Model of Care for Complex Home Mechanical Ventilation

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SUMMARY

The British Thoracic Society (BTS) has developed this guidance to establish standards of care and infrastructure for Complex Home Mechanical Ventilation (HMV) services, which provide long-term respiratory support to patients with ventilatory failure in the community setting.

This resource builds on guidance documents produced in recent years in the field of enhanced respiratory care, following on from the publication of *Respiratory Support Units: Guidance on development and implementation* in 2021*,* and the *Model of Care for Specialised Weaning Units*, published in 2023.

The document provides guidance in a number of areas such as commissioning, governance, workforce, service and pathway development and is derived from the pooled knowledge and expertise of a multidisciplinary group of experts in this field. Expertise was also received from patient and care representatives on the group and from stakeholders who contributed to the consultation on the document.

In addition to the guidance, the resource also sets out examples of documents currently in use by Complex HMV services. These are set out in the separate Appendix to the document and are intended to support implementation, so services can adapt these to local requirements.

SUMMARY OF KEY GUIDANCE

Definitions

- The definition of complex home mechanical 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 quality improvement

- 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 complex HMV service and Integrated Care Board (ICB) to ensure recognition of 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 developed

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

- Complex HMV services should have a robust risk assessment to mitigate the risk of equipment failure out of hours. This may include a 24/7 helpline or provision of back up equipment

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

- Complex HMV services should have an active research programme and contribute to national and international research

Service model

- All complex HMV services should have ring fenced inpatient beds, such that care can be delivered whenever needed in a ward area with appropriate monitoring and specialist staff

- 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, but the sourcing, supply and funding of equipment such as consumables, not being supplied by the HMV service, is the responsibility of the ICBs

- The following is advised as minimum staffing levels for a complex HMV service: one Whole Time Equivalent (WTE) nurse, physiotherapist or healthcare scientist or other suitably trained healthcare professional per 40 patients and one WTE consultant per 300 patients who meet the definition of requiring complex HMV

- Complex HMV services should have dedicated and funded 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 Specialised Weaning Unit (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 responsibility for the competence of carers within a care package lies with the care agency and the ICB commissioning the package

- Complex HMV services may use cascade training by training a lead carer or trainer

- The complex HMV team should develop individual ventilator/interface management plans which will include plans for emergencies and admission

- 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/multi-professional 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 with close collaboration with critical care

A. Introduction

Rationale

Home Mechanical Ventilation (HMV) services provide long-term respiratory support to patients with ventilatory failure in the community setting. Ventilatory failure may result from a diverse range of respiratory, neuromuscular, and chest wall disorders. Such significant differences in the causes of ventilatory failure lead to considerable individual variation in the complexity of patient care. Presently, HMV services are structured into two tiers: HMV for complex patients with ventilatory failure (hereafter referred to as complex HMV services) and HMV for non-complex patients with ventilatory failure (hereafter referred to as HMV services).

Complex HMV is a tertiary service under the remit of specialised commissioning to support those patients with ventilatory failure who have additional, complex health needs that relate to the delivery of their HMV care.[1] Centres commissioned to provide complex HMV are responsible for managing all aspects of advanced HMV respiratory care, such as ventilation via tracheostomy, specialised MDT Interventions (e.g. cough-assist), and patient cohorts with complete dependence on assisted ventilation or at risk of its development (e.g. patients with progressive neuromuscular disease such as Motor Neurone Disease[MND]).

In contrast, HMV services outside the remit of specialised commissioning are funded via local commissioning and are typically designed to manage their local population of patients with a lower complexity of care needs, such as the provision of non-invasive ventilation (NIV) overnight alone (e.g. patients with obesity-related respiratory failure [ORRF]).

However, significant overlap between these differing service models has emerged in practice. Many locally commissioned HMV centres provide care for patients with complex needs, yet referrals to complex centres are often inconsistent. This mismatch may result in suboptimal care for patients who would benefit from access to specialised services. Conversely, complex centres frequently manage local patients with non-complex conditions. Whilst acceptable for those living nearby, this may be inefficient for those who reside closer to non-complex HMV centres.

With the forthcoming delegation of services from specialised commissioning to Integrated Care Boards (ICBs), a document is required outlining the population of patients who should be recognised by specialised commissioning and the infrastructure to support such patients. It is also recognised that the planned delegation of complex HMV care provides an opportunity to review the provision of HMV services in general, such that current HMV services operating outside of specialised commissioning may be recognised, funded and supported within a cohesive networked approach.

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 guidance documents concerning the management of patients with ventilatory failure, which examined areas such as acute NIV

services, respiratory support units (RSUs) and specialised weaning units (SWUs).[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 joint 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 joint BTS/ICS guidance document setting out a 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, clarity and direction is required in commissioning HMV services. This is especially so given the variation of care highlighted in the GIRFT review of respiratory services for adults,[7] and from the findings of NCEPOD's 'Balancing the Pressures' document,[8] which reviewed the quality of care provided to children and young adults who were receiving HMV. It recommended formalisation of service planning and commissioning and improvements in transition planning from child to adult services.

Definition of the complex ventilated 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.

A pragmatic consensus can be agreed, however, centred upon the characteristics of the complex ventilated group of patients, to help with their ongoing care and management by integrated healthcare teams within community and acute hospital settings.

These will include but are not limited to the below:

Patient characteristics

Patients with neuromuscular disease with (or at risk of) ventilatory failure such as:

- Motor neurone disease
- 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

- Complex 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 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 challenge

Exclusions and application across the four nations

This document does not make recommendations about paediatric care (16 years and under), or about the care of patients receiving Continuous Positive Airway Pressure (CPAP) therapy alone. It is acknowledged, however, that both patient groups may be highly dependent and require complex respiratory care which may involve complex adult HMV services; complex HMV services should flex according to patient need.

This document provides specific guidance about commissioning arrangements which will pertain to NHS services operating within England. The evidence and general principles underlining the guidance, will have applications for services across all the devolved nations of United Kingdom.

B. Commissioning of complex home mechanical ventilation services

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 fund 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

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 and geographical coverage.[7] 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.[9] Such centres are typically commissioned on a local basis.

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 Chronic Obstructive Pulmonary Disease (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 would 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. These patients would be followed up in clinic (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 would be Tier 2 services.

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

Some organisations have developed shared care models that enable movement between centres as clinically indicated and depending upon local networks and 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 an RSU is not available. The staffing, infrastructure and training requirements outlined in the BTS NIV and RSU guidance document should be followed.[2,3]

HMV service
A dedicated service that includes the provision of a variety of ventilators and interfaces for home and/or 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.

The service will have evidence of HMV service delivery training for medical staff, nursing staff and Allied Healthcare Professionals (AHPs).

The service will have a designated area for outpatient care which includes availability of equipment required to deliver HMV.

There will be support for the service from electronics and biomedical engineering. Services will be expected to enter information onto a national registry when developed.

Complex HMV service
As per specialised commissioning document.[1] 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 community 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 may be some distance from the complex service, for elective interventions and acute deterioration. Appropriate adjustments need to be made for individuals with learning disability, autism, cognitive impairment, communication issues, etc.

Activity recording and payment mechanisms

Background

Across the NHS, 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 are remunerated. The WHO-owned ICD-11 diagnosis codes[10] are used to capture diseases and complications while the UK OPCS-4 procedure codes[11] 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 NHS England National Tariff Payment System (previously known as Payment by Results [PBR]) rules applying to 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:

E85.2 (NIV not otherwise specified)
E98.5 (MI-E)
E85.6 (CPAP)
X52.2 (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. The codes should be shared with primary care services for their own databases and to enable them to identify patients who may benefit from specific interventions such as vaccination. 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 E85.6.

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 a significant uplift in tariff. This reflects the resource use associated with the activity/staffing within the NIV unit and will provide some financial support to run a service delivering 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 E85.2 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 or intervention.[12] 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 significantly higher for set up on NIV as a day case than for a routine outpatient appointment. This income should be sufficient to fund the majority of complex and non-complex HMV service activity in an outpatient setting. HMV teams should check their activity is being

appropriately recorded in day-case (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 which will include travel time and mileage.

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.

Tariffs are subject to regular change but Appendix 1 details the current NHS payment scheme and tariffs for outpatient HMV activity.

Future commissioning

In the near future, potentially in April 2025, complex HMV services are likely to be delegated 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 provider and the ICB/region to ensure recognition of the appropriate tier of service it is providing, based upon the patient population, that there is an appropriate volume of referrals to maintain skills (see referral criteria below) and that it has the infrastructure and staffing to deliver high quality care as outlined in previous sections. Service planning and commissioning should also specify and formalise local transition pathways from child to adult HMV services.

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, nursing, therapy and technical leads for the complex HMV service. Regular meetings should take place between the service operational and clinical leads.

The development of a separate complex HMV service line management structure is advised 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 a healthcare organisation. Larger complex HMV services, or those combined with sleep services, may function as a separate business unit.

The healthcare organisation is 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 an 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 requirements, equipment specification and pathways for inpatients, outpatients and outreach.

Research, audit and quality improvement

Complex HMV services should have an active research programme and contribute to national and international research.

All complex HMV services will need to demonstrate regular audit against national guidance and quality improvement projects leading to improved patient outcomes. Regular patient feedback on the service is also essential.

Research, audit and QI may also involve working with partners from industry.

A national registry and core dataset for complex HMV

There is a significant need for the development of a national registry for complex HMV, underpinned by a core dataset. Services would be expected to enter data into such a registry when developed. The rationale for a registry and dataset is outlined below.

Patient numbers and diagnoses

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 are anticipated. Factors favouring HMV service growth include

the obesity epidemic, enhanced access to diagnostics and tools to detect hypoventilation earlier, and an increased evidence base for the efficacy of HMV across several disease groups. To inform this document, a survey of services commissioned to provide complex HMV was undertaken, which identified that not all services knew exact numbers of patients under their care.

Equipment

Furthermore, the requirement to utilise unused ventilators during the COVID-19 pandemic[13] and recent national recalls of ventilators with significant faults,[14] have highlighted that there can be organisational difficulties in ensuring accurate location of devices. Finally, the cost-of-living crisis and in particular the cost of electricity have limited usage of ventilation in some users.[15] Home oxygen and dialysis services have a clear mechanism for reimbursement for patients receiving these treatments at home, however, no such mechanism currently exists for HMV patients. There are, therefore, clear potential advantages of a national registry given the patient safety and equipment governance issues presented by the current absence of such a registry.

Patient outcomes

Whilst it is essential that individual services have an accurate database to keep track of patient numbers, diagnoses, and equipment, there is also a clear requirement for data to be collected on a national basis. This would facilitate structured priority setting at a national level as well as allowing patient reported outcome measures to be captured. It is only through research and analysis of systematically collected national data, that clear insight into service delivery and areas of improvement are 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 of clinical benefit. A complex HMV service would be expected to enter data into a national registry once established.

A core dataset for CHV

A core dataset would need to be established by consultation, which 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. Annual audit would allow the registry to highlight potential future areas for quality improvement through nationally identified themes.

There are already examples within respiratory medicine of how registries can transform the lives of patients, such as the BTS UK Interstitial Lung Disease Registry and the UK Cystic Fibrosis (CF) Registry. The CF Registry, for example, has over 950 datapoints, and annual data submission from all commissioned services for >98% of the entire patient population.[16] 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 wealth of clinical, commissioning, and research opportunities that would act to enhance standards of care.

Clinical governance meetings

Mortality/morbidity

A robust and 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 discussing and reviewing patient deaths with other members of the 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 2.

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 supply of disposables to community patients should be agreed at a local level.

Complex HMV services should have a robust risk assessment to mitigate the risk of equipment failure out of hours. This may include a 24/7 helpline or provision of back up equipment.

Patients and families 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 should include all aspects of clinical patient management and equipment care and use.

Members of the multi-professional team should ensure they are competent in the correct use and 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. In a care package, the ongoing competence of carers is the responsibility of the care agency and the ICB which commissions the package. This training and assessment of competence should be documented.

Local networks

A complex HMV Service provides the necessary infrastructure for all aspects of complex inpatient assessment and long-term community 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 if, and when, the "complex" intervention has been completed. A collaborative approach between specialised and local centres is required.

In cases of less complexity, for example nocturnal home NIV in a patient with COPD, specialist expertise is still required to ensure safe and effective care.

Commissioners should ensure that all HMV providers within their region are appropriately integrated, so that patients have equitable networked access to the best possible care. HMV service patient pathways should be sufficiently flexible to enable an appropriate level of care based on clinical complexity, regardless of geographical location. This would facilitate timely referral of complex patients to specialised centres when needed, and more local care where feasible and appropriate, achieving high levels of integration and collaboration between existing services. Commissioners should apply the same outcome measures to all providers of HMV, including those who do not manage patients with complex ventilation requirements.

The need to demonstrate clear network links with a regional complex HMV service should be a requirement when commissioning any HMV service.

The complex HMV service should run the SWU (where present) within the same healthcare organisation. Close clinical collaboration between respiratory medicine and critical care and within multi-professional teams is crucial. Remote weaning advice and on-site assessment to regional critical care networks should be provided through the SWU.

The following enabling structures are very important:

- a structure for person-centred integrated care for people on HMV
- structures for interprofessional collaboration such as regional multi-professional meetings
- structures for case conferences and integrated care that enable collaboration

D. SERVICE MODEL

Estates

Inpatient

All complex HMV services should develop 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 guidance for RSUs.[3] These may be within a dedicated ward or co-located with RSU, SWU, critical care or respiratory ward beds. RSUs should be able to admit existing patients with acute problems from HMV service providers and this workload should be taken into account when calculating bed numbers on an RSU. Staff should have the required competencies to care for patients with any of the ventilators used by the complex HMV service.[17] 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 (polygraphy, transcutaneous CO2), blood gas analysis and imaging services. Outpatient facilities 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, rooms that allow easy wheelchair access, beds to enable assessment of patients, appropriate toilet facilities, accessible 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 should 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 be funded to provide and maintain:

- An appropriate ventilator and a second device if clinically required, with internal and external batteries and mobility bag
- A range of appropriately licensed ventilators capable of delivering NIV, mouthpiece ventilation and tracheostomy ventilation
- An active humidification unit, if appropriate
- For NIV, a range of appropriate interfaces
- A positive expiratory pressure device
- An MI-E device
- Peripheral secretion mobilisation devices, which usually require a specific funding agreement

Additional equipment needed by some complex HMV users that is *not* routinely supplied by HMV services should be sourced, supplied and funded by the ICBs directly, or via a care agency. This may include:

- Portable suction machines and suction catheters
- Nebulisers
- Tracheostomy tubes including emergency tracheostomy change kit
- Pulse oximeters

If the extra equipment is not being supplied by the HMV provider, then this will need to be sourced, supplied and funded by the community team within the agreed Continuing Healthcare (CHC) budget. All other ongoing essential consumables should be placed on a regular rolling order. Advice on the type of equipment and consumables needed should be directed by the HMV team. Please see Appendix 2 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.

Workforce: the complex home mechanical ventilation 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 or community based, or a mixture of the two models. Staffing ratios may not be applicable where a complex HMV service is co-located with an SWU. They will also depend upon whether the service is predominantly a complex HMV service, non-complex service or a combination of the two.

Whilst there is no consistent formal guidance on staffing ratios throughout the NHS, it remains important to maintain safety and the BTS has previously published guidance on staffing ratios for acute NIV, RSU staffing and on staffing of the respiratory workforce in the future.[2,3,18] Furthermore, although staffing numbers cannot be exactly mapped to income, there are opportunities for complex HMV services and HMV services to generate significant income from inpatient activity during hospital admissions and by coding outpatient activity which is detailed in Appendix 1.

The following is advised as a minimum for a complex HMV service:

- One Whole Time Equivalent (WTE) nurse, physiotherapist, healthcare scientist or other suitably trained healthcare professional per 40 patients who meet the definition of requiring complex HMV[18]
- One WTE consultant (7 direct clinical care programmed activities) per 300 patients who meet the definition of requiring complex HMV. This should include inpatient and outpatient work. Consultants can be a combination of medical and non-medical personnel
- Dedicated and funded specialist physiotherapy time
- Dedicated and funded specialist SLT 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 healthcare professional per 80 patients and one WTE consultant per 600 patients meeting the definition of requiring HMV services.

There are multiple staff groups who are essential for the effective function of the complex HMV service and are core members of the multi-professional team. Description of multi-professional roles within a complex HMV service can be found in Appendix 3. Access to other members of the multi-professional team is essential but access alone is insufficient and more formal arrangements are required. Complex HMV services should be able to demonstrate close collaboration and availability of these services to reflect the complex needs of this patient group. Depending upon the local configuration of services, this may take the form of:

- A formalised role in the HMV multi-professional team with funded sessions (e.g. via a service level agreement with therapy services)
- Ring-fenced funded time in other multi-professional clinics for HMV patients
- Members of the multi-professional team in all professional groups demonstrating a specialist interest in HMV/weaning/complex discharge of HMV patients
- Input into multi-professional meetings for HMV patients

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. See Appendix 4 for an example of a five-year staffing strategy document.

Complex HMV services should have a medical lead clinician with appropriate Supporting Professional Activity (SPA) time for service development (1 SPA) and clinical leadership (1 SPA). All complex HMV services should have a dedicated service delivery manager, business manager 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, who should be at consultant level.

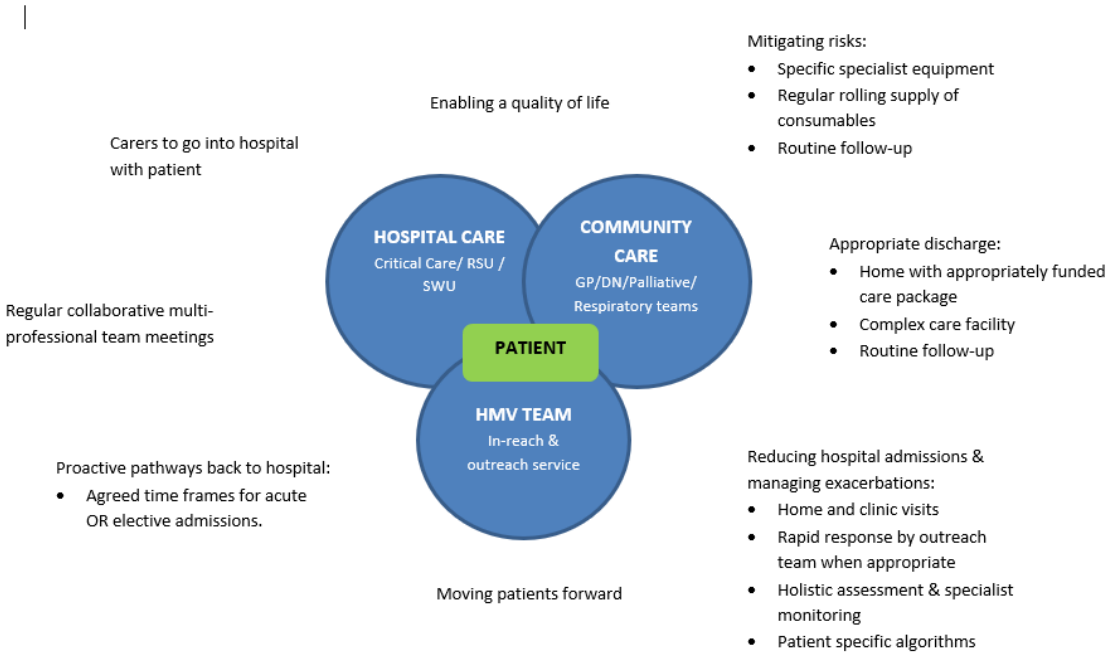
Complex HMV services should be supported by appropriately staffed administrative teams to ensure that clinical staff spend their time undertaking clinical rather than administrative duties.

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, and respiratory physiology–including hypoxic challenge testing.

E. PATIENT PATHWAYS

A model of care that places the patient at the centre means that services will deliver care that is individualised to the patient need, supports a proactive and flexible approach and facilitates delivering the right care, at the right time, in the right setting, 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 mechanical 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 multi-professional 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 a requirement for HMV and may result in increased ventilator dependency; this includes 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 complex HMV MDT with experience in the assessment of patients with complex HMV requirements.

Referral criteria

Complex 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.[19] Based on current evidence, patient populations who are most likely to benefit from home mechanical ventilation are detailed in Appendix 5.[20-32] Examples of typical treatment pathways are included in Appendix 6-8.

Where complex HMV services and HMV services overlap geographically, it is advised 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 depending on local provision, but examples include patients:

- Transitioning from NIV to long-term invasive ventilation
- Requiring advanced airway clearance techniques
- Experiencing changes in condition or stability that require 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[27]
- Referring neuromuscular teams should be encouraged to refer patients well before the suspicion of hypercapnia for routine review: 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 complex HMV centre and to maintain an organisational skillset, services should be able to demonstrate a significant complex patient cohort along with the service structure outlined in this document. As an example, a complex HMV centre should look after at least 80 patients who meet the complex commissioning criteria and at least 15 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 20 referrals a year of patients who meet the complex commissioning criteria. These numbers have been reached through consensus and via the consultation process to inform this document. Numbers will depend upon local geography and referral patterns. It is also recognised that some services may be delivering complex HMV services to a smaller number of patients and under the circumstances there should be close working and regular meetings with recognised complex HMV centres.

Establishing complex home mechanical ventilation

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 ventilatory 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. For other patients, however, 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 clinician
- Diagnostic screening tools such as full pulmonary function tests, (mainly spirometry, 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;
- 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 initiated on complex HMV should have an established diagnosis and be under review by respiratory specialists, who will monitor the progression of ventilatory failure, allowing an elective approach to setup. A proportion of patients, however, will be established on complex HMV following an episode of acute ventilatory 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[33], so too does the number of people who transition from child to adult complex HMV services.[34] The NCEPOD 'Balancing the Pressures' report noted, as for adult populations, the precise number of children who receive HMV is uncertain. They identified 3,061 children and young adults receiving HMV though concluded that this was an underrepresentation in the absence of specific coding for HMV and the likelihood that a proportion of patients had already transitioned to adult services.[8,32] It is often the case that the exact support provided by children's services is not mirrored in adult services; services may not be available in the same way or are 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.[35]

The process of moving care from child to adult services should have commenced by at least the young person's 14th birthday,[36] however, early discussions may commence from age 11.[37] Those with the most complex needs may require an extended transition period.[38] The process should be person-centred and developmentally appropriate; aiming to minimise disruption and ensure seamless provision of HMV care.[39]

Not all patients transitioning between paediatric and adult services will need to be cared for by complex HMV services but those patients with ventilatory needs corresponding to 'severe' or 'priority', according to the 'National Framework for Children and Young People's Continuing Care', would need to be transitioned into complex HMV services.[40] 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 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[8,32]
- 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[37]

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[39]

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.[41] A regional SWU should be co-located with a complex HMV service. A regional SWU should have the multi-professional 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 should 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 SWU 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 the process 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 should work with the ICB and CHC teams to develop and co-ordinate an appropriate and safe community discharge location 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. Care requirements will depend

on ventilator interface and dependency as well as other factors. A hierarchy of care requirements is suggested below:

- 24 hours per day long-term tracheostomy ventilation (LTTV) with tracheostomy tube cuff up with secretion management and gastrostomy feeding
- 24 hours per day LTTV with tracheostomy tube cuff up at night only with secretion management and gastrostomy feeding
- 24 hours per day LTTV with tracheostomy tube cuff up at night only with secretion management
- 24 hours per day LTTV with cuffless tracheostomy tube with secretion management and gastrostomy feeding
- 24 hours per day LTTV with cuffless tracheostomy tube with secretion management
- NIV > 14 hours per day with secretion management and gastrostomy feeding
- NIV < 14 hours per day with secretion management and gastrostomy feeding

Discharge pathways

Discharge process

Patients who are established electively requiring 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 care agency and recruit and train carers. This process can currently take several months to complete with data from a national study 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.[42] 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 9.

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. 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 in some circumstances. The CHC Decision Support Tool document may be useful to establish care requirements.[43]

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

- The patient's home with a fully funded package of care depending upon the clinical need, which may require 24-hour awake care
- A community care facility, for example:

- A complex care facility with a track record of managing and caring for patients who require complex home mechanical ventilation

Or

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

The decision on discharge location should be based on the patient's preference and healthcare needs and should be reached through collaboration between the ICB, CHC team (when required), hospital team and HMV service to ensure that it is a safe and effective package of care and/or destination for discharge. Funded occupational therapy time should be available where required to review the discharge destination. Complex HMV teams should 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 all the equipment 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 prior to 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 is set up for discharge. This includes, ensuring a sufficient number of appropriately trained carers to cover the care package, including contingency for when carers are unwell, on leave or leave the package. Any mandatory training would be the responsibility of 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 will involve assessment by an occupational therapist, who will then 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 advised which should include an OT where required. 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 ensure that:

- They are able to demonstrate competence, skills, and knowledge in caring for complex HMV patients
- Each care package is managed by and has oversight from an appropriately experienced and skilled registered healthcare professional
- Each care package or complex care facility has carers who are trained and competency assessed to a level specified by the complex HMV service. (See Appendices 10 and 11 for examples)
- Each care agency/complex care facility provides core training for their carers specific to the complex HMV patient needs

Where possible the HMV team will use cascade training to train 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 and the ICB commissioning the care package, to ensure that their staff have up-to-date and 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 individual's care and management. Appendix 10 is an example of a carer skills document for tracheostomy ventilated patients.

Ventilator passports and management plans

During the discharge process, the complex HMV team should help to develop individual ventilator/interface passport and management plans (examples give at Appendix 12 & 13) which should include proactive treatment interventions for common clinical scenarios that the patient may experience (Appendix 14 a-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 should 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 acute hospital admissions
- Help the patient negotiate acute hospital admissions, when these required
- Detail ceilings of care if appropriate

Tracheostomy ventilated 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 (see Appendix 13) 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.

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 patient's 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 ongoing 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 medically 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 multi-professional team and goal-setting agreed with the patient.

Follow up

Following treatment initiation 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

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

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

- MND: 3 monthly[28]
- DMD: 6 monthly (with pulmonary function tests prior to initiation of ventilation)[44]
- Other muscle disease: 6-12 monthly[28]

Monitoring

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

- 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 (mainly spirometry, 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
- 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
- Weight/anthropometry and consideration of bowel management

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 home mechanical ventilation 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 often 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 year's 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 clinical stability, avoiding hospital admission and unscheduled care contacts and is an important role of any complex HMV service. Complex HMV services should have 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 should 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 that the pathway to clinical review is clear to patients and that a 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 management of both 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 liaise with their patient's local hospital to assist with coordination of routine review and emergency care when required.

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 to 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 patient's care team
- 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:
    - Advocating for 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
    - Reducing the risk of care package breakdown and delayed discharge when care teams are reallocated to other packages during prolonged hospital admissions
    - Facilitating carers to have bespoke understanding of best practice relating to the patient's routine needs especially lifting, handling and positioning
    - Supporting ward staff that may not have detailed knowledge of a patient's care plan and therefore improve trust between patient and hospital teams
    - Ensuring the presence of previously competency assessed and trained carers during a hospital admission so that the admission does not result in a reduction in the quality of care

- If cared for in a complex facility to ensure that the patient's bed is reserved until discharged
- Regular communication with the patient's 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 will also require emergency admission. Furthermore, common acute non-respiratory issues such as dislodged gastrostomy tubes, catheter associated infection, may require 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 an 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 decisions on emergency management, assessment and appropriate 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 with input from critical care teams where needed is essential, to allow for care within an appropriate clinical area and support from the patient's own care team. Early involvement from the acute hospital's critical care team is required to help plan location of care and to discuss/plan any ceilings of care if appropriate.

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- Specialists in Long-term Ventilation at Home (SiLVaH)

DISCLAIMER

This document reflects the expert views of a group of convened by the British Thoracic Society. Production of this document did not involve a formal evidence review and has not been developed in accordance with clinical practice guideline methodology. This guidance document is not intended as a legal document or a primary source of detailed technical information.

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Appendices

Below is a list of the accompanying appendices, which can be found in the supplement published alongside the main document.

Appendix 1: NHS Payment Scheme

Appendix 2: Consumables for tracheostomy invasive ventilated patients

Appendix 3: Examples of multi-professional working within complex HMV services

Appendix 4: Five-year staffing plan

Appendix 5: Evidence for long term ventilation

Appendix 6: Ventilator set-up - neuromuscular and chest wall disease

Appendix 7: Ventilator set-up - COPD

Appendix 8: Ventilator set-up – obesity related respiratory failure

Appendix 9: Phases of discharge

Appendix 10: Carer skills document

Appendix 11: Carer training standards

Appendix 12: Ventilation care plan

Appendix 13: Patient tracheostomy passport

Appendix 14a: Management of possible chest infection

Appendix 14b: Management of suspected sputum plug with MI-E

Appendix 14c: Suspected sputum plug (uncuffed or cuffed down tracheostomy)

Appendix 14d: Management of suspected sputum plug TIV

Appendix 14e: Management of possible chest infection TIV

Appendix 14f: Dislodged tracheostomy tube (algorithm a)

Appendix 14g: Dislodged tracheostomy tube (emergency algorithm b)

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