BTS Model of Care for Complex Home Ventilation

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Summary of Recommendations

Definitions

• The definition of complex home ventilation will depend upon patient characteristics, ventilator dependence, requirement for other respiratory support and requirement for extensive skilled packages of care

• A tier system is suggested to organise commissioning for HMV services with tier 3-a complex HMV service, tier 2-a HMV service caring for patients not meeting the criteria for complex commissioning and tier 1-a provider of acute NIV

Commissioning, governance, research and QI

• There should be designated operational, medical, and non-medical leads for the complex HMV service

• Each complex HMV service should have an operational policy setting out referral criteria, workforce and equipment requirements, and patient pathways

• HMV activity should be accurately coded to reflect the type of service provided

• Discussions should take place between the HMV service and the ICB to ensure recognition of the tier of service it is providing, that it is managing the correct patient population, receives an appropriate number of referrals and has an infrastructure in terms of estate, equipment and staff to deliver high quality care

• A national registry of HMV patients should be urgently developed

• All HMV services should have a robust clinical governance structure which will include mortality and morbidity, equipment governance and education

• Local networks of HMV services should be developed and strengthened with clear mechanisms for ensuring collaboration between different HMV services

Service Model

• All complex HMV services should have ring fenced inpatient beds

• All complex HMV services should have access to outpatient facilities with appropriate access to services required to manage complex HMV patients

• All complex HMV services should provide and maintain essential equipment for complex HMV patients and equipment which is not being supplied by the HMV service, will be sourced, supplied and paid for by the community team

• There should be a 24 hour helpline for patients to contact in case of equipment failure so that where appropriate, replacement equipment can be immediately sent out

• The following would be recommended as minimum staffing levels for a complex HMV service: one WTE nurse, physiotherapist or healthcare scientist per 40 patients and one WTE consultant per 300 patients who meet the definition of requiring complex HMV

• Complex HMV services should have dedicated specialist physiotherapy and speech and language therapy staff

Patient Pathways

• Complex HMV services should be accessible for advice from other services around the region

• There should be clear referral criteria for complex HMV services based on best practice according to published evidence

• Complex HMV services should be able to review new referrals in a timely manner and this should be defined by local policies

• Complex HMV services should receive a minimum number of referrals per year and meet minimum numbers of complex patients under their care

• Complex HMV services should have written policies for transition between paediatric and adult services

• A regional SWU should be co-located with a complex HMV service

• A multi-disciplinary approach to discharge planning is essential

• Discharge planning for patients being initiated on complex HMV should be started as soon as the need for long term ventilation is recognised

• The HMV team will use cascade training by training a lead carer or trainer

• The complex HMV team should develop individual ventilator/interface management plans

• For complex HMV patients who are ventilated via a tracheostomy, the HMV team will also need to provide the patient with a tracheostomy passport

• When admitted to hospital for acute or elective care, whenever possible, the community carers should support care of patients receiving complex HMV within hospital

• All complex HMV patients should have, at minimum, a holistic annual assessment by the multi-professional complex HMV team and there should be a policy for the recommended minimum frequency of follow-up in specific situations

• Complex HMV services should hold joint clinics/multiprofessional meetings with other specialties for patients with significantly complex medical issues

• Complex HMV services should have operational policies to ensure safety during acute and planned hospital admissions

A) Introduction

Rationale

Complex home mechanical ventilation (HMV) is a service commissioned by specialised commissioning for the provision of home support of patients with complex HMV needs and/or a protracted duration of ventilation (greater than 14 hours per day) and those receiving tracheostomy ventilation.[1] However, many patients who do not meet the definition of requiring complex HMV receive HMV outside of specialised commissioned services. These services need to be both supported and recognised in light of the increasing number of patients requiring both more basic ventilatory support (such as chronic obstructive pulmonary disease (COPD) and obesity-related respiratory failure (ORRF)) and the more complex patient population of neuromuscular diseases, neurodisability and transition from children to adult services.

With the forthcoming devolution of services from specialised commissioning to Integrated Care Boards (ICBs), a document outlining the population of patients who should be recognised by specialised commissioning and the infrastructure to support such patients is required.

Specialist respiratory care

This document has been developed by a multi-professional group under the auspices of the British Thoracic Society (BTS). It follows on from documents concerning acute Non-Invasive Ventilation (NIV) services, respiratory support units (RSUs) and specialised weaning units (SWUs) and is the fourth and final document concerning the management of patients with ventilatory failure.[2-4] These documents outline the necessary infrastructure to deliver services and are needed to inform discussions about commissioning currently and for future devolution of services to ensure safe and high-quality care. In other areas where specialised commissioning is devolving respiratory services to ICBs, such as asthma and interstitial lung disease, a tiered approach to services is being considered. This document outlines a similar approach.

Repeated BTS audits of acute NIV as well as the NCEPOD 'Inspiring Change' document have highlighted high mortality rates and opportunities for quality improvement in the delivery of acute NIV.[5-6] This was one driver for the development of RSUs across the UK and led to publication in 2021 of a combined BTS/Intensive Care Society (ICS) document issuing guidance on the development and implementation of RSUs.[3]

SWUs are less commonly provisioned in the UK than RSUs but UK data have suggested a requirement based on numbers of critical care patients requiring prolonged mechanical ventilation. This led to publication in 2023 of a combined BTS/ICS document issuing guidance for the model of care for SWUs.[4]

Complex HMV is closely linked with RSU and SWU work. The expertise required and the staff working in such environments are very similar. Complex HMV services have a central role in the seamless care of these patients from acute admission to discharge from acute hospitals.

With the need to expand all HMV services, both complex and non-complex, there is a need for clarity and direction in commissioning HMV services. This is especially so given the variation of care that has

been noted in two national reviews – the NCEPOD 'Inspiring change' and the GIRFT respiratory review which support the findings of variability of care noted in the regular BTS NIV audits.[5-7]

Definition of the Complex HMV Patient

Defining the 'complex HMV patient' is difficult as currently there are no agreed definitions or national registries identifying such patients. Limiting definitions to diagnosis or ventilator dependency time will restrict definition and not help with the development of pathways and models of care for this group of patients.

However, a pragmatic consensus can be agreed as to the characteristics of the complex ventilated group of patients to help with their ongoing care and management from an integrated healthcare team within the community and acute hospital setting.

These will include but is not limited to:

Patient characteristics

Patients with neuromuscular disease such as:

- Motor neuron disease (MND)
- Duchenne muscular dystrophy (DMD) and other inherited/metabolic muscle disease
- Severe respiratory disease in association with a learning disability where ventilatory issues are the main clinical issue
- Patients transitioning from paediatric HMV to adult HMV services

Patients receiving tracheostomy ventilation

Ventilator dependency

Dependent on HMV for at least 14 hours of a 24 hour period

Other equipment

Patients receiving NIV who also require:

- Cough augmentation techniques
- Secretion management requirements e.g. Suction, Sialorrhoea management

Other dependency

Patients receiving NIV who also require a skilled 24 hour package of care in the community where ventilatory issues are the main clinical issue

Exclusion

This document does not make recommendations about paediatric care (less than 16 years old). Neither does this document make recommendations about the care of patients receiving CPAP therapy alone. However, it is acknowledged that both patient groups may be highly dependent and require complex respiratory care which may involve complex adult HMV services and complex HMV services will flex according to patient need.

This document makes specific recommendations about commissioning arrangements which will therefore pertain to NHS England. The clinical guidance and the general principles underlining the commissioning recommendations, will have applications across all the devolved nations of United Kingdom.

B) Commissioning HMV services, including Complex HMV

Confusion exists over commissioning HMV services between ICBs and specialised commissioning. Irrespective of who commissions the actual service it is the responsibility of ICBs to pay for equipment such as ventilators, mechanical insufflation-exsufflation devices (MI-E), suction machines and nebulisers as these are not part of the national tariff for high-cost drugs and devices. Commissioning structures can be considered in three broad groups.

Commissioning structures

Complex HMV services are included within the remit of Specialised Respiratory commissioning through NHS England. Services have evolved in differing ways, with variability in centre size (GIRFT ref) and geographical coverage. A prior UK survey highlighted that many additional hospitals provide HMV services for patients who require HMV, but whose clinical presentation does not require the input of the complex HMV centre.[8] Such centres are typically commissioned locally.

There are currently three broad groups:

Acute NIV providers who start HMV during non-elective admissions: Patients may be started on ventilation during an acute hospital admission but their ongoing care as an outpatient is with a different service, usually one that is recognised via specialised commissioning. For example, this pathway may be used for patients with COPD who have failed to wean from an episode of acute NIV and have stabilised to an overnight NIV requirement. Within a tiered approach to commissioning, these services will be Tier 1 services.

HMV service: Patients may be initiated on long term ventilatory support after an acute hospital admission or electively for those patients with COPD or ORRF. Such patients would be followed up in clinic as an elective day case attendance (see funding mechanisms below) by that organisation. Such services are often, but not always, linked to a larger sleep apnoea service that provides home CPAP therapy for patients within their catchment area. Within a tiered approach to commissioning, these services will be Tier 2 services.

Complex HMV service: This is a service that corresponds to definitions recognised by specialised commissioning for patient groups, the level of ventilator dependency and the nature of the ventilatory support as detailed above.[1] Within a tiered approach to commissioning, these services will be Tier 3 services.

Some organisations have developed shared care models that enable movement between centres as clinically indicated and depending upon local networks/geography. The requirements for centres according to their function are listed below.

Requirements

Acute NIV providers

A recognised area for initiation of acute NIV that fulfils BTS RSU criteria. This may be delivered from a critical care High Dependency Unit (HDU) if not available. The staffing, infrastructure and training requirements outlined in the BTS NIV and RSU guidelines should be followed.[2,3]

HMV service

A dedicated service that includes the provision of a variety of ventilators and interfaces for home/community use. They may have ring fenced beds for HMV patients or demonstrate close working relationships with the RSU which consistently enables HMV patient admission when required.
Evidence of training in delivering HMV services by medical staff, nursing staff and AHPs
Designated area for outpatient care which includes availability of equipment required to deliver HMV.
Support by electronics and biomedical engineering. Entry of information onto a national database.

Complex HMV service

As per specialised commissioning document.
Staffing and infrastructure as detailed in this document.

Communication between differing HMV providers within regional networks is essential. All who are receiving HMV in a home setting should have an appropriate alert on the electronic patient record. Communication should always occur with the patient, GP and local hospital with a clear management plan for individuals who are admitted to a local hospital which is some distance from the complex service for elective interventions and acute deterioration. Appropriate adjustments need to be made for individuals with learning disability/autism/communication issues.

Activity recording and payment mechanisms

Introduction

Within England and the devolved nations, clinical activity in secondary care is captured by the coding departments. Notes and/or discharge summaries are reviewed post discharge to code the activity, which is the process by which providers get paid. The WHO-owned ICD-10 diagnosis codes[9] are used to capture diseases and complications while the UK OPCS-4 procedure codes[10] capture interventions and procedures. The coding department enters the appropriate codes into the hospital administration systems, which is processed via a 'Grouper'. This generates a Health Resource Group (HRG) on which the payment is based, via the National Tariff Payment System (previously known as Payment by Results [PBR]) rules applying national tariffs. More recently, different payment mechanisms such as block contracts or aligned payment processes have been implemented, though data capture remains important to determine the activity for benchmarking purposes. While coding is key, two other factors influence payment: the setting of the activity (non-elective admission, day case/elective or outpatient attendance) and the clinician delivering the care (nurse, doctor, physiologist, multiple clinicians etc), though the latter is not applicable to ventilatory support.

Coding

There are several OPCS codes that should be used to capture the activity, recognising the last two may be more related to the acute setting and sleep services rather than HMV:

E852 (NIV not otherwise specified)

E985 (MI-E)

E856 (CPAP)

X522 (high flow oxygen)

It is important that these named activities are clearly documented in the inpatient notes / outpatient letters and data capture forms if used for outpatients. To ensure clarity teams should discuss this information capture with coding departments and service managers, specifying the setting of inpatient, day case and outpatient as noted above.

For non-elective settings (i.e. acute admissions), the underlying diagnosis should be at the top of the discharge summary or diagnosis 'position 1'. In position 2, the term 'ventilatory failure' should be used. If the patient has other conditions which represent complications or comorbidities (e.g. diabetes, heart disease) and these are coded, they may contribute to slight increase in the tariff. It is also important that any procedures, both diagnostic and therapeutic are captured, e.g. if a patient receives CPAP, then the procedure should be captured as E856.

For example, in a patient who has an exacerbation of COPD and receives NIV, then a different HRG would be generated than a patient who did not receive NIV, and this results in an uplift in tariff of approximately £600. This reflects the resource use associated with the activity/staffing within the NIV unit and will provide some financial support to run a service providing acute NIV if the activity is recorded correctly.

The 'setting' as either day case or outpatient is important as this will impact upon income and discussions are ongoing nationally regarding the correct phrasing. The activity of E852 should be recorded and this will generate an HRG of DZ37A Non-Invasive Ventilation Support Assessment, 19 years and over and is independent of the staff member performing the test/intervention.[11] The use of the code provides payment direction and therefore, it does not matter which member of the clinical team delivers the care.

Payment

When used, the National Tariff Payment System generates a payment (tariff) for activity. The tariff for activity captured using the above codes and hence HRG is approximately £700 for a day case and £150 for an outpatient.

This income should be sufficient to fund the majority of HMV service and complex HMV service activity in an outpatient setting. HMV teams should check their activity is being appropriately recorded in daycase (and outpatient where relevant) as a way of ensuring funding is hypothecated to the service.

For those services who do a significant amount of home visits for their dependant population discussions should occur to ensure such activity is captured and recognised for payment processes.

For those services currently recognised by specialised commissioning there is an additional 'top up' for their activity. How this works with the devolution of services as noted below is still to be determined.

Future commissioning

In the future, potentially in April 2025, HMV services are likely to be devolved to ICBs or regions. At present there is variability across England where the aspects of respiratory specialised commissioning are delivered by regions or ICBs. It is important that such discussions take place between the HMV service and the ICB/region to ensure recognition of the appropriate tier of service it is providing, based upon the patient population, an appropriate volume of referrals to maintain skills and has an infrastructure in terms of estate, equipment, and staff to deliver high quality care as outlined in previous sections.

C) Governance

Management

Complex HMV services should have a clear place within the overall management structure of a healthcare organisation. Typically, complex HMV services would be part of respiratory medicine and would collaborate closely with critical care.

There should be designated operational, medical, and non-medical leads for the complex HMV service (where non-medical professionals would be determined by the local staffing model, e.g. nurse, AHP or healthcare scientist). Regular meetings should take place between the service operational and clinical leads.

Creation of a separate complex HMV service line management structure is recommended to facilitate day-to-day operational management. There should be clear lines of reporting for complex HMV services within a directorate or divisional management structure of the healthcare organisation. Larger complex HMV services or those combined with sleep services may function as a separate business unit.

The healthcare organisation will be accountable for ensuring that the complex HMV service meets local and national service standards; supports workforce recruitment, retention, and training; and is responsible for establishing and maintaining physical infrastructure (including estates, facilities, equipment and consumables).

Where a SWU exists in the same healthcare organisation, this should be geographically co-located with the complex HMV service.[4]

Each complex HMV service should have an operational policy setting out referral criteria, workforce and equipment requirements, and patient pathways.

Research, audit and QI

National Registry for HMV services, including Complex HMV

Whilst the definitions for HMV and complex HMV have been outlined earlier in this document, the absolute number of patients under such services nationally is still not accurately known. Further increases in the patient population is anticipated. Factors favouring HMV service growth include the

obesity epidemic, enhanced access to diagnostics and tools for early detection of hypoventilation, and an increased evidence base for the efficacy of HMV across several disease groups.

A survey conducted to help inform this document across services commissioned as providing complex HMV services identified that not all services knew exact numbers of patients under their care. Furthermore, the requirement to utilise unused ventilators during the COVID-19 pandemic[12] and recent national recalls of ventilators with significant faults[13] has demonstrated that organisations do not accurately record the location of such devices. Finally, the cost-of-living crisis and in particular the cost of electricity has limited usage of ventilation in some users.[14] Whilst home oxygen and dialysis services have a clear mechanism for reimbursement for patients receiving these treatments at home; no such mechanism currently exists for HMV patients. There are clear potential advantages of a national registry which should be funded by NHS England given the patient safety and equipment governance issues presented by the current absence of such a registry.

Whilst it is essential that individual services will have an accurate database to keep track of patient numbers, diagnoses, and equipment; there is also a clear requirement for a detailed national registry. Specifically this would allow structured priority setting at a national level as well as allowing patient reported outcome measures to be captured. It is only through ongoing research and audit into national data that clear insight into service delivery and areas of excellence and potential need for improvement is possible. This would drive improvements in standards of care and allow better collaboration across the UK. A central registry would allow detailed consideration of specific underlying pathologies and phenotypes for whom HMV is used, to help define criteria for HMV use, and evidence for clinical benefit.

Cystic Fibrosis (CF) is the respiratory condition with the most comprehensive data registry in the UK currently with over 950 datapoints, and annual data submission from all commissioned services for >98% of the entire patient population.[15] Registry reports are published every year and help individual centres to benchmark themselves against peers. In addition, since April 2013 NHS England commissioners have used the CF registry data to adjust tariff payments to centres based on the severity of disease, the 'year of care tariff'. This has enabled resource allocation to match the complexity of the patient population. For HMV, a similar centrally held registry would offer a similar wealth of clinical, commissioning, and research opportunities that would act to enhance standards of care. This is already in place across much of Europe. The core dataset would focus upon underlying demographics including diagnosis and comorbidities (to include carer needs) as well as equipment needs (to include MI-E and suction devices), ventilator settings and hours of use, date of initiation, admission data and service contact points. Core datasets would be reported annually with additional areas such as care of specific diagnostic groups highlighted every few years. Through annual audit the registry could then highlight potential future areas for quality improvement through nationally identified themes.

Clinical governance meetings

Mortality/Morbidity

A robust regular mortality and morbidity (M&M) process should be in place which should include deaths of all patients under the care of the complex HMV service.

There should be an aligned process for patient deaths with other members of the collaborative MDT to ensure shared learning, including learning from good practice. There should be full representation

from the extended multi-professional team, including nurse and AHP leadership at these meetings, with time in job plans to attend.

All critical incidents should be reported via local reporting guidelines and discussed regularly at M&M meetings.

A peer review process including external mortality reviews between other complex HMV services should be encouraged.

Equipment governance

A complex HMV service should have an operational policy setting out equipment requirements.

Complex HMV services need large amounts of equipment with adequate storage space. They should have the facility to provide loan/replacement equipment as required, to establish new patients on treatment and to provide breakdown replacement into the community. Exact requirements will depend upon the size and location of the department, but typical requirements are listed in Appendix 1.

There should be an agreed standard on the use and application of all equipment. Any deviation from this standard should be discussed, agreed, and recorded within a clinical governance meeting.

Local policies should be in place to define the frequency of changes of disposable equipment for infection control purposes. The provision and supply of disposables to community patients should be agreed at a local level.

Patients and families should have access to a 24/7 helpline for equipment enquiries and mechanical failure. They should also have a clear list of whom to contact for consumables and clinical issues once discharged into the community.

Education

A complex HMV service should have a senior member of the team who takes responsibility for ensuring the delivery of clinical education. This will include all aspects of clinical patient management and equipment care and use.

Individual members of the multi-professional team should ensure they are competent in the management of all equipment, accessing relevant training as required.

The multi-professional team should ensure that the 'end users' of any equipment issued by the complex HMV service for use in the community, are fully trained and can demonstrate competence in the use of this equipment. This should take place via a cascade training approach. This training and assessment of competence should be recorded in the patient notes.

Local networks

A complex HMV Service provides the necessary infrastructure for all aspects of complex inpatient assessment and long-term home care for patients who require HMV. It also provides a reference point for clinicians and commissioners to ensure a network approach to patient care. Patients should have access to specialist, complex HMV care when indicated and care may return to an existing HMV service when the "complex" intervention has been completed. A collaborative approach between specialised and local centres is required.

Less complexity, for example nocturnal home NIV in a patient with COPD, still requires specialist expertise to ensure safe and effective care.

Commissioners should ensure appropriate integration of all HMV services within their regions so that there is equitable network access to the best possible care for all patients who require it. It is also recommended that commissioners apply the same outcome measures to all providers of HMV. The need for clear network links with a regional complex HMV service should be a requirement when commissioning any HMV service.

The complex HMV service will run the SWU within the same healthcare organisation. Close clinical collaboration between respiratory medicine and critical care and input from the multiprofessional team is crucial. Remote weaning advice and on-site assessment to regional critical care networks should be provided through the SWU.

Consistent outcome measures should apply to all providers of HMV services, including those who do not manage patients with complex ventilation requirements.
The following structures are very important:

- person-centred integrated care structure for people on HMV
- structures for interprofessional collaboration such as regional multiprofessional meetings
- case conferences and integrated care structures enabling collaboration

D) Service model

Estates

Inpatient

All complex HMV services should have ring fenced inpatient beds. HMV services should also be able to demonstrate a consistent ability to admit HMV patients either with ring fenced beds or close working relationships with local RSUs. The structure of these should adhere to previously published guidelines for RSUs.[3] These may be within a dedicated ward or co-located with RSU, SWU critical care or respiratory ward beds. Staff will have the required competencies to care for patients with any of the ventilators used by the complex HMV service.[16] Where possible, patients with tracheostomy ventilation should be managed on such wards. If this is not possible, close relationships with critical care services within the hospital are essential.

Outpatient

All complex HMV services should have access to outpatient facilities with immediate availability of pulmonary function testing (including mouth pressures and sniff nasal pressures), assessment of ventilation/sleep disordered breathing (polysomnography, transcutaneous CO2), blood gas analysis and imaging services. Out-patient facilities which are used to undertake clinical reviews of patients having complex HMV should meet the minimum accessibility requirement for patients with complex needs (including but not limited to: medical gases, large enough rooms which can allow easy wheelchair access, beds to enable assessment of patients, appropriate toilet facilities, accessibility, nearby same level parking).

Equipment

Complex HMV patients will require specialist equipment and ongoing supplies of essential consumables.

Regional difference will be seen in how essential equipment is supplied. However, all equipment supplied by HMV teams will be covered by an appropriate service contract, either in-house or

outsourced. The response time for equipment supply will be dictated by level of ventilator dependency.

All complex HMV services should provide and maintain:

- Appropriate ventilator and according to clinical need a second device, internal and external batteries and mobility bag
  - A range of ventilators should be available capable of delivering NIV, mouthpiece ventilation and tracheostomy ventilation
- Active humidification unit, if appropriate
- For NIV, an appropriate interface
  - Lung Volume Recruitment bag
  - Positive expiratory pressure device
  - MI-E device
  - Vest (usually requires specific funding agreement)

Additional equipment needed by some complex HMV users that is *not* routinely supplied by HMV services should be provided by community teams:

- Portable suction machines and suction catheters
- Nebuliser
- Tracheostomy tube including emergency tracheostomy change kit
- Pulse oximeter

If the extra equipment is not being supplied by the HMV service, then this will need to be sourced, supplied and paid for by the community team within the agreed continuing healthcare budget with all other ongoing essential consumables which should be placed on a monthly rolling order. Advice on the type of equipment and consumables needed should be directed by the HMV team. Please see Appendix 1 for standard equipment and consumables.

The lack of a standard process for the provision of consumables for complex HMV patients in the community can generate significant safety concerns and leads to avoidable unplanned admissions. The development of an agreed process nationally that can provide central or regional hubs for consumables would be a significant improvement in the care of this vulnerable group.

There should be a 24-hour helpline for patients to contact in case of equipment failure so that where appropriate, replacement equipment can be immediately sent out.

Workforce: The HMV team

Although the structure and funding stream for each HMV team will vary across regions, the essence of the team will be multi-professional and will support both in-hospital and community outreach working.

Availability of the following staff groups is essential for the delivery of complex HMV care:

- Dietetics
- Healthcare Scientists (Respiratory and Sleep)
- Medical
- Nursing
- Occupational therapy (OT)
- Physiotherapy
- Psychology
- Speech and language therapy (SLT)
- Technical services (ventilator maintenance)

Staffing ratios will depend upon local factors such as whether a complex HMV service is predominantly inpatient based, predominant community based or a mixture of the two models. They will also depend upon whether the service is predominantly a complex HMV service, predominantly a HMV service or a mixture of the two. The following would be recommended as a minimum for a complex HMV service:

• One Whole Time Equivalent (WTE) nurse, physiotherapist, healthcare scientist or other suitably trained allied healthcare professional (AHP) per 40 patients who meet the definition of requiring complex HMV

• One WTE consultant (8 direct clinical care programmed activities) per 300 patients who meet the definition of requiring complex HMV. Consultants may be medical and non-medical

• Dedicated specialist physiotherapy time

• Dedicated specialist speech and language therapy time

It is important to note that services providing complex HMV also frequently act as the provider of HMV services to large numbers of local patients who would not meet the criteria for requiring complex HMV. Staffing numbers should take into account the workload for complex HMV services from these local patients. Although staffing will vary depending upon the local service set up, there should be one WTE nurse, physiotherapist, healthcare scientist or other suitably trained AHP per 80 patients meeting the definition of requiring HMV services.

Access to other AHPs such as psychology, occupational therapy and dietetics is essential but complex HMV services should be able to demonstrate close collaboration with and availability of these services to reflect the complex needs of this patient group. Depending upon local configuration of services, this may take the form of:

• A formalised role in the HMV multi professional team with funded sessions (eg. via a service level agreement with therapy services)

• Ring-fenced funded time in AHP clinics for HMV patients

• AHPs in all professional groups demonstrating a specialist interest in HMV/weaning/complex discharge of HMV patients

• Feeding into multi professional meetings for HMV patients eg. psychology in patients weaning from invasive mechanical ventilation, OT in complex discharges and dietetics in long term patients receiving long-term nutritional support

The adequacy of staffing should be defined by local governance arrangements and there should be a defined escalation processes for an uplift in staffing as patient numbers grow.

Complex HMV services should have a medical lead clinician with appropriate SPA time for service development (1 SPA) and clinical leadership (1 SPA). All complex HMV services should have a dedicated service delivery manager, business partner and administrative staff proportionate to the patient population covered to support service delivery and development. Additionally, complex HMV services should have a senior, non-medical clinician with overall management responsibilities for the service which should be at consultant level or 8a.

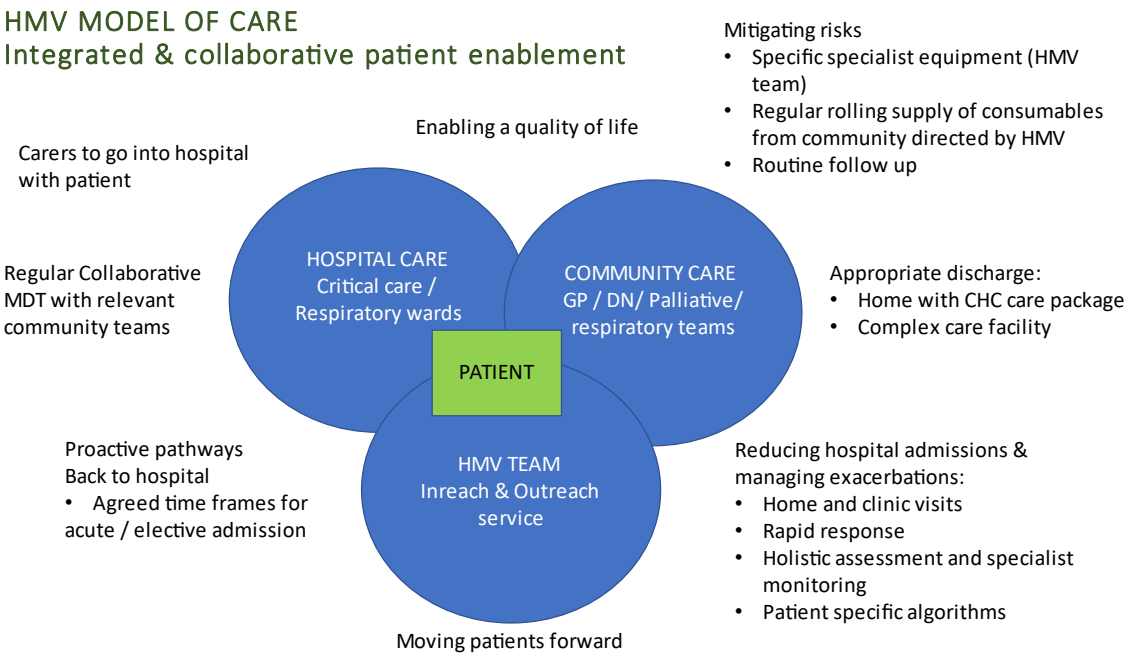
All complex HMV services should have established pathways to support access to affiliated key clinical services. Some complex HMV services may have dedicated clinical time within the HMV team, however this will vary across regions. Affiliated members of the HMV team may include but are not limited to:

- Augmentative & alternative communication team
- Cardiology
- Critical care
- Ear, nose, and throat (ENT)
- Gastroenterology
- Neurology
- Palliative care
- Learning disability teams
- Paediatric / transition services
- Respiratory–including flight assessment (which may include a hypoxic challenge test)

E) Patient Pathways

A model of care placing the patient at the centre means that services will deliver care that is individualised to patient need, supporting a proactive and flexible approach, facilitating the right care at the right time in the right environment by the right team. It should direct best practice for this group of patients.

Figure 1: Model of HMV care: Patient enablement



Accessing complex home ventilation services

Specialist advice

Complex HMV services should offer access to advice and support to local HMV services, and also to external providers such as GPs and community teams in primary care, and other members of the multiprofessional team working in secondary or tertiary care in relation to patient referral. Early discussion may be relevant for patients with pre-existing conditions that are expected to be associated with the requirement for HMV and may result in increased ventilator dependency; these include patients with neuromuscular disease. Joint MDT meetings with other healthcare professionals involved in the care of these patients are helpful to discuss the ongoing care and management.

Complex HMV services should have a system for recording referrals and advice provided. The contact point for advice should be a senior member of the HMV MDT with experience in the assessment of patients with complex HMV requirements.

Referral criteria

HMV services should develop local protocols which include guidance for referrers, referral criteria, and treatment pathways. Guidance for referrers and referral criteria may improve patient selection in line with evidence-based practice.[17] Based on current evidence, patient populations who are most likely to benefit from home ventilation are detailed in Appendix 2.[18-30] Examples of typical treatment pathways are included in Appendix 3-5.

Where complex HMV services and HMV services overlap geographically, it is recommended that referral criteria be developed collaboratively to ensure clarity of service provision. This should include description of circumstances in which transfer between complex HMV services and HMV services would be considered. Situations in which patients may transfer from HMV services to complex HMV services will vary dependent on local provision, but examples include:

- Patients transitioning from NIV to long-term invasive ventilation
- Need for advanced airway clearance techniques
- Change in condition or stability requiring close ongoing collaboration with other specialties

Time to review patients following referral will vary between conditions and patients' presentations but complex HMV services should have the resource to review different patient cohorts within the timescales below:

• MND with hypercapnia or symptoms suggestive of hypercapnia: within one week[25]
• Referring neuromuscular teams should be encouraged to refer patients well before the suspicion of hypercapnia for routine review which should take place within 1 month
• DMD (or other muscle disease where ventilatory failure is inevitable) with symptoms of sleep disordered breathing or a vital capacity below 50% of predicted: within 1 month
• Routine outpatient referral for ORRF, COPD within 2 months
• COPD inpatient set up: within one week

To meet the specifications to be a level 3 or complex HMV centre, services should be able to demonstrate a significant complex patient cohort. They should have at least 100 patients who meet the complex commissioning criteria and at least 20 patients with either a tracheostomy or ventilator dependency (and/or 5% of the total number of patients). A complex HMV service should receive at least 30 referrals a year of patients who meet the complex commissioning criteria.

Establishing complex HMV

Patients can be established on HMV via several pathways (inpatient, outpatient and community). The timing of HMV setup may occur electively or following an admission with acute respiratory failure. The proficient setup of complex HMV requires an expert multi-disciplinary team. The method used to establish HMV should be tailored to the needs of the patient and the local service. There are data to support different setup strategies for HMV with no evidence to support a single model as providing a higher standard of care. For many patients being established on HMV in an outpatient or community setting is preferable as it reduces the impact on care provision for patients with complex needs. However, for some patients the need for specific investigations or assessments not available in the community will require admission to hospital. The setup of HMV requires access to the following:

- Clinical assessment by an experienced HMV practitioner.
- Diagnostic screening tools such as full pulmonary function tests including sniff nasal inspiratory pressure (SNIP), Mouth inspiratory pressure (MIP) and mouth expiratory pressure (MEP) and imaging (e.g. plain radiography & CT scanning).
- Assessment of cough strength and secretion management.
- Assessment of gas exchange (e.g. arterial blood gas (ABG), ear lobe capillary blood gas (ELCBG), transcutaneous CO2 (TCCO2).
- NIV interface review: ability to assess for and competently use a range of interfaces for NIV including full face, nasal, oro-nasal and mouthpiece.
- Tracheostomy management (basic): review and troubleshoot common tracheostomy problems, manage tracheostomy emergencies and recommend suitable tubes including reusable and disposable tubes; subglottic port requirement; cuffed or cuffless; tube length.
- Tracheostomy management (advanced): assessment of upper airway patency, secretion management and tracheobronchomalacia should be available.
- Method to objectively assess sleep disordered breathing: this may be delivered at home or in hospital and may involve simple (e.g. oximetry +/- TCCO2) or more advanced (e.g. respiratory polygraphy) monitoring.

The majority of patients being established on complex HMV will have an established diagnosis and be under review by respiratory specialists monitoring the progression of respiratory failure, allowing an elective approach to setup. However, a proportion of patients will be established on complex HMV following an episode of acute respiratory failure which may be a presenting feature of a complex neuromuscular condition e.g. MND.

Transition

As more young people with complex conditions survive into adulthood, and as the number of children receiving HMV in the UK grows[31], so too does the number of people who transition from child to adult complex HMV services.[32] It is often the case that the exact support provided by childrens' services is not mirrored in adult services; they may not be available in the same way or need to be provided by several different specialty teams, further complicating the transition process and the experience of loss and change for the young person and their family.[33]

The process of moving care from child to adult services should have commenced by at least the young person's 14th birthday[34] however early discussions may commence from age 11.[35] Those with the most complex needs may require an extended transition period.[36] The process should be person-centred and developmentally appropriate; aiming to minimise disruption and ensure seamless provision of HMV care.[37]

Complex HMV teams play a pivotal role in ensuring that the transfer of care to adult services, and hence the subsequent care received, is a positive transition experience. This requires:

- Effective partnership between children and adult ventilation services, to support the early identification of all young people eligible for future care in adult HMV services and the development of a local transition pathway, with clear communication and documentation throughout.[30]
- A multi-professional approach with handover of relevant details between child and adult counterparts.

- Inclusion and empowerment of the young person, families, and carers throughout the process.
- The provision of joint transition clinics and service visits for young people, their families and carers prior to transition.[38]

Additional factors to consider during transition include the following potential differences:

- Differing funding processes.
- New sources of their usual equipment.
- Changes in consent process.
- Differing practices for visiting or overnight stays during future admissions.[37]

Prolonged mechanical ventilation

A small number of patients will be referred to complex HMV services following prolonged mechanical ventilation (PMV). Up to 40% and 20% of such patients may be discharged from SWUs and require non-invasive or invasive ventilation respectively.[39] A regional SWU should be co-located with a complex HMV service. A regional SWU should have the multiprofessional team detailed in national guidance.[4]

Services managing patients with complex HMV needs should offer a range of assessment pathways for patients who are experiencing PMV and may therefore return home or to the community mechanically ventilated. The mode of assessment should meet the needs of the patient and should include remote advice on weaning strategies and rehabilitation, on-site assessment at referring critical care units or transfer to a regional SWU.

SWUs will work collaboratively with complex HMV teams to support decision making around the need for long term HMV and further weaning. As soon as a clinical decision is made that a patient will require long term complex HMV, discharge planning should be started; the specialist weaning unit and complex HMV team supporting identification of community placements alongside the current clinical team providing acute care e.g. local general critical care or respiratory team. It is important that this process occurs irrespective of the location of the patient to avoid delays in treatment and should not wait for transfer to the complex HMV service.

Where feasible these complex patients should be transferred to an appropriate clinical area outside of acute critical care/respiratory high dependency. Stepdown requires the carers to have achieved a level of competency.

The complex HMV team will work with the ICB and CHC teams to develop and co-ordinate an appropriate and safe community placement and care team. The funders and commissioners will be responsible for confirmation that the discharge destination is appropriate for this patient group with support from the local complex HMV service if needed.

Discharge pathways

Discharge process

Patients who are established electively on complex HMV should have a comprehensive assessment of their care needs prior to setup. This may require a discussion regarding funding, revision and/or provision of a home care package.

Early engagement with appropriate funders and commissioners is essential if this process is not to be unduly protracted. Patients should be aware that, even with appropriate engagement, this process can require a prolonged hospital admission due to the need to secure funding, identify a suitable complex care facility or appoint an appropriate care agency, recruit and train carers. This process can currently take several months to complete with data from a national audit of patients with MND showing a mean wait of 136 days [40-564] during which the patient will usually be required to remain within a critical care or enhanced care area within the hospital.[40] A focus of this model of care is to reduce excessive delays in the process and reduce the time the patient remains away from their usual or chosen long-term location of care. An example of best practice in coordination of patient discharge is provided in Appendix 6.

Place of discharge from hospital

There should be a flexible and patient centred approach to the commissioning of care packages for patients being discharged back to their home as some patients may not require a 24-hour care package, in the first instance, due to their own home set up where family members are fully involved in their care and the patient is also able to manage some or all of their own care. Commissioning a personal health budget (PHB) may be more appropriate for some patients.

Patients being established on complex HMV (whether electively or following an emergency admission) may, depending on regional availability and practice, be discharged to either:

- Patient's home with a fully funded package of care commensurate with the clinical need, which will frequently require 24-hour awake care
- A community care facility
    - Complex care facility with a track record of managing and caring for patients who require complex home ventilation

    OR
    - With a fully funded 24-hour health care package within the care facility

The decision of place of discharge should be based on; patient preference, patient healthcare needs and there should be full collaboration & ongoing discussion between the ICB, CHC team and HMV service to ensure that it is a safe and effective package of care and/or destination for discharge. Complex HMV teams will work to advocate for patients' choice of discharge location but the decision sits with the relevant funding organisation; currently ICBs.

Once a discharge destination is determined and agreed, a multi-disciplinary approach to discharge planning is essential. It is imperative to ensure that the patient has everything that they need to leave the hospital and simultaneously has everything in place in the community setting to prevent re-admission to the acute setting. Consideration should go beyond that of the ventilation requirements and consider the patient's wider needs.

The discharge planning pathway usually consists of, but is not limited to:

• Determination of ongoing ventilation (+/- cough augmentation) needs. Training will need to be completed for relevant caregivers on discharge. Ensuring initial supply of consumables, and any other essential equipment is delivered and in place prior to estimated discharge date. A plan will need to be made regarding ongoing supply of consumables for equipment provided as processes/pathways vary across the UK

• Contact and liaison with local social and/or CHC services about the discharge pathway to be followed, and the paperwork to be completed to ensure appropriate funding and care is in place for discharge. Nationally, patients being discharged home from hospital should follow the discharge to assess pathway, however for patients with complex health needs such as tracheostomy ventilation, it may be more appropriate for early CHC involvement.

• Discussion and completion of paperwork recommending care at home, to ensure a patient's HMV and other care needs are met, and risk is minimised.

• Once a complex care agency is allocated there should be ongoing liaison between the agency, the complex HMV MDT and local social services/CHC to ensure a robust package of care set-up for discharge. This includes, ensuring carers are recruited with an appropriate skill-set and previous experience, ensuring sufficient carers are recruited to cover the package including contingency for when carers are unwell, on leave or leave the package. Any mandatory training should be completed by the agency.

• Within the final stages of discharge planning, it is important to move towards a care plan that can be delivered within the community setting, ensuring stability of the patient at this level of care. Steps to achieve this may include care being delivered predominantly by the patient's own care team (once sufficient skills and knowledge are demonstrated), reduction in frequency of physiological observations, cessation of routine blood testing, step down to a lower acuity ward or facility and reduced frequency of medical review.

• The appointed carers should carry out funded shadow shifts in the hospital with the patient prior to discharge to ensure that they have the appropriate skill set for that individual.

• Adaptive equipment provision to ensure a home environment set-up to enable delivery of HMV, participation in daily activities, and ensure carers can support with care needs to minimise risk. This may involve liaison with local community services (e.g. social services, OT) to arrange funding and ordering of specialist equipment.

• Prior to discharge, plans should be in place for follow-up, and all onward referrals made in a timely manner for any other follow-up required (e.g. community therapy input, community dietitian input, district nurse referrals).

• In more complex cases, the completion of a face-to-face follow-up visit to the patient's home is recommended. This may occur prior to, at the time of, or following discharge.

On discharge home the complex HMV patient will be under their local GP service who will be responsible for their general healthcare. Therefore, the patient's local HMV team should ensure effective communication and early liaison with the GP practice as well as wider community services and ensure detailed discharge summaries, medication changes and care plans are shared appropriately.

Carer training: complex care facility and/or care agency package

The care agency or complex care facility who will be supporting the complex HMV patient in the community should:

- be able to demonstrate previous experience, skills, and knowledge in caring for complex HMV patients
- ensure that each care package is managed by and has oversight from an appropriately experienced and skilled registered healthcare professional.
- Ensure the care package or complex care facility have level 3 or equivalent carers. Appendix 7 outlines level 3 carer role skill set)
- Ensure each care agency / complex care facility has in-house core training for their carers specific to the complex HMV patient needs

Where possible the HMV team will use cascade training by training a lead carer or trainer to ensure all core skills can be supported with the care package as new members join the care team. This should be coordinated with the agency clinical lead. It would be expected that all care packages for patients undergoing complex HMV are led by a member of staff with professional registration to provide the appropriate level of governance and skills required for this level of patient need. The HMV team are not responsible for the on-going competency and training of carers within a package of care of complex care facility. It is the responsibility of the care agency or care facility to ensure that their staff have up to date appropriate competencies and skills.

Training and education of the care agency staff commissioned to care for the complex HMV patient should be guided by the HMV team in core aspects of the individuals care and management. (Appendix 7).

Ventilator passports and management plans

During the discharge process, the complex HMV team should develop individual ventilator/interface passport and management plans which will include proactive treatment interventions for common clinical scenarios that the patient may experience (Appendix 8a-g). The plans and passport should be written and developed in collaboration with the patient and their carers. There should be paper and electronic copies available for the patient and those involved in their care once discharged. This will include primary/community care (GP, district nursing team, care agency) and secondary care (local hospital emergency department, RSU and critical care).

The aims of the passport and management plans are to:

- Incorporate details of the HMV care into the holistic individual patient care plan that the care team develop for the complex HMV patient they are looking after at home
- Provide a prescription for and information on the type of ventilation, level of ventilator dependency and interface the patient uses for other healthcare professionals who are involved with the complex HMV patient care at home
- Provide contact details of the HMV team, including who to contact in an emergency
- Support and direct the carers in the management of possible emergency scenarios the patient might experience such as pulmonary infection and tracheostomy emergencies
- Reduce risks
- Reduce acute hospital admissions

TIV patients

For complex HMV patients who are invasively ventilated via a tracheostomy tube, the HMV team will also need to provide the patient with a tracheostomy passport (for example see appendix 9) and document a plan for the patient's tracheostomy tube changes including the location, frequency and

staff undertaking tracheostomy tube changes. This will depend upon factors such as the type and size of tracheostomy tube, the upper airway patency, the anatomy of the airway and any 'red flags' including bleeding or desaturation during previous changes.

However, all key carers involved with the patient's day to day care should be able to change the patient's tracheostomy tube in an emergency situation and/or manage the patients airway using other adjuncts such as a bag/mask/valve device if a tracheostomy tube cannot be replaced, as per the individual patient's emergency management plan.

Management of continued ventilator weaning and rehabilitation at home

There may be a small cohort of patients that will require on going ventilator weaning once discharged home, for example, patients with Guillain Barre Syndrome (GBS). This can only happen if the:

- Complex HMV service has an HMV community outreach team that can visit regularly and oversee, review, support and direct the weaning process
- The patient's care agency/care home agree and are able to support the weaning plan at home
- The weaning plan is aligned with the patient's needs and wishes
- The patient remains medical stable during the weaning process
- The process is safe in the community and risks are reviewed and mitigated

Weaning plans and progress should be reviewed regularly by the complex HMV multiprofessional team and goal-setting agreed with the patient.

Follow up

Following treatment commencement and discharge into the community, patients often require intensive support. This may be provided over the telephone, face to face review, or via community visits by members of the nursing and AHP team. This level of patient specific support should continue until treatment is fully established.

There should be regular, planned reviews throughout the year by the patient's HMV team which will triage the patient according to their needs. How and where the reviews are conducted will be guided by their local HMV team service model and may include a mixture of the following:

- Telephone clinics
- Virtual clinics
- Hospital clinics
- Outreach hospital at home clinics or responsive clinical reviews in the following settings:
    - Patient's home
    - Care Home
    - Other hospital trusts
    - Hospice

All complex HMV patients should have, at minimum, a holistic annual assessment by the multi-professional complex HMV team. Complex HMV services should also hold joint clinics/multiprofessional meetings with other specialties for patients with significantly complex medical issues such as MND, DMD and other neuromuscular disease.

Recommended minimum frequency of follow-up in specific situations is detailed below:

• MND: 3 monthly[27]
• DMD: 6 monthly (with pulmonary function tests prior to initiation of ventilation)[41]
• Other muscle disease: 6-12 monthly[27]

Monitoring

Ongoing regular monitoring of the complex HMV patient should be part of their planned reviews and should include the following:

- Clinical assessment
- Ability to assess for, and competently use, a range of interfaces for NIV including full face mask nasal, oro-nasal and mouth-piece
- Diagnostic screening tools such as full pulmonary function tests including SNIP, MIP and MEP
- Assessment of effective ventilation:
  - Remote ventilator monitoring data
  - Gas exchange (ABG, ELCBG, TCCO2) including point of care gas machine
  - Sleep studies
- Chest clearance efficacy
  - Peak cough flow
  - Chest infection frequency
- Telemonitoring where appropriate
- Assessment of tracheal airway and tracheostomy for tracheostomy invasive ventilated patients
  - Scope of airway via tracheostomy tube
  - CT/MRI scan
- Communication, swallow and upper airway assessment
  - Scope of upper airway

Established pathways should exist for ancillary testing including:

- Venous blood testing
- Imaging: CXR, CT scan
- FEES (Fibreoptic Endoscopic Evaluation of Swallowing) for assessment of laryngeal function, secretion management and swallowing
- Videofluoroscopy for assessment of swallowing

Outreach clinical HMV care

The ability to deliver timely and comprehensive assessment and management of complex HMV patients in the community is essential for a complex HMV service to deliver care. To this end an outreach team is an essential part of a complex HMV service and should have appropriate funding to achieve the aims of the model of care, which are:

• To champion, improve, support and enable the well-being of complex ventilated patients in the community.

• To be responsive, dynamic and flexible in the management of patients with complex HMV in referring hospitals and the community setting.

• To support and enable joined up care between all care agencies and healthcare institutions involved with the patient's management and encourage collaborative working.

• To offer support and advice in relation to weaning patients from invasive and non-invasive ventilation in other critical care units.

• To assess suitable patients within other hospitals and support discharge of both patients receiving NIV and tracheostomy ventilation back into the community. This may involve:

    - Setup onto complex HMV in the local hospital
    - Recommendation to transfer to a local SWU or complex HMV service to optimise prior to discharge
- Develop dynamic individual patient pathways to:
    - Reduce acute hospital admissions
    - Reduce hospital length of stay
- Be an expert resource and develop educational and training programmes in relation to the management and care of patients requiring long term ventilation and long-term tracheostomy tube placement. This will be to support:
    - Patients
    - Carers
    - Healthcare professionals within the community and hospitals

The delivery of care using an outreach team offers requires specific attention to the following areas:

- Lone working
    - A local lone working policy needs to be established for all outreach staff seeing patients within the community.
- Competency and experience of clinician
    - A minimum of 1 years appropriate experience in either critical care or respiratory care alongside a specialist course relevant to HMV.
    - Roles and responsibilities should be decided on competency assessed clinical knowledge and skills rather than professional role alone.
- Expectations of patients
    - Patients should have a clear understanding of scope and role of an outreach team and escalation pathways for acute and sub-acute deterioration.
    - Patients should be aware of both in and out of hours support and there should be complete clarity on emergency pathway using local services
- Clinical governance
    - Medical input from a consultant with dedicated time for role
    - Weekly MDT
    - Patient database

Responsive clinical review

The ability to deliver a responsive assessment of patients with complex HMV is important in maintaining the clinical stability, avoiding hospital admission and unscheduled care contacts and is an important role of any complex HMV service. Complex HMV services should have 24-hour access to technical and clinical support to troubleshoot HMV device or equipment issues, triage, and direct more urgent clinical issues to appropriate services either within or outside the complex HMV service.

The exact pathway for clinical review will be bespoke to individual complex HMV services accounting for a range of factors including staffing model, skill mix, geography, and bed base. It is important the pathway to clinical review is clear to patients and that an appropriate safety net is placed to direct emergency issues to an appropriate local care provider. There should be a clear pathway for out of hours support for technical (mask/device) issues and for clinical triaging of patient calls, especially if the technical support is provided by an external provider.

Hospital admission

Access to inpatient assessment is vital for this group of patients for both management of their respiratory and non-respiratory needs. Patients should have access to appropriate care within their local hospital for both elective and acute care. Some procedures or admission indications will be best coordinated at the complex HMV centre to allow direct input e.g. procedures using sedation in conjunction with NIV and others will require care locally due to the nature of the service e.g. ophthalmology or other services which may not be co-located with the complex HMV service. Furthermore, as this patient group may have specific care needs that are met by a community team, the local hospital should be aware of patients requiring complex HMV within their area to allow a collaborative relationship between complex HMV services and local clinicians. The complex HMV service should coordinate with a named consultant for each patient under their care, usually from respiratory medicine, to support and coordinate local care. Therefore, proactive planning with the patients HMV team and local hospital is paramount. To this end all complex HMV centres should be able to identify their patients and post-codes to assist with coordination.

Elective admission

An elective admission may be required to investigate or treat respiratory or non-respiratory problems. The patients care plan should be shared with the admitting team and careful consideration should be given to the following:

• Appropriate area for admission. This will require an individual clinical assessment to ensure the patients are managed in an area with skills to manage patients with complex HMV, such as experience with tracheostomy and ventilator management but also afford input from the specialist care team if not a primary respiratory issue. This could involve admission to critical care or respiratory HDU or to a specialist ward with appropriate monitoring and support from carers.

• Elective admissions should be scheduled in line with an appropriate risk assessment of the underlying indication for admission. For example, if the patient is coming in for an annual review or a cataract procedure the priority is lower compared to patients requiring admission for recurrent chest infections or tracheostomy tube change difficulties.

• Collaboration with patients 24-hour community care package

• If the patient has an established care package, then carers should be able to continue to care for the patient during the admission. This helps to support the following aims:

- Advocates for patients' individual communication needs and strategies in patients with communication issues. This is of particular importance in those patients not able to independently operate alarm systems in hospital.

- Reduces the risk of delayed discharge when care teams are reallocated to other packages during prolonged hospital admissions

- Carers have bespoke understand of the patients everyday routine needs especially lifting, handling and positioning facilitating best practice.

- Support ward staff that may not have detailed knowledge of a patients care plan and therefore improve trust between patient and hospital teams.
- If cared for in a complex facility to ensure that the patient's bed is reserved until discharged.
- Regular communication with the patients HMV team

Acute admission

Emergency admission to hospital may be required for management of intercurrent respiratory infection requiring intravenous therapy, additional oxygen or ventilatory support or enhanced secretion management. Tracheostomy or airway emergencies that are not resolved immediately by the care team similarly will require emergency admission. Furthermore, common acute non-respiratory issues such as dislodged gastrostomy tubes, catheter associated infection, may necessitate acute hospital care delivered by the local hospital with remote support from the appropriate complex HMV service. More complex non-respiratory emergencies may require transfer to a centre delivering complex HMV (e.g. to support a HMV patient through a laparotomy requiring critical care admission).

It is important that patients, carers, and local care teams (including primary care team) are aware of the limited physiological reserve of this patient group which requires prompt and clear decision on emergency management, prompt assessment and appropriate decision on timing of admission (urgent within 48 hours or emergency 999 and immediate transfer to hospital). An individual care plan built with the local hospital team, to allow for care within an appropriate clinical area and support from the patient's own care team is therefore essential. Early involvement from the acute hospital's critical care team is required to help plan location of care.

References

1. https://www.england.nhs.uk/wp-content/uploads/2018/08/Complex-home-ventilation-adult.pdf
2. Michael Davies, Martin Allen, Andrew Bentley, et al. British Thoracic Society quality standards for acute non-invasive ventilation in adults. BMJ Open Respiratory Research 2018; 5:e000283. doi:10.1136/bmjresp-2018-000283
3. Respiratory Support Units | British Thoracic Society | Better lung health for all (brit-thoracic.org.uk)
4. bts-ics-model-of-care-for-specialised-weaning-units.pdf (brit-thoracic.org.uk)
5. National Adult Non-Invasive Ventilation Audit 2019 | British Thoracic Society | Better lung health for all (brit-thoracic.org.uk)
6. InspiringChange_FullReport.pdf (ncepod.org.uk)
7. https://gettingitrightfirsttime.co.uk/wp-content/uploads/2021/11/Respiratory-Medicine-Oct21L.pdf
8. Mandal S, Suh E, Davies M*, et al* Provision of home mechanical ventilation and sleep services for England Thorax 2013;**68:**880-881.

9. International Classification of Diseases (ICD) (who.int)

10. OPCS Classification of Interventions and Procedures (datadictionary.nhs.uk)

11. PBR ref ? 22-23NT_Annex-A-National-tariff-workbook_Apr22.xlsx (live.com)

12. Investigation into how government increased the number of ventilators available to the NHS in response to COVID-19 (nao.org.uk)

13. National Patient Safety Alert: Removal of Philips Health Systems V60 and V60 Plus ventilators from service: risk of shutdown leading to complete loss of ventilation (NatPSA/2023/005/MHRA) - GOV.UK (www.gov.uk)

14. Impact of the rising cost of electricity on home mechanical ventilation patients | British Thoracic Society | Better lung health for all (brit-thoracic.org.uk)

15. UK Cystic Fibrosis Registry Annual Data Report 2022

16. Non-Invasive Ventilation | British Thoracic Society | Better lung health for all (brit-thoracic.org.uk)

17. Ward K, Ashcroft H, Ford V, Parker R. An evaluation of a physiotherapy proforma for referral to a home non-invasive ventilation service following acute hypercapnic respiratory failure. Journal of ACPRC 2017; 49: 95-104.

18. Ergan B, Oczkowski S, Rochwerg B, Carlucci A, Chatwin M, Clini E, Elliott M, Gonzalez-Bermejo J, Hart N, Lujan M, Nasilowski J, Nava S, Pepin JL, Pisani L, Storre JH, Wijkstra P, Tonia T, Boyd J, Scala R, Windisch W. European Respiratory Society guidelines on long-term home non-invasive ventilation for management of COPD. Eur Respir J 2019; 54: 1-18.

19. Murphy PB, Rehal S, Arbane G, Bourke S, Calverley PMA, Crook AM, Dowson L, Duffy N, Gibson J, Hughes PD, Hurst JR, Lewis KE, Mukherjee R, Nickol A, Oscroft N, Patout M, Pepperell J, Smith I, Stradling JR, Wedzicha JA, Polkey MI, Elliott MW, Hart N. Effect of home noninvasive ventilation with oxygen therapy vs oxygen therapy alone on hospital readmission or death after an acute COPD exacerbation. JAMA 2017; 317 (21): 2177-86.

20. National Institute for Health and Care Excellence. Chronic obstructive pulmonary disease in over 16s: diagnosis and management. NICE guideline NG115. Last updated 26 July 2019.

21. National Institute for Health and Care Excellence. Obstructive sleep apnoea/hypopnoea syndrome and obesity hypoventilation syndrome in over 16s. NICE guideline NG202. Published 20 August 2021.

22. Masa JF, Mokhlesi B, Benitez I, Gomez de Terreros FJ, Sánchez-Quiroga MA, Romero A, Caballero-Eraso C, Terán-Santos J, Alonso-Álvarez ML, Troncosco MF, González M, López-Martin S, Marin JM, Martí S, Díaz-Cambriles T, Chiner E, Egea C, Barca J, Vásquez-Polo FJ, Negrín MA, Martel-Escobar M, Barbe F, on behalf of the Spanish Sleep Network. Long-term clinical effectiveness of continuous positive airway pressure therapy versus non-invasive ventilation therapy in patients with obesity hypoventilation syndrome: a mulitcentre, open-label, randomised controlled trial. Lancet 2019; 393: 1721-32.

23. Annane D, Orlikowski D, Chevret S. Nocturnal mechanical ventilation for chronic hypoventilation in patients with neuromuscular and chest wall disorders (Review). Cochrane Database of Systematic Reviews 2014; Issue 12: Art. No CD001941.

24. Bourke SC, Tomlinson M, Williams TL, Bullock RE, Shaw PJ, Gibson GJ. Effects of non-invasive ventilation on survival and quality of life in patients with amyotrophic lateral sclerosis: a randomised controlled trial. Lancet Neurol 2006; 5: 140-47.

25. National Institute for Health and Care Excellence. Motor neurone disease: assessment and management. NICE guideline NG42. Last updated 23 July 2019.

26. McKim DA, Road, J, Avendano M, Abdool S, Côté F, Duguid N, Fraser J, Maltais F, Morrison DL, O'Connell C, Petrof BJ, Rimmer K, Skomro R; Canadian Thoracic Society Home Mechanical Ventilation Committee. Home mechanical ventilation: A Canadian Thoracic Society clinical practice guideline. Can Respir J 2011; 18 (4); 197-215.

27. Schönhofer B, Barchfeld T, Wenzel M, Köhler D. Long-term effects of non-invasive mechanical ventilation on pulmonary haemodynamics in patients with chronic respiratory failure. Thorax 2001; 56: 524-8.

28. Wadsworth LE, Belcher J, Bright-Thomas RJ. Non-invasive ventilation is associated with long-term improvements in lung function and gas exchange in cystic fibrosis adults with hypercapnic respiratory failure. Journal of Cystic Fibrosis 2021; 20:e40-e45.

29. Moran F, Bradley JM, Piper AJ. Non-invasive ventilation for cystic fibrosis (Review). Cochrane Databse of Systematic Reviews 2017; Isue 2: Art. No CD002769.

30. Freeth H, Mahoney N, Juniper M, Moses R, Wilkinson K. Balancing the pressures: a review of the quality of care provided to children and young people aged 0–24 years who were receiving long-term ventilation. *Br J Hosp Med 2020;* **81**(9):1-4. https://doi.org/10.12968/hmed.2020.0260

31. NHS England. 2014. Children who are Long Term Ventilated - Pathfinder Project: Engaging with Families and Children/Young People. An independent quality improvement review by the Patient Experience Network http://patientexperiencenetwork.org/resources/report/ Paediatric%20Long%20Term%20Ventilation%20 Report-v12%20-%20final.pdf https://books.ersjournals.com/content/ers-handbook-ofrespiratory-medicine

32. Chatwin M, Hui-Leng T and Bush A et al. 2015. Longterm non-invasive ventilation in children: impact on survival and transition to adult care. PLoS One. 10(5)

33. Care Quality Commission (2014) From the pond into the sea: children's transition to adult health services. Gallowgate: CQC Transition arrangements for young people with complex health needs from children's to adult services - Care Quality Commission (cqc.org.uk)

34. National Institute for Health and Care Excellence. 2016. Transition from Children's to Adults' Services for Young People using Health or Social Services https://www.nice.org.uk/guidance/ng43/resources/ transition-from-childrens-to-adults-services-foryoung-people-using-health-or-social-care-servicespdf-1837451149765

35. Wellchild. 2023. 8 Principles for Transition: Transition reference guide and tools to support health and care professionals to improve practice for all children and young people transitioning to adult services. https://www.wellchild.org.uk/wp-content/uploads/2023/06/Principles-of-Transition-2023.pdf

36. The Royal College of Paediatrics and Child Health. 2019. NHS Long Term Plan – A summary of child health proposals https://www.rcpch.ac.uk/resources/nhs-long-term-plansummary-child-health-proposals

37. PCCS guidance for Paediatric to Adult Critical Care Transition 2022: https://pccsociety.uk/paediatric-to-adult-transition-guidance/

38. Well child. 2023. 8 Principles for Transition: Transition reference guide and tools to support health and care professionals to improve practice for all children and young people transitioning to adult services. https://www.wellchild.org.uk/wp-content/uploads/2023/06/Principles-of-Transition-2023.pdf

39. Davies M, Quinnell T, Oscroft N, Clutterbuck S, Shneerson J, Smith I. Hospital outcomes and long-term survival after referral to a specialized weaning unit. Br J Anaesth. 2017;118:563-569

40. Jonathan Palmer, Ben Messer, Michelle Ramsay. Tracheostomy ventilation in motor neurone disease: a snapshot of UK practice. Amyotroph Lateral Scler Frontotemporal Degener. 2021 May 8;1-7. doi: 10.1080/21678421.2021.1916534

41. Childs A-M, Turner C, Astin R et al. Development of respiratory care guidelines for Duchenne muscular dystrophy in the UK: key recommendations for clinical practice. Thorax 2023;0:1–10. doi:10.1136/thorax-2023-220811

List of appendices (please see separate document)

Appendix 1: Consumables for tracheostomy invasive ventilated patients

Appendix 2: Evidence for Long Term Ventilation

Appendix 3: Ventilator set-up - neuromuscular and chest wall disease

Appendix 4: Ventilator set-up - COPD

Appendix 5: Ventilator set-up – obesity related respiratory failure

Appendix 6: Phases of discharge

Appendix 7: Carer skills document

Appendix 8a: Management of possible chest infection

Appendix 8b: Management of suspected sputum plug with MI-E

Appendix 8c: Suspected sputum plug (uncuffed or cuffed down tracheostomy)

Appendix 8d: Management of suspected sputum plug TIV

Appendix 8e: Management of possible chest infection TIV

Appendix 8f: Dislodged tracheostomy tube (algorithm a)

Appendix 8g: Dislodged tracheostomy tube (emergency algorithm b)

Appendix 9: Patient tracheostomy passport