various staff providing his care would have been extremely difficult for him, even if the care he received was of a high standard.

Some facilities to support this such as a fold down bed by his side, showering facilities and tea/ coffee/ kitchen facilities would in an ideal world be of great help.

We think that strong links with an assistive technology team could make a big and positive difference to patients with a disability.

Support with communication, ability to watch tv, use an iPad or computer are things that are set up at home specific to the persons needs but on coming into hospital are lost even if there is general provision on the ward.

From a personal perspective and as an example my son was unable to press a hospital buzzer due to muscle weakness and then lost his voice following tracheostomy so had no means of attracting the attention of staff.

Using his computer or watching tv on his iPad created challenges as it was difficult to position them adequately. With the right kind of help these barriers could probably have been overcome quite easily with a few adaptations and would have made such a difference to his long hospital stay.

We think it would be great to have a hospital to home link nurse/professional to help with the transition from hospital to home, which can feel scary and daunting when the patient is going home in a very different situation to when they were admitted.

Support with changing tracheostomy tubes at home, help with training for carers, assistance with medical issues as they arise and liaison with the hospital staff would feel very supportive.

Links with the local wheelchair service could be helpful in getting alterations for example holders for oxygen cylinders, ventilators etc as soon as needed and prior to discharge from hospital.

Psychological support we feel is really important as there can be many changes and traumatic events taking place that deeply affect patients and families which you somehow have to cope with and carry on.

The right kind of professional having a presence on the ward, getting to know them over time means that when you do need support you can access it easily with someone who you are familiar with and who understands the situation you are in.

A family centred approach to breaking bad news or starting difficult conversations in a gentle and collaborative manner is crucial to alleviate some of the stress and upset for the patient and their families. Young people with a lifelong physical disability may be in a very different place developmentally and emotionally than a person of the same age who has grown into an independent adult, having had many different life experiences.

The weaning unit should have access to specialist skills and expertise specific to the end of life care needs of younger patients and those with additional developmental needs.

The weaning centre should make sure to tap into knowledge and experience of parents and families as experts in the patient's needs, not viewing the patient in isolation but considering the family unit as a whole when planning and delivering care, for example, learning from families how might be best to collaboratively progress difficult conversations.

## **Appendix Two – Story from adult patient weaned from intensive mechanical ventilation**

Intensive care saved my life but broke my spirit.

Once I was out of danger and left on a breathing machine because they said that I could not breathe on my own, I felt forgotten.

I became the woman in the side room who kept “failing”... to come off the breathing machine.

I did not know who I was. What time of day it was? Who was supposed to be looking after me?

I saw a different nurse each day. Some were nice, some were indifferent. Some talked to me either as a child or as an adult and some talked at me. Some did not talk to me at all.

There was no routine in my life. I felt lost. I did not know what my future was or even if I had one.

I thought my family had been kidnapped as I had not seen them or spoken to them for what seemed a lifetime.

I always felt really hungry and thirsty.

I was uncomfortable for most of the time in bed and out of bed.

I felt that I needed a really good wash, I thought that I smelt terrible.

There was something in my neck (I now know it was a trache tube). – it was uncomfortable.

I had no control.

### **The kind things that kept me going:**

Being able to talk again with my “cuff” down

Soaking my feet in a bowl of warm soapy water

Having ice cold water to drink

Having a normal conversation about other things rather than me, my body, my health, the ventilator.

Eventually seeing my family

### **What I think would help other patients like me:**

A routine / plan for each day – achievable goals so we don’t keep failing

Given choices

Having staff who were interested in the “failures” – that can’t breathe on their own when they should or supposed to

Be part of planning my own care.

Daily family time – or letting my family help with my care

Get dressed in clothes

Appendix 3

Check List/Quality Improvement Tool

<b>1. Involve patient and family in goal setting and decision making</b>	<input type="checkbox"/>	Develop a care plan that includes weaning and rehabilitation with patient and family outlining goals of care
	<input type="checkbox"/>	Involve patient in bedside rounds/goals of care discussions as early as able
	<input type="checkbox"/>	Provide regular proactive family meetings to set goals, devise a care plan, and share information. Last family update:
	<input type="checkbox"/>	Engage family in medical care (present/participate on rounds, participate in care, minimize visiting restrictions)
<b>2. Optimise Patient Communication</b>	<input type="checkbox"/>	Restore voice and communication to facilitate patient participation in care and treatment decisions, and enable humanisation of care.
<b>3. Promote physical comfort and minimize complications</b>	<input type="checkbox"/>	Prevent/treat complications associated with prolonged bed rest/ICU stay
	<input type="checkbox"/>	Provide regular oral care including toothbrushing
	<input type="checkbox"/>	Prevent ocular disorders arising from incomplete eyelid closure
	<input type="checkbox"/>	Minimize physical restraint
	<input type="checkbox"/>	Assess/manage symptoms (pain, breathlessness, tiredness, thirst)
<input type="checkbox"/>	Use patient preferences for strategies to promote sleep	
<b>4. Promote self-care and restore normalcy</b>	<input type="checkbox"/>	Enable access to activities and personal possessions (including clothes) to prevent boredom, loneliness, and restore normalcy
	<input type="checkbox"/>	Provide activities to promote cognitive stimulation based on patient preference
	<input type="checkbox"/>	Engage patient in self-care activities (washing face, brushing hair) as able
<b>5. Optimize ventilator weaning</b>	<input type="checkbox"/>	Assess and track ventilator weaning progress
	<input type="checkbox"/>	Use a structured tool (protocol or individualized weaning plan) to plan and guide weaning
	<input type="checkbox"/>	Include the patient (when able) and family in the development of the weaning plan
	<input type="checkbox"/>	Assess readiness to deflate the tracheostomy cuff, downsize or decannulate the tracheostomy as part of the weaning process
	<input type="checkbox"/>	Use strategies to manage excess secretions or inability to cough up secretions
	<input type="checkbox"/>	Assess endocrine function and treat in relation to weaning failure
<b>6. Optimize physical therapy</b>	<input type="checkbox"/>	Establish and track rehabilitation/physiotherapy goals
	<input type="checkbox"/>	Assess and treat non-respiratory muscle wasting
	<input type="checkbox"/>	Assess respiratory muscle weakness and provide respiratory muscle training as appropriate
<b>7. Assess swallowing function and establish safe return to normal drinking and eating</b>	<input type="checkbox"/>	Assess and treat swallow dysfunction
	<input type="checkbox"/>	Assess and optimise saliva management
	<input type="checkbox"/>	Develop a care plan for oral or alternative feeding in line with patient and family wishes
<b>8. Deescalate/optimize pharmacotherapy including previous medications for existing comorbidities</b>	<input type="checkbox"/>	
<b>9. Assess and treat psychological and emotional issues</b>	<input type="checkbox"/>	
<b>10. Minimize delirium risk</b>	<input type="checkbox"/>	Provide activities to promote cognitive stimulation based on patient preference
	<input type="checkbox"/>	Use patient preferences for strategies to promote sleep
	<input type="checkbox"/>	Minimize physical restraint
	<input type="checkbox"/>	Minimize practices such as nighttime light/noise
	<input type="checkbox"/>	Review ongoing feed for sedation and decrease as able



<b>11. Ensure appropriate referrals are made</b>	<input type="checkbox"/>	Palliative care
	<input type="checkbox"/>	Occupational therapy
	<input type="checkbox"/>	Speech & language therapy
	<input type="checkbox"/>	Dietetics
	<input type="checkbox"/>	Psychology
	<input type="checkbox"/>	Social worker
	<input type="checkbox"/>	Spiritual care
	<input type="checkbox"/>	Skin and wound specialist
	<input type="checkbox"/>	Pain Specialist
	<input type="checkbox"/>	Other (describe)

## Appendix 4

### SAFER NIV/CPAP

A checklist for use in Pandemic Response and on Respiratory Support Units

Complete on initiating NIV/CPAP and every shift change

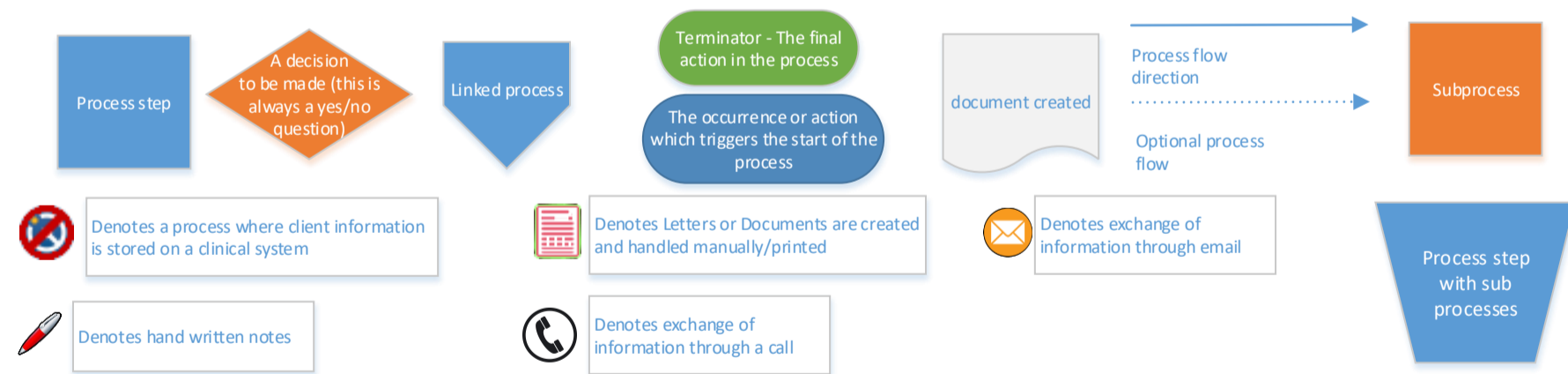
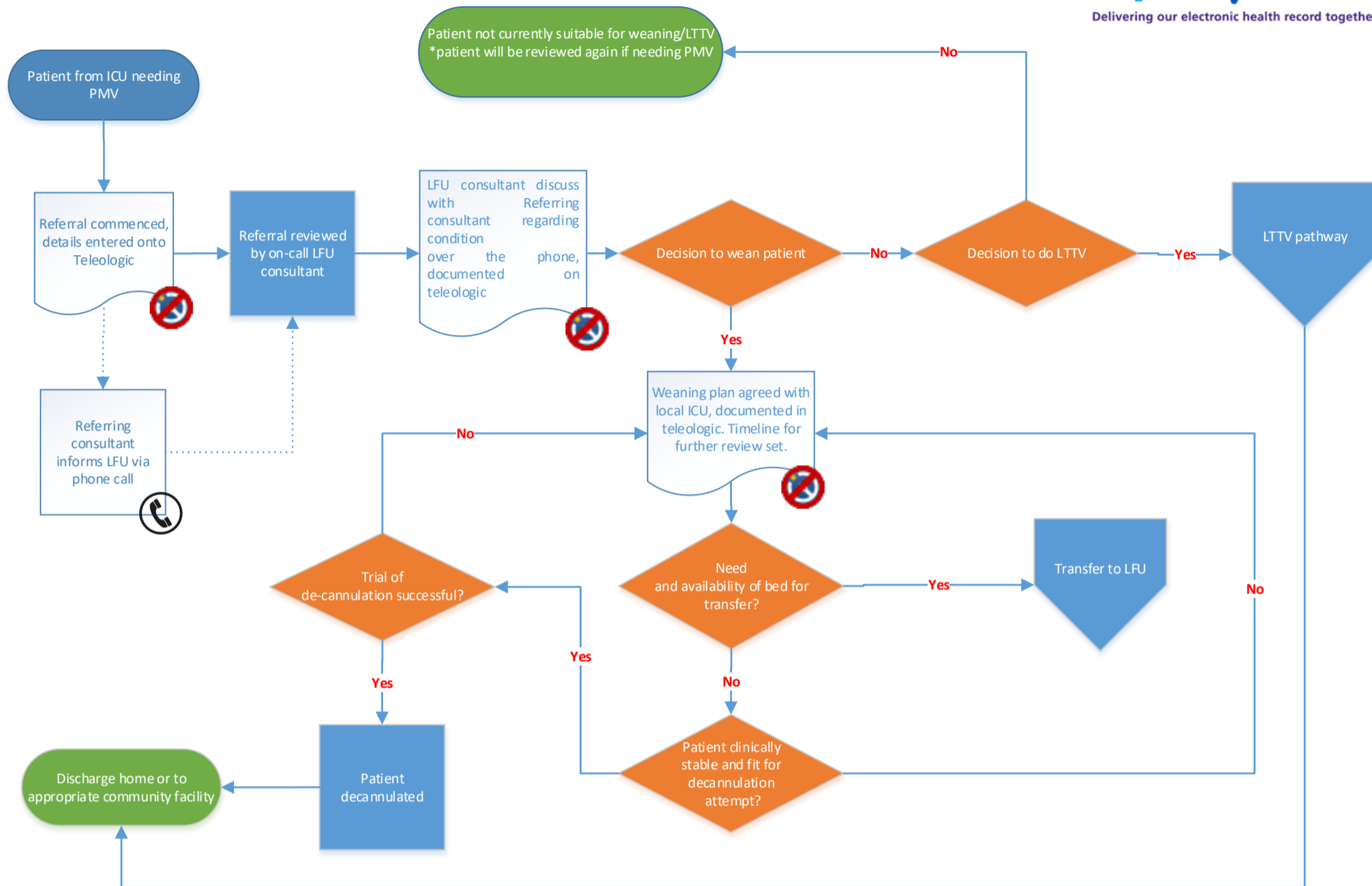
**DO NOT PROCEED WITH NIV/CPAP UNTIL ALL QUESTIONS ANSWERED YES**

Where doubt exists, or where an answer is NO - give supplemental oxygen sufficient to prevent desaturation, and STAY WITH THE PATIENT.

	Tick
<b>System</b>	
Has each team member read and understood the NIV machine quick start guide? (This guide should be laminated, and permanently attached within arms' reach of the machine)	
Has a suitable filter been fitted to the expiratory/exhaust pathway?	
Are all machine alarms on and set appropriately?	
Has the patient been reviewed as being at higher risk of deterioration?	
If higher risk, are they in the appropriate place on the ward (i.e. proximity to nurses' station etc)	
Is their Treatment Escalation Plan known, documented and handed over?	
<b>Airway</b>	
Is the machine tubing as short, direct, and protected as possible? Confirm that no improvements can be made.	
Confirm that the patient cannot disconnect the oxygen supply by moving, rolling, or pulling?	
Can the machine tubing be better protected by loosely taping (masking tape) the tubing out of reach?	
Has operation of the mask bypass valve been checked as operational?	
Has each and every connection between the patient and the machine been checked for security, and then double checked?	
Has the mask fit been checked and there is minimal leak?	
<b>FiO2</b>	
Have you confirmed that the machine is attached to <b>oxygen (not medical air)</b>	
Are the target ranges for key observations documented?	
o O <sub>2</sub> saturation	
o RR	
Does the patient have continuous pulse oximetry with alarms set appropriately and within earshot of a staff member?	
<b>Electricity supply</b>	
Is the electricity supply to the NIV/CPAP machine as safe and protected as possible?	
Where the electricity supply cable must cross a walkway, has the cable been taped to the floor, using masking tape, or covered with a rubberised mat?	
Has the electricity supply cable been checked for pinch hazards?	
<b>Rescue</b>	
Which named team member will respond to an alarm?	
Can this team member stay within earshot of machine/pulse oximeter alarm at all times?	
Do you know the location of the nearest fire extinguisher? Do you know how to use it to attack an oxygen fire?	
Which named BLS trained team member will respond in an emergency?	
Can this team member remain close to the patient at all times?	

**Appendix 5**  
**CORE CARE STRATEGIES FOR THE WHOLE BODY REHABILITATION AND WEANING**  
**PATHWAY**

<b>Core Strategies</b>	<b>Areas to consider within strategy</b>
A. Daily routine planned and established	<ul style="list-style-type: none"> <li>• Active rehabilitation times</li> <li>• Time patient sits out of bed</li> <li>• Rest period agreed</li> <li>• Getting patient dressed in own clothes</li> <li>• Personal time (e.g. listening to music, family visits)</li> <li>• ? off unit visits</li> </ul>
B. Communication strategies trialled and established (patient, family, MDT)	<ul style="list-style-type: none"> <li>• Cuff deflation (Above Cuff Vocalisation if cuff inflated)</li> <li>• Speaking valve – PMV or other one way valve</li> <li>• Pen and paper</li> <li>• Alphabet / picture boards</li> <li>• Other AAC tools</li> <li>• Rehabilitation and weaning plan written up on patients write and wipe board</li> </ul>
C. Effective wake and sleep cycle established	<ul style="list-style-type: none"> <li>• Usual sleep pattern / routine at home</li> <li>• ? night sedation</li> <li>• Assessment and treatment for delirium / agitation</li> <li>• Change into night clothes at night time</li> </ul>
D. Rehabilitation interventions	<ul style="list-style-type: none"> <li>• Short term and long term goals agreed</li> <li>• Strength and endurance</li> <li>• Active and passive</li> <li>• Planned rest days</li> </ul>
E. Weaning strategies	<ul style="list-style-type: none"> <li>• Developed on an individual basis</li> <li>• Weaning and rehabilitation may not be able to be carried out in the same day</li> <li>• Wean during the day</li> <li>• Effective And supportive ventilation following weaning episode</li> <li>• Stop weaning for 24 hours if: <ul style="list-style-type: none"> <li>○ Frequent diarrhoea</li> <li>○ Septic shower</li> <li>○ Clinical judgement</li> </ul> </li> <li>• Ventilator CPAP should not be used as a prolonged strategy for weaning unless needed.</li> </ul>
F. Nutrition optimised and established	<ul style="list-style-type: none"> <li>• Fine bore tube</li> <li>• Swallow test for oral diet</li> <li>• ? PEG</li> <li>• ? supplements</li> </ul>
G. Comfort strategies	<ul style="list-style-type: none"> <li>• Regular analgesia</li> <li>• Bowel care</li> <li>• Massage therapy</li> <li>• Music and TV</li> <li>• Reading material</li> <li>• Outside visits</li> </ul>
H. Psychological strategies	<ul style="list-style-type: none"> <li>• Patient diary</li> <li>• Days off</li> <li>• Pet therapy</li> </ul>
I. Reduce invasive monitoring	<ul style="list-style-type: none"> <li>• Urinary catheter</li> <li>• Central line</li> <li>• Cardiac monitor</li> </ul>



Glossary of terms:

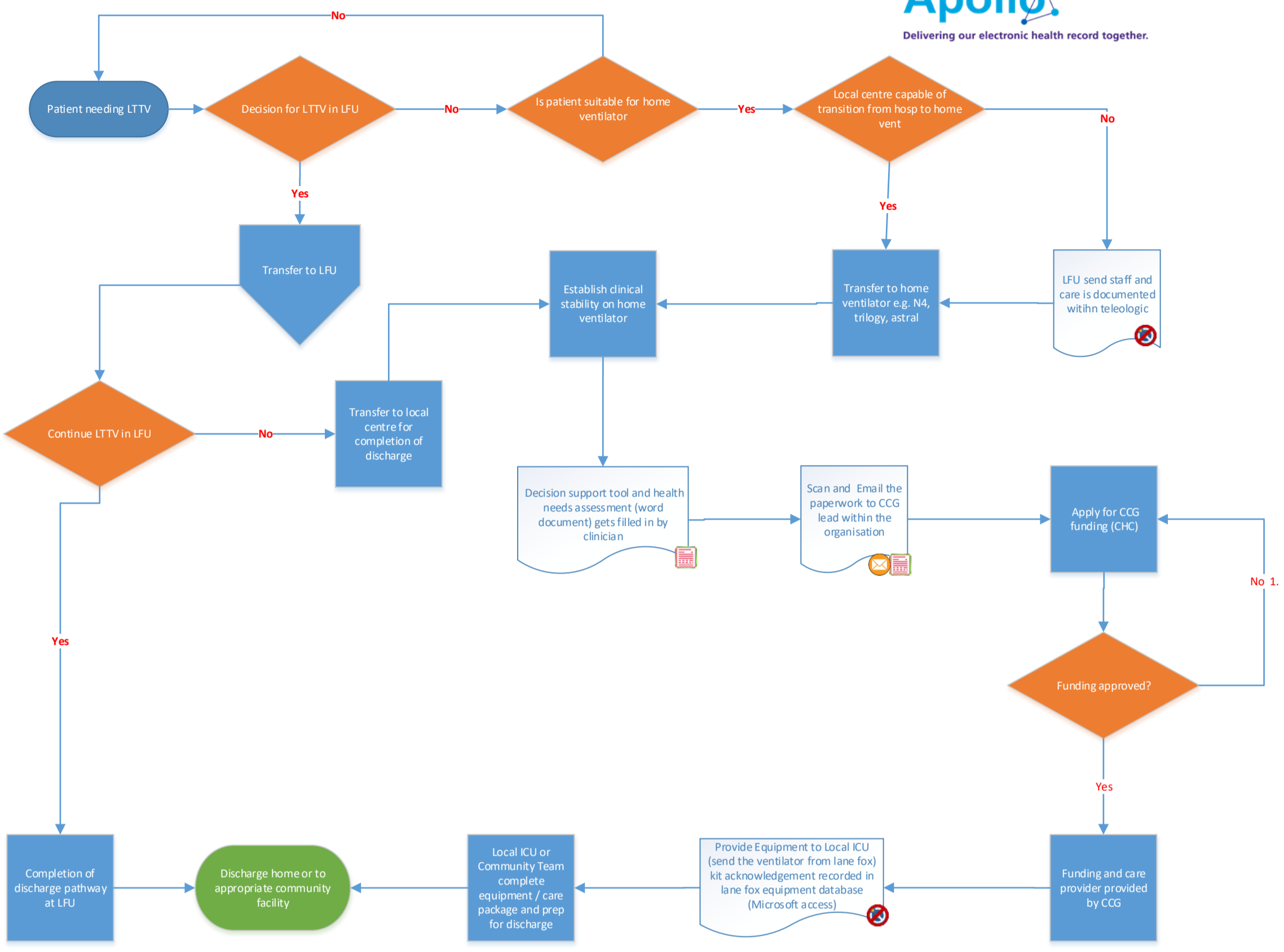
- Teleologic – Referral website
- LFU – Lane fox Unit
- LTTV – Long term Tracheostomy Ventilation
- PMV – Passir Muir Valve ( speaking valve)

Notes:

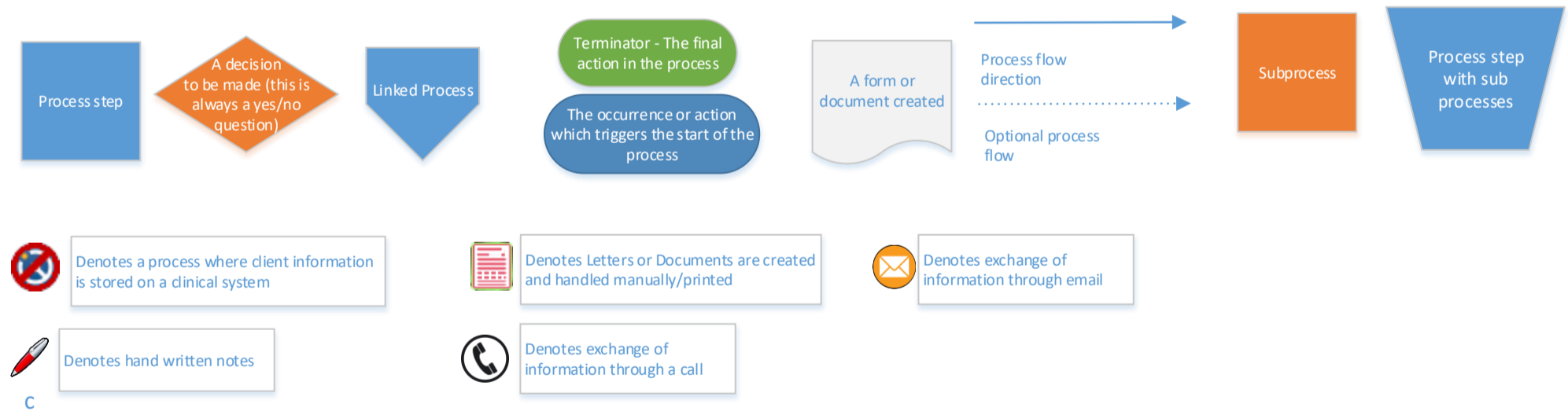
Home NIV and Discharge pathway the same regardless of site.



LTTV Pathway



Legend



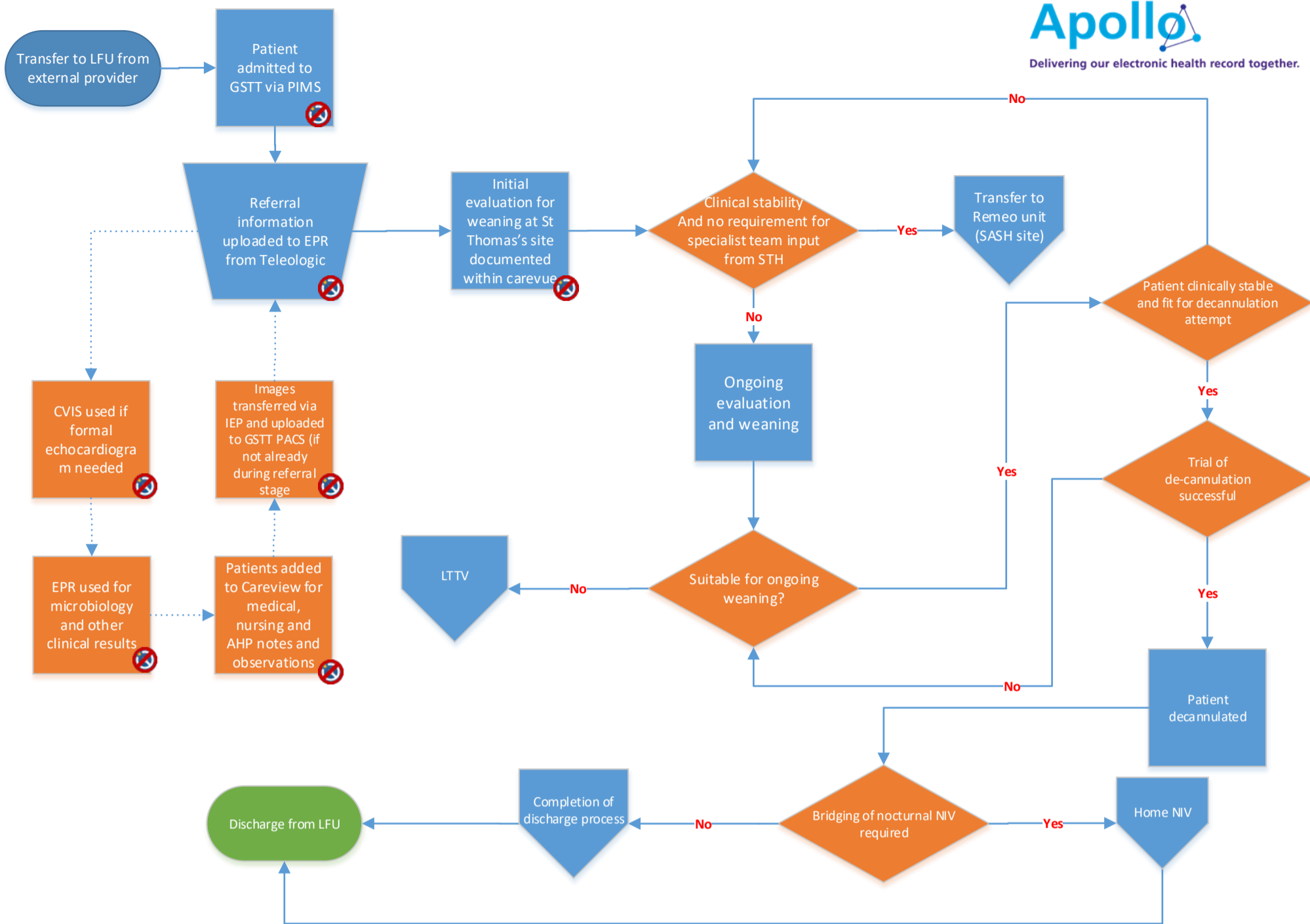
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- CHC – Continuing healthcare (package of care provided outside of hospital)
- CCG – Clinical commissioning group
- NIV – Non invasive ventilation

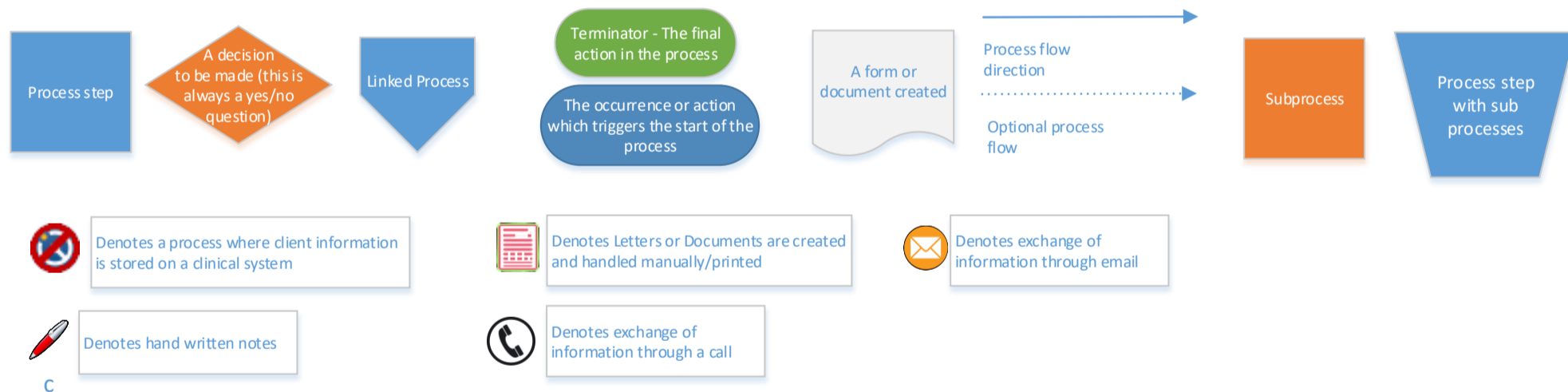
**Notes:**

1. Reapplication of funding may be needed, however the majority of times clarification is sufficient for funding to be approved.

Transfer to LFU



Legend



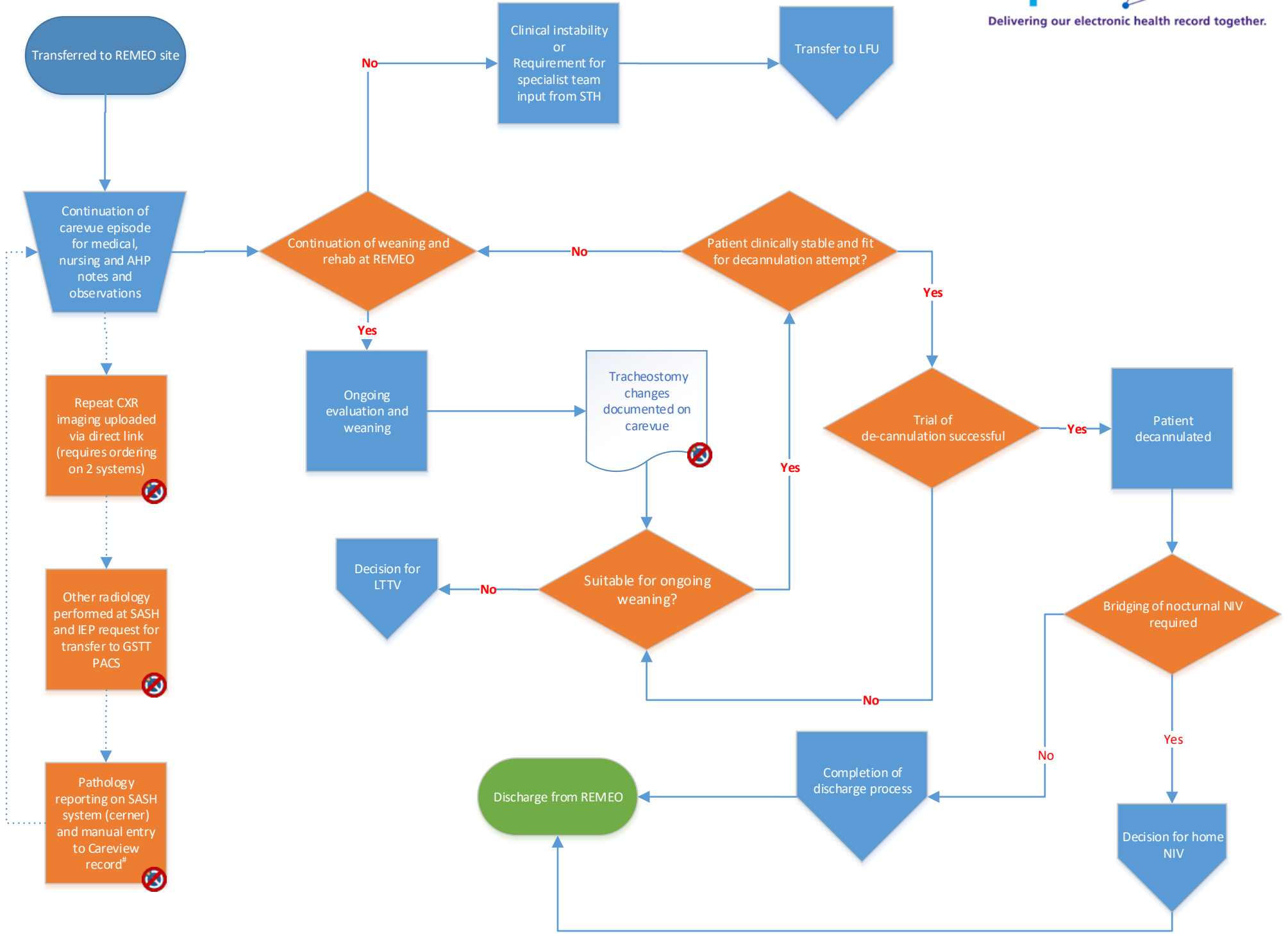
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- CCG – Clinical commissioning group
- NIV – Non invasive ventilation
- CVIS/TOMCAT – Echocardiogram/Cathlab procedure storage
- EPR – Electronic patient record
- PACS – Imaging viewer
- STH – St Thomas Hospital

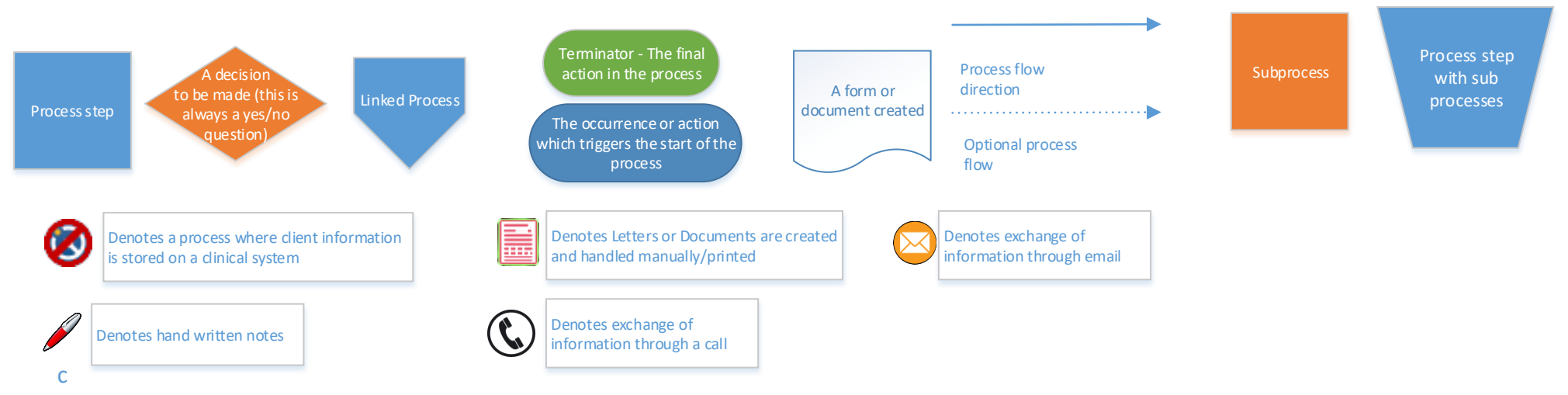
Notes:

Home NIV and Discharge pathway the same regardless of site.

Transfer to REMEO



Legend



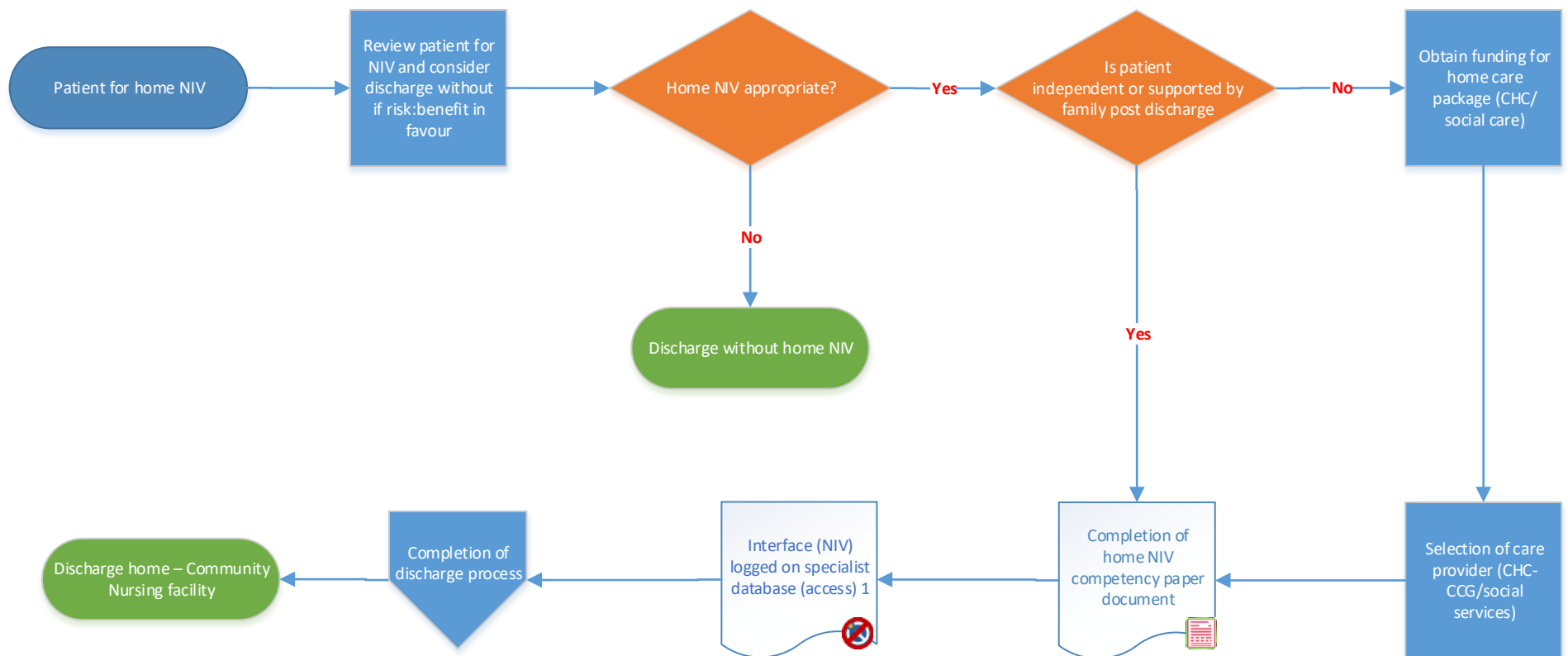
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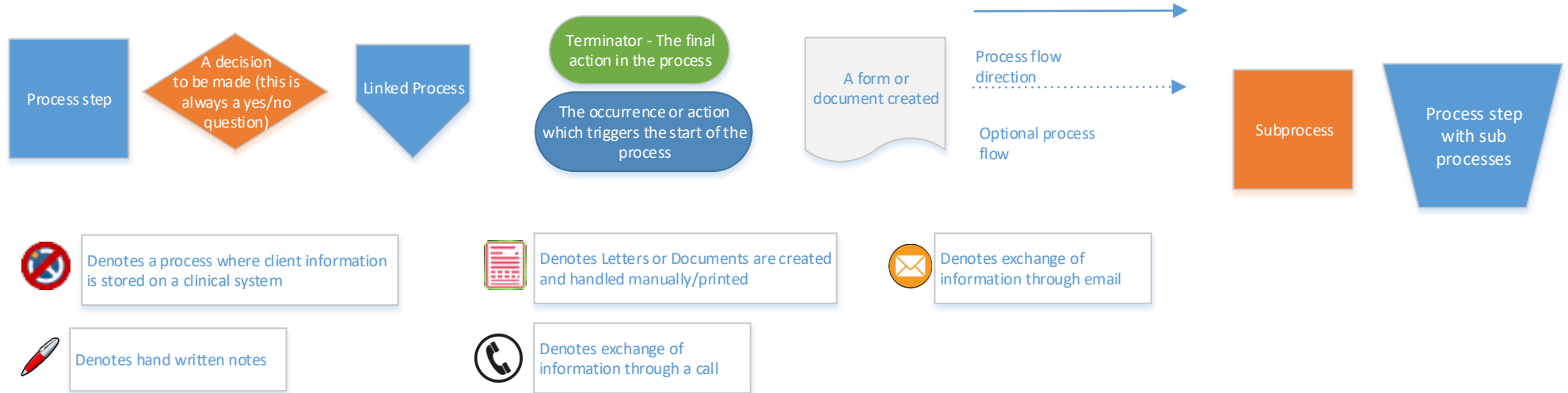
**Notes:**

Home NIV and Discharge pathway the same regardless of site.

Home NIV



Legend



**Glossary of terms:**

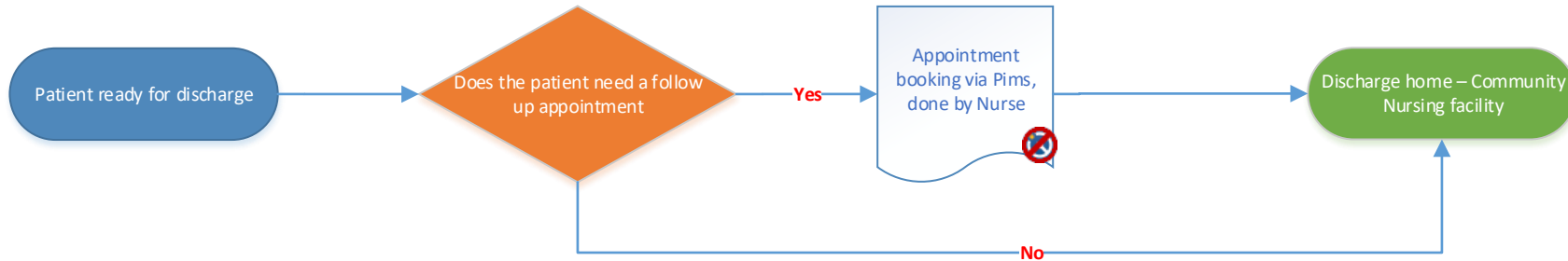
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**Notes:**

1. Access database acts as a repository for patients receiving home NIV. Used by technical services to ensure that servicing of machine is maintained. Also contains data regarding device settings and can be used as reference for troubleshooting. Limited access because of limited login. Database is maintained by technical services within LFU.



Discharge Process



Function



Notes:

Discharge criteria decided on preceding process

Dear Colleague

We are pleased to announce that the Ventilation Service at University Hospital Aintree has completed the establishment of its dedicated ventilation facility known as the "Ventilation Inpatient Centre" which includes dedicated weaning beds. The unit is now fully operational and is able to accept referrals. The Ventilation Service would be pleased to receive referrals for possible transfer of "slow to wean" patients. A brief guide to aid patient selection is outlined below.

Suggested criteria for referral are:

- 1) Patient deemed to have weaning potential by parent ICU team
- 2) Delayed wean after 21 days of attempted weaning by the ICU team
- 3) Transfer acceptable to patient and or relatives
- 4) No immediate further acute treatment planned e.g. surgery
- 5) Haemodynamically stable (pulse <140 bpm; BP < 180 and >90 systolic) and no requirement for pressor agents/inotropes
- 6) Neurologically and cognitively stable
- 7) All sedation/neuromuscular relaxants withdrawn
- 8) No instability involving other organ systems requiring organ support other than long term renal replacement i.e. dialysis
- 9) No evidence of acute sepsis

The Ventilation Service would also be able to assist with establishment of a long term Ventilation package for those deemed non-weanable and therefore not suitable for transfer. **The Ventilation Business Manager and/or the Ventilation secretary may be contacted for this purpose.**

A referral letter should be faxed to the Ventilation Business Manager or the Ventilation Secretary containing patient details, NHS number, original diagnosis at presentation, any active problems and whether the referral is for weaning assessment and potential transfer or for support with establishment of a home ventilator package.

Patients who are referred as a potential "weaning" candidate will be reviewed in the referring unit by the duty "Weaning" Respiratory Consultant. If deemed suitable for transfer after formal nursing liaison and agreement with patient and/or next of kin, the referring hospital will be invited to arrange transfer. Liaison between all the para-medical disciplines i.e. between the Physiotherapists, Speech and Language therapists, Occupational therapists and Dieticians is recommended prior to transfer.

The Ventilator Business Manager (**Marie Pearce; Tel 0151 529 3504; Fax: 0151 529 3129**) will facilitate the transfer process. In her absence, the Ventilation secretary (**Tel: 0151 529 8944; Fax 0151 529 2873**) may be contacted.

**Ventilation Manager - Fax: 0151 529 3129 or Ventilation Secretary - Fax 0151 529 2873**

The rota for the ventilation consultant is held by the Ventilation Secretary and Marie and they can be contacted for discussion via them or the **Ventilation Inpatient Unit on 0151 529 3602.**

Visits to the Ventilation Inpatient Centre would be welcome and may be arranged by contacting the **Ward Manager Julie Cheney on 0151 529 3625.**

Yours sincerely

\_\_\_\_\_  
Dr Robert M. Angus

\_\_\_\_\_  
Dr Biswajit Chakrabarti

\_\_\_\_\_  
Dr John F. O'Reilly

\_\_\_\_\_  
Dr Nick Duffy

Longmoor Lane  
Liverpool  
L9 7AL

## Ventilation Service Referral

Referrer: .....

Unit: .....

Contact number: .....

Name of Patient: .....

Date of Birth .....

NHS Number: .....

Address: .....

.....

.....

.....

Contact Number : .....

Next of Kin: .....

GP details: .....

.....

.....

Weaning assessment and potential transfer or for support with establishment  
of a home ventilator package **(please delete appropriately)**

Diagnosis: .....

.....

.....

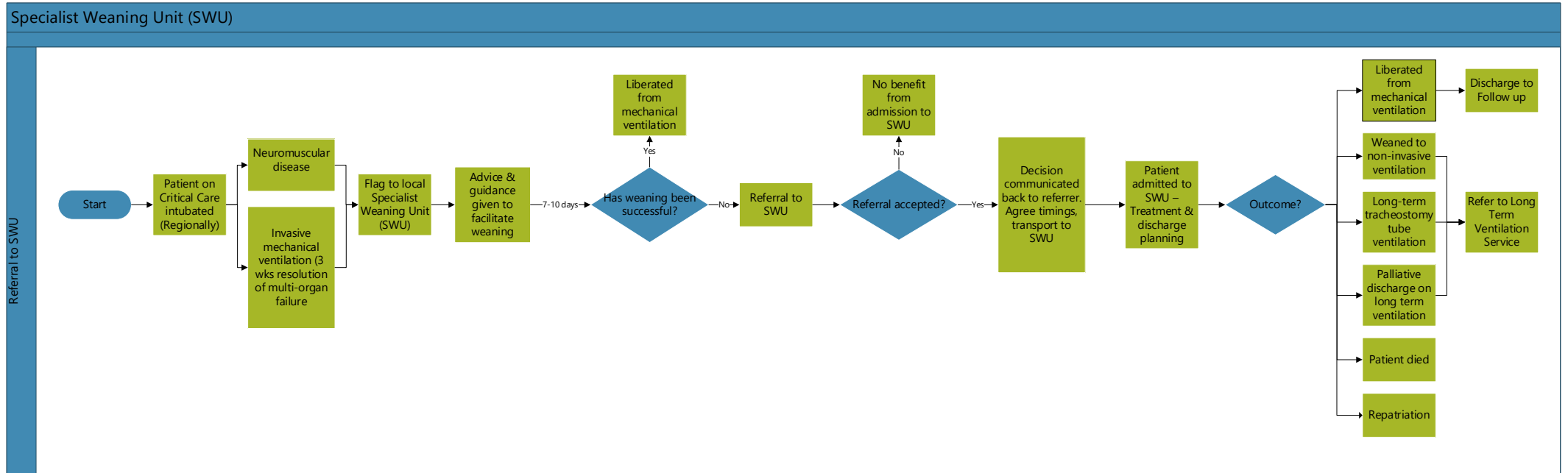
Active problems: .....

.....

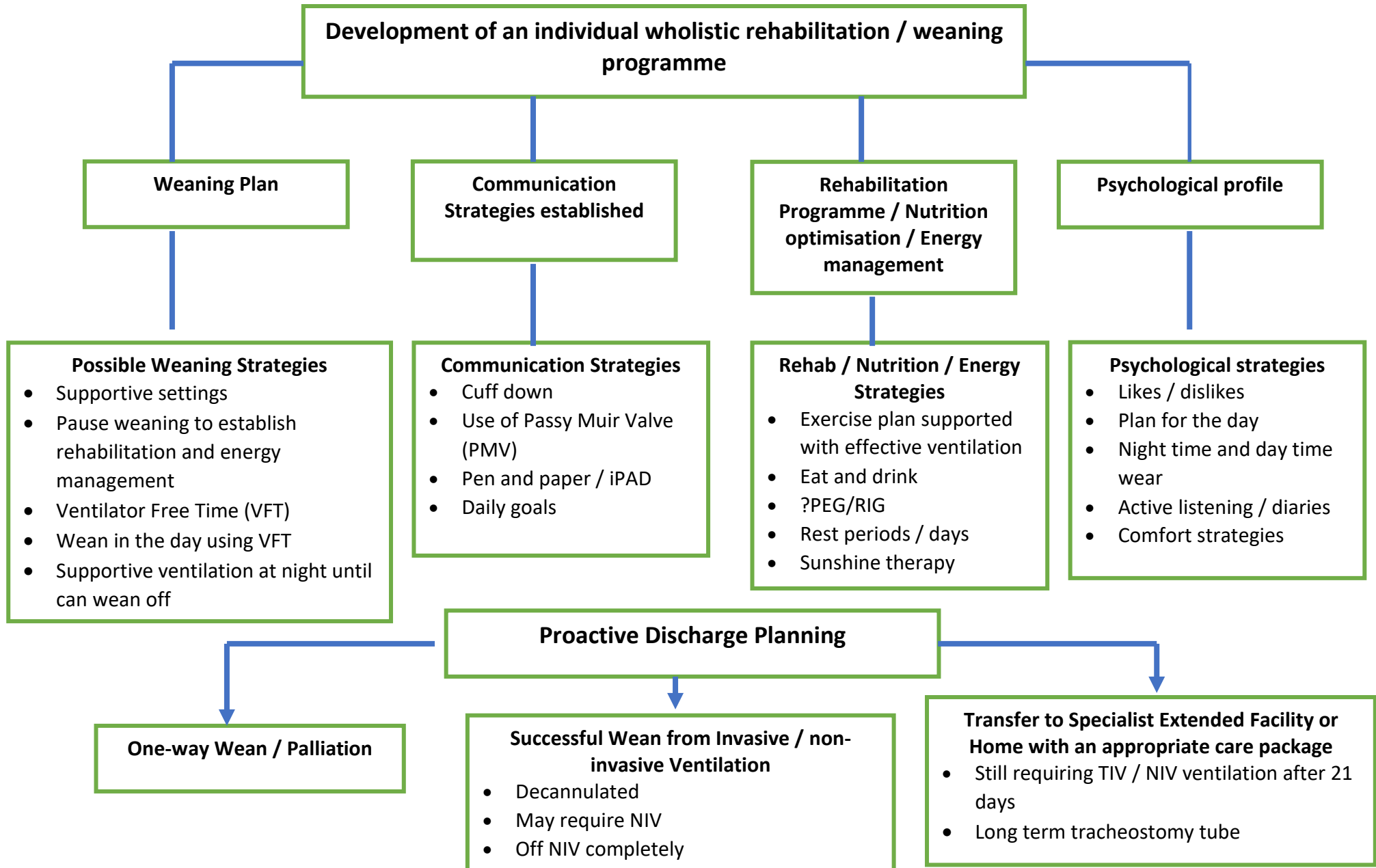
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## Appendix 8: Referral flow diagram



**WHOLE BODY REHABILITATION PATHWAY  
DAILY MDT REVIEWS AND PLANNING**





## Appendix 10 – EQUIPMENT LIST

- Mixture of ventilators for Non-invasive and invasive ventilation
  - Internal battery
  - Access to external battery
  - Single limb
- MI-E devices
- Bronchoscopy
- FEES equipment and nasendoscopy
- Expiratory Muscle Strength Training equipment
- sEMG biofeedback and Pharyngeal Electrical Stimulation (Phagenyx) equipment
- Blood gas machine
- Ultrasound for the purposes of pleural procedures and intravascular access
- Transcutaneous CO2 monitors
- Sleep study equipment
- iSTAT machines
- ABG static machine
- Respiratory vests
- Active heated humidifiers
- Lung volume recruitment bags
- Aerogen Nebuliser
- Spirometry and muscle strength measurement
- ECG machine
- Mobile USS
- Portable airway scope
- Rehabilitation equipment
  - Seating
  - Wheelchair
  - Therapy bikes
  - Resistive bands
  - Weights
  - IMT / EMT
  - Walking frames
- Mixture of tracheostomy tubes
- Tracheostomy cuff manometers
- One-Way Valves for tracheostomies
- Mixture of NIV masks
  - Full face



- Nasal
  - Total
  - Hybrid
- AAC equipment
- Ceiling hoists
- Standing hoists
- Communication aids
- iPads
- Headphones
- Eye shades
- Ear plugs
- Entertainment
  - Board games
  - Cards
  - Art material
  - Audio books
- Hairdryers
- Electric toothbrushes
- Mirrors
- In bed hair wash bowls
- Foot spas

## Appendix 11

PRODUCT	SUPPLIED BY:	MODEL	SUPPLIER	NUMBER REQUIRED
Ventilator and filters	weaning centre	B&D Electromedical NIPPY 3+ x 2	Lane Fox Unit	X2
Battery and charger	weaning centre	B&D Electromedical 1 x portable	Lane Fox unit	1 each
Humidification unit	weaning centre	Fisher & Paykel	Lane Fox Unit	X1
Suction Unit	CCG	Local policy	Local policy	X2 (at least 1 portable)
Nebuliser Compressor unit	Lung function, local hospital	Local Policy		X1
Cough assist machine	weaning centre	NIPPV Clearway Cough assistor B&D Electromedical	Lane Fox Unit	X1
Heated wire vent/humidifier circuits	District Nurses/CCG	Fisher & Paykel Healthcare RT202 including MR290 chamber (box of 10)	NHS supplies FDC205	One circuit per fortnight
Whisper swivel valve	District Nurses/CCG	Respironics 332113	NHS supplies FDE078	X1 per month
Clearway Disposable 2mm circuit	District Nurses/CCG	B&D Electromedical 0960.101	NHS supplies FAG2243	X1 per month
Smooth bore breathing system limb 1.8m	District Nurses/CCG	Intersurgical 5018000	Intersurgical	x1 per fortnight
Water for inhalation (sterile)	District Nurses/CCG or Prescription	Aquilant Critical Care Carefusion Airlife 2D0737	NHS supplies FDD2093	1 2L bag per 24-48 hours
Catheter mount	District nurses/CCG	Intersurgical 3521	NHS supplies FDE148	1 per week
HME (Heat moisture exchange)	District Nurses/CCG	Intersurgical 1942	Intersurgical / NHS supplies FTC048	2x weekly
Hard Ambu bag and mask	On discharge from Lane Fox	Intersurgical 7152	NHS supplies FDE658	1x yearly or PRN
Suction catheters Size 10	District Nurses/CCG	GBUK Healthcare Tender tip TTO1-10-060	NHS supplies FSQ580	1-2x box of 100/week
Suction tubing	District Nurses/CCG	Universal Hospital Supplies Ltd UN30026FFM	NHS Supplies FWP204	X7 per week
Yankauer sucker	District Nurses/CCG	Medtronic MITG Argyle (Covidien)	NHS supplies FWP501	3 per week

		1180501106		
Trache tube with Innertubes	District Nurses/CCG	Smiths Medical International Blue Line Portex size 7.0 cuffed suctionaid 100/860/070	NHS supplies FDG181	1 per month
Spare trache tubes	District Nurses/CCG	Smiths Medical International Blue Line Portex Size 6.0 cuffed suctionaid 100/860/060	NHS supplies FDG926	As emergency and spares
Spare inner tubes for trache	District Nurses/CCG	Smiths Medical International Blue Line Ultra Size 7.0 100/850/070	NHS supplies FDG341	2 per month
Nebuliser acorn and T piece	District Nurses/CCG	Intersurgical kits. Code 2505	NHS supplies FDE083	1 per fortnight
Trache dressings	District Nurses/CCG	Activa Healthcare Lahmann metalline 23094 8x9cm	NHS supplies EJI191	1 per day
Trache holders	District Nurses/CCG	Insight Medical Products Ltd TH/100	NHS supplies FTH000	2 per week
Gauze Swabs to clean trache site	District Nurses/CCG	Any brand	NHS supplies ENK004	7 packs per week
Saline Ampoules 10mls	GP/CCG	Any brand	Prescription	7 ampoules per week
Gloves	District Nurses/CCG	Any brand	NHS supplies	DNs to assess