Long-term ventilation in children and young people

Information for parents,
carers and families

Pan Thames Paediatric LTV Programme

North Thames
Paediatric Network
Connecting paediatric services

South Thames
Paediatric Network
Transforming Healthcare for
Children and Young People

Content

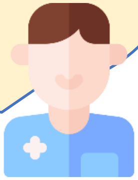
The Pan Thames Paediatric LTV Programme brings together the skills and knowledge of clinicians and commissioners from across London, East of England and South East England who have extensive experience in working with children with complex needs.

This booklet should be used as part of the Pan Thames Long Term Ventilation Ethical Framework.

You have been given this booklet because the team looking after your child is considering using a form of long-term breathing support. The aim is to let your child leave hospital and live at home with this support. This is known as “Long Term Ventilation”.

We understand that this is a difficult time for you and your child, and it might follow a long and worrying stay in hospital. It is very important that you understand the issues that come with this support, and that you know about the alternatives.

We also recognise that every child and family is different. Long Term Ventilation may be provided in different ways and for different reasons.



What is Long Term Ventilation?

Long Term Ventilation (LTV) is the use of a machine (ventilator) to provide breathing support overnight and for all or part of the day. The ventilator moves air/oxygen in and out of the lungs to support or replace a child’s own breathing. There are 2 types of LTV.

Invasive tracheostomy ventilation

The ventilator is connected to a breathing tube which sits directly in the windpipe (trachea). For home ventilation, this is done by making a hole in the windpipe and inserting a tracheostomy tube (this happens during an operation in hospital). The tracheostomy tube remains in place all the time.

To note: Tracheostomy insertion has its own consent and parent/carer/family information resources, which should both be used alongside this booklet.

Non-invasive ventilation

The ventilator is connected to a mask which is placed over the mouth and/or nose. This can be removed when ventilation is not needed. Children who only need ventilation at night and for part of the day might be able to use non-invasive ventilation (NIV).

When LTV is considered

LTV is considered when a child's own breathing cannot fully support their needs. The body has difficulty getting oxygen into the blood and getting rid of carbon dioxide. This is known as chronic respiratory failure.

LTV might be needed if there is a serious problem in the lungs, or with the mechanics of breathing. With LTV the child's quality of life and life expectancy could be improved.

Examples when LTV might be considered:

- when the lungs are not working well enough to do their job. This includes some babies who are born very prematurely, or children with severe inflammation of the lungs.
- when the airways (tubes in the lungs) are damaged or floppy.
- when the breathing muscles are weak. This includes some genetic or neuromuscular conditions.
- when the nerves that supply the breathing muscles are affected. This can happen after a spinal injury, infection, or tumour.
- when the breathing centre in the brain that controls our breathing pattern is affected (respiratory drive). This can result in slowing or stopping of breathing, especially when sleeping.

In exceptional cases, LTV can also be used to support children with end-of-life care.

Notes

When considering LTV there are many things to think about. For some children, LTV may only be needed for a certain period of time while their condition improves. For others, LTV may be necessary for the rest of their life because their need for support is unlikely to improve. However, sometimes LTV might not turn out to be helpful. Your child's situation might also change, leading to an increase in their needs, the treatment aims, or the predicted length of treatment.

LTV also carries a risk of complications, which cannot always be prevented or predicted. Your clinicians will discuss these issues with you. Sometimes in discussions it becomes clear that using LTV is not in the best interest of your child so an alternative care plan will be a better option.

How long will Long Term Ventilation be needed?

This depends on the reason your child needs the support. This can be:

- a period of time while the underlying condition improves, or while a different treatment is given time to work. The need for LTV will be continually reassessed and reduced or stopped when possible.

- lifelong, if the underlying condition has no chance of a full recovery or treatment. The use of LTV will be continually reassessed to make sure it is helping your child and is always in their best interest.

Some children do not improve in the way their LTV team hope, so they might need it on a long term basis. The use of LTV will be continually reviewed to make sure it is the right form of treatment.

Sometimes LTV is not tolerated, or helpful, and so might be stopped. This will always be discussed with you as part of the consent process.

It is also possible that your child's conditions might change, which can alter their needs, treatment aims or the length of treatment.

What are the potential benefits of LTV?

When LTV is used to support your child, it can help them in many ways. It can:

- improve symptoms such as shortness of breath, tiredness or daytime sleepiness.
- reduce the effort of breathing, which may help them gain weight and have more energy for other activities.
- improve your child's growth and development.
- allow them to leave hospital, and/or reduce the need for emergency hospital admissions.
- let you care for them at home and keep the family together.
- maximise your child's quality of life.
- increase life expectancy or sustain life.

What are the potential downsides of LTV?

LTV also has a risk of complications which cannot always be prevented or predicted. Your clinicians will discuss these issues with you.

LTV is a complex form of treatment. It is important to understand that it:

- will not cure the underlying medical problem.
- will not always be sufficient to avoid further hospital admissions.
- may change your child's feeding, speech, and communication.

- may require ongoing, often frequent, and intrusive, interventions, such as suctioning to clear mucus and secretions.
- May require a lot of equipment and adjustments to your family's day-to-day living and mobility.
- needs your child to be observed while on treatment, which can mean having additional support from nurses or carers in your home.
- can result in complications that may include brain damage or lung damage.
- can lead to further serious complications or death if the ventilator is not used correctly or malfunctions and is not responded to appropriately.

Using LTV might also lead to other medical complications, depending on whether it is invasive or non-invasive ventilation.

Possible complications from invasive tracheostomy ventilation

- blockages or displacement of the tracheostomy tube
- bleeding from the windpipe
- scarring of the windpipe
- further damage to the lungs
- mucus, fluids, or vomit (sick) 'going down the wrong way' (aspiration into the lungs)
- bloating of the stomach

Possible complications from non-invasive ventilation

- sore skin on the face
- changes to the shape of the face

- mucus, fluids, or vomit (sick) ‘going down the wrong way’ (aspiration into the lungs)
- bloating of the stomach

What does a ventilator look like and what other equipment is needed?

There is a range of ventilators specially designed for use at home. They are small, portable and can be run on electricity or on a battery for a short period of time. The device will be chosen to meet your child’s needs and the type of ventilation they require. The ventilator has a tube that attaches to either the mask or the tracheostomy tube. An oxygen supply can be attached if needed.

As well as the ventilator, your child may also need other equipment and supplies including:

- humidifier
- suction equipment
- oxygen – a concentrator, plus fixed or portable cylinders (a concentrator delivers oxygen by filtering the air around us)
- oxygen saturation monitor
- nebuliser (a machine that allows your child to breathe in medicines as a fine mist, through a mask and tubes)
- hospital cot or bed
- suitable buggy or customised wheelchair, to carry your child and the equipment

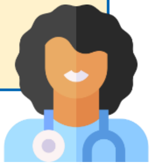
Home ventilators are much smaller than the ventilators you will have seen in the hospital. They are usually about the size of a toaster but heavier. Here are some examples of home and portable ventilators:

Nippy 4+

Trilogy Evo

Once your child has been established on LTV in the hospital, the team will start to plan the journey home with you. This process may take several months. It will include many steps, such as training you to care for your child at home.

Your child's LTV team will work with the community team and commissioners[1] to create a support package, which may include skilled and trained carers at home to help you look after your child.



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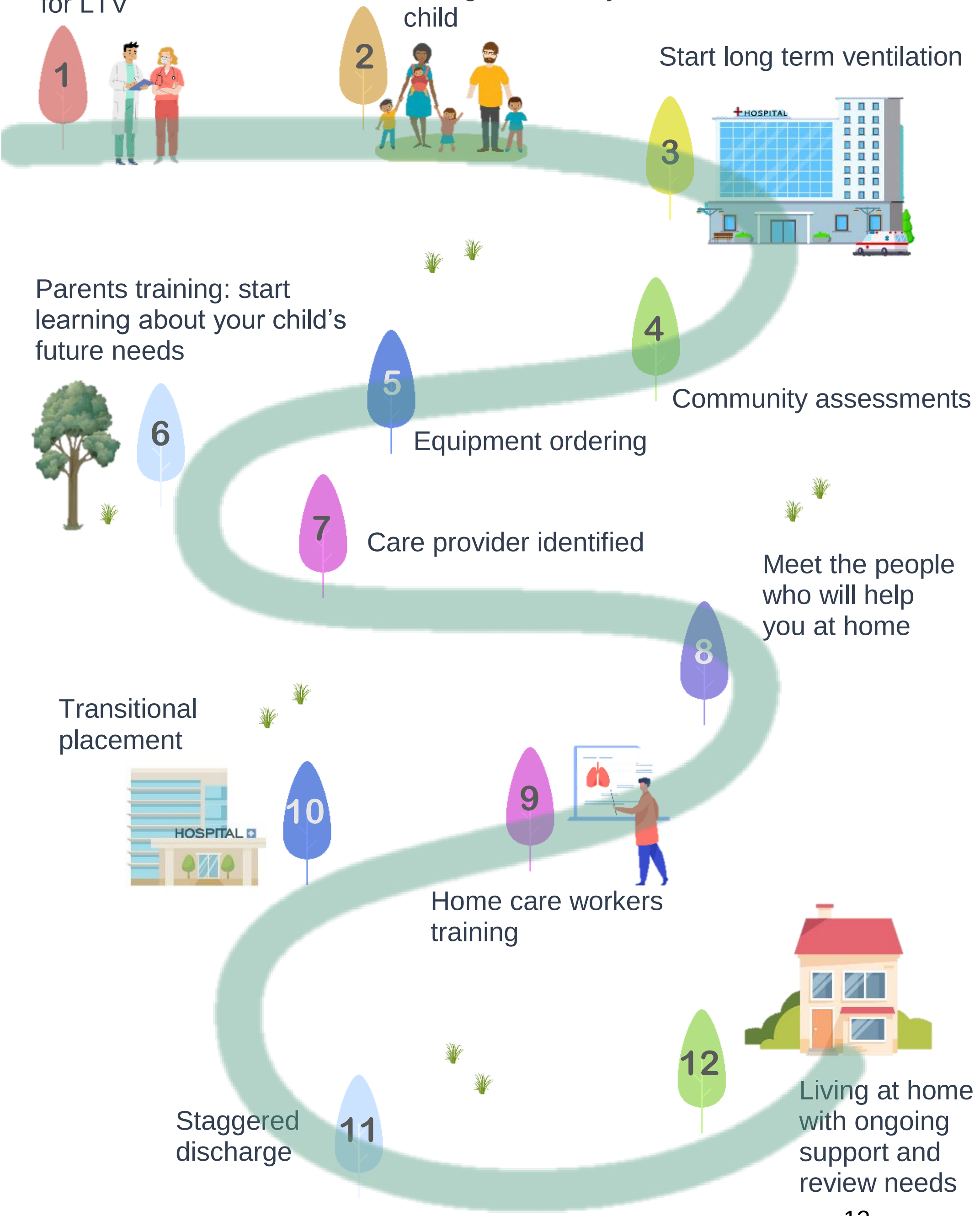
[1] A commissioner is someone who assesses local needs and has the responsibility for approving many NHS services.

Your journey home

The process of discharging your child from hospital to home includes several steps. These are the steps that are necessary to go through before getting home, however every child is different, and their journey home reflects this. The process is not always straightforward and may take different lengths of time. Some parts of the journey may happen at the same time. The diagram on the next page shows an example of what the discharge pathway might look like.

Long Term Ventilation Pathway



1. Identify a potential need for LTV
2. Making decisions about the right care for your child
3. Start long term ventilation
4. Community assessments
5. Equipment ordering
6. Parents training: start learning about your child’s future needs
7. Care provider identified
8. Meet the people who will help you at home
9. Home care workers training
10. Transitional placement
11. Staggered discharge
12. Living at home with ongoing support and review needs

1. **Identify a potential need for LTV**
   Your child is referred to the LTV service in your hospital or to an LTV centre.
2. **Make decisions about the right care for your child**
   Starting LTV is a complex decision made in the best interest of your child. A team of health care and sometimes, social care professionals will meet you and your child to discuss the options.
3. **Start LTV**
   Some children need a tracheostomy tube for ventilation. Others use a face or nasal mask. They will move to a portable ventilator designed for home use.
4. **Community assessments**
   A referral will be made to your child’s local community nurse to update them on your child’s needs. Your home will also be assessed for any changes that are needed. A care package may be agreed to support your child at home (see pages 14 -16).
5. **Order equipment**
   Your local community services team will order all the equipment needed to treat your child safely at home.
6. **Parent and carer training**
   You will get full training to make sure you are confident and fully able to take care of your child’s LTV requirements and other medical needs.
7. **Identify care provider**
   Your local community services team will identify a care provider to recruit home care workers to support your child at home.
8. **Meet the people who will help you at home**
   You and your child will meet and get to know the carers.
9. **Train home-care workers**
   Before your child leaves hospital, the carers get the training they need to look after your child.
10. **Transitional placement**
    Your child might be moved to a centre closer to home. This might be your local hospital or another place that would suit your and your child’s needs, such as a hospice.
11. **Staggered discharge**
    A few ‘trial runs’ to find any unforeseen issues and help you and the carers feel confident. This could include day trips, or an overnight stay at home.
12. **Live at home with ongoing support**
    Your child can leave hospital and receive continuing support at home. There will be regular reviews of all aspects of care by your community and hospital team

Housing

A suitable and stable home environment is essential for children on LTV. An assessment will be carried out to review if your current accommodation meets your child's medical and care needs, identify any necessary adaptations, or to consider alternative housing options.

Housing Assessment Process

- **Early Assessment:** Home suitability should be reviewed as soon as possible in the discharge planning process. Ideally, this should be an in-person assessment, but virtual assessments may be used where needed.
- **Multi-Disciplinary Involvement:** The assessment will involve Occupational Therapists (OTs), the hospital discharge team, and community professionals to ensure a comprehensive evaluation.
- **Housing Suitability Checklist:** Tools such as the **WellChild Home Assessment Form** can support the assessment process.
- **Suitability Decision:** A decision will be made based on safety, space, accessibility, and equipment needs. If the property does not meet these requirements (e.g., unsafe access, overcrowding), alternative housing options may need to be explored.

Housing Outcomes

Following assessment, the home will be classified as:

1. **Suitable – No action required:** The property meets all necessary criteria.

2. **Suitable with adaptations:** Minor modifications (e.g., power sockets, ramps) are needed.
3. **Interim suitability:** The property can support discharge temporarily, but a long-term housing plan is required.
4. **Unsuitable – Alternative options required:** If the home cannot be adapted, options may include:
    - **Medical priority housing applications** for urgent rehousing.
    - **Temporary or emergency housing** referrals where immediate risks exist.
    - **Alternative housing pathways** (e.g., social housing transfers, private rental options).

If adaptations are required, the Occupational Therapist will assess and support applications for Disabled Facilities Grant (DFG) funding or other available resources. If housing is unsuitable, the LTV team may support a Duty to Refer (DTR) application to the local authority. Cases may be escalated to senior housing leads, and NHS network leads for resolution if delays arise

This approach ensures a safe and timely discharge while addressing long-term housing stability.

Care package and social funding

Your Child may be assessed for a **Children and Young People's Continuing Care Package (CYPCC)** to support their care at home. The local Children's and Young People's Continuing Care Team and the professionals familiar with your child's needs will work with you to establish appropriate support to help your child transition home and to continue to be supported in the community as needed, based on their medical needs.

Assessment and Approval Process

- The Children’s Continuing Care Team completes a needs-based assessment, considering medical complexity and level of care required.
- The assessment is reviewed by a funding panel, where commissioners work with clinical experts to decide on a safe level of care that will be needed after discharge.
- If additional support is required, a referral to Social Care will usually be made, and a Social Worker allocated. It is important that families receive a holistic approach to support.

What a Care Package May Include

Each care package is individualised to meet the needs of the child and may include:

- Funded care hours – A set number of hours per week that a suitable care provider will be found and highly trained carers will support the journey home and continued care. As this is not typically 24-hour care, we recommend more than one family member is trained and signed off to ensure continuous support. Your LTV team can provide more details.
- Social care support, which may include short breaks (respite care) or additional support hours during the day.

- Personal Health Budget (PHB) – This allows families greater control and flexibility in arranging care but also requires managing employment responsibilities, such as hiring and overseeing carers.

Financial Support

Families may also be eligible for financial assistance, including:

- Disability Living Allowance (DLA**)** – For children under 16 years old.
- Carer's Allowance (CA) – For parents or guardians providing full-time care.
- Personal Independence Payment (PIP) – For children aged 16 and over.

A social worker will be able to help you to navigate these application processes.

Additional **grants and financial resources** may be available through charitable funding, depending on your circumstances. For more information on benefits and financial support, visit the Welfare Resources section on the Pan Thames LTV website at https://ltv.services/

Arranging and Managing Care

If a care package is approved:

- The Children’s Continuing Care Team will identify and arrange trained carers, either through the NHS Continuing Care Team or an external care agency.

- The teams will work with you collaboratively to ensure clear roles and responsibilities and that everybody involved in your child’s care understands what support at home will look like.
- Carers will meet your child and complete specific training, usually while your child is still in hospital.
- If using a Personal Health Budget (PHB), families will receive guidance on employment responsibilities, including recruitment and training of care staff.

Families should discuss funding options and ongoing support with their specialist nurse and social worker, who can provide advice on managing care at home.

Training and skills

You will need to be trained to look after your child’s needs at home, and you will have to demonstrate that you are able to do everything you have been taught.

This will include what to do each day, as well as what to do in an emergency or if your child is unwell. You will be trained how to:

- use the ventilator, oxygen, and other equipment
- give medicines
- recognise respiratory distress and what to do if it happens
- manage mucus and fluids, and suction them
- care for and change the tracheostomy tube (for tracheostomy patients only)
- position and adjust the ventilator mask (for non-invasive patients only)
- perform basic life support

At least 1 person with parental responsibility **must be fully trained**. However, it is always better to have 2 fully-trained responsible people.

Having a child with complex needs, including LTV, affects the whole family. While being together at home is the goal, there are often pressures that affect work, siblings, and family members, and how you manage typical day-to-day activities. Your child will also need frequent reviews by therapists, as well as hospital clinics to check their progress.

Impact on your child

The impact of LTV on your child will be influenced by their need for LTV, their age, and the underlying cause or reason for its use. Being at home with their family, rather than in hospital, will offer comfort and consistency to your child.

Your child may need help and extra support to adapt to changes in their lifestyle.

- **Communication.** LTV might affect their speech and other communication, so they will need ongoing support from a speech and language therapist.
- **Swallowing, eating and drinking**. Your child might need an assessment and a plan to support feeding. As food or liquids ‘going down the wrong way’ into the lungs could damage the lungs and make their breathing worse.

- **Education**. This may include access to nursery or school, individual support, or other special educational help. There may be additional support put into place to accommodate your child's needs in a nursery or school. If a child is too ill to go to school, other learning support might be put in place to provide continuity of learning.
- **Psychological support**. Children may need support to make sense of their journey and manage the next steps.

Your child will also need regular hospital reviews, and often more tests (such as sleep studies and X-rays). This will include regular reviews of the benefits of LTV.

Children's community nurses and other therapists may provide some care and assessment at home. Your local children's community nurse and other therapists will work collaboratively with your GP.

Impact on your family

Having your child at home on LTV may be a significant challenge for you, your other children, and your wider family. The effects might be wide ranging and complex and all emotions are valid. Some of the impacts that you may experience are as follows, though each individuals experience will be different.

- **Emotional.** You may be uncertain about the future, or be anxious or stressed about managing illness, and the responsibility of caring for a child with complex needs. This can put strain on relationships. We would encourage seeking psychological support to help you to manage your own wellbeing.
- **Family.** Your other children might feel ignored, or have restrictions placed on them due to competing needs.

They may feel that they have less of their parents' time or attention. They might also be anxious about their brother's or sister's health. There is support available from charities such as Sibs (sibs.org.uk).

Locked in time
"It is inspired by me being trapped or not being able to go outside. Many people may have experienced this during quarantine, although I felt being indoors wasn't hard as I had been doing it for most of my life with my disabled brother (Ihsaan).

This is a portrait of emotion that I really felt. This is a time where I can display those feeling on the canvas Without having to word it all out".

Painting by Liyana Ahmed, aged 13

- **Financial.** Being a full-time carer can involve long hospital visits and frequent appointments. This may affect your ability to work or earn as you did before. There may be some sources of financial support from social care.
- **Social.** Other aspects of life may become more challenging. Time for dining out, playing sport, and other forms of relaxation and hobbies can be reduced. Holidays and other travel, particularly abroad, need a lot more planning, are logistically difficult (and sometimes not possible at all) and can mean extra expenses. Your child will need a Hypoxic Challenge Test to assess if they will need additional oxygen and/or ventilation while on an

aircraft. Certain countries have limited or no resources for children on LTV. People you know now and those who you meet may have questions about your child, and hold different opinions about their care, this can be supportive at times but it may also be challenging knowing how to respond.

There are a number of services or organisations that may be able to provide advice and support to you. You might want to speak to other families who have already been through this experience. WellChild, the national charity for sick children, have a network of families who are caring for children with exceptional needs.

https://www.wellchild.org.uk/get-support/join-our-community/

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Are there any other options to LTV? How are these decisions made?

Understanding other options

Sometimes when considering LTV, you and your medical team may wonder if it will be helpful or not, or even if it could cause more difficulties.

Sometimes LTV is not right for a child, perhaps because they are too unwell or because it will make their life more difficult or uncomfortable. Some children are too unwell for LTV to be the right thing for them.

Using LTV to support a child with chronic respiratory failure must be in the child's best interests and has to be a shared decision between parents/carers and the medical team. You may need support in order to make a decision if you have different opinions.

Sometimes it is difficult to know how a child will tolerate or benefit from ventilation. Where Non-invasive ventilation is being considered, planning a trial of use for a few days or weeks may be proposed before deciding whether it is likely to be helpful or not.
If LTV would not improve your child's quality of life or if it would lead to more harm or discomfort, the medical team will talk with you and make sure you understand the situation and the reasons why they think that LTV might not be right

for your child. This conversation might be emotional, especially if your child might die without LTV. It might take more than one conversation to make sense of all the information and it may be helpful to have support for this conversation.

In these circumstances, it is important to consider the options and for you to be able to ask questions. Your LTV team may discuss your child with a group of experts and seek a second opinion from a different independent medical team. This is to ensure the decision is in the best interest of your child.

If the medical team recommend that LTV is not right for your child, it does not mean that they are 'giving up' or taking away care from your child. It means they want to make sure that your child is well cared for, is not in pain and has the best possible level of comfort.

The specialist palliative care team (sometimes known as the Symptom Care Team) will get involved for children with reduced life expectancy to help make plans to support their comfort. Palliative care is not just for when a patient is nearing the end of their life. It can also be used alongside treatment for controlling an illness and can include support for families. Palliative care also helps to make sure that your plans and family's wishes are fully considered and understood. The palliative care team can also offer extra support and care at home, alongside other clinical teams.

Your medical team will be happy to discuss the role of the Palliative Care or Symptom Care Team with you in more detail and arrange a meeting with the Team. Please discuss with your keyworker for more information

We hope this information booklet has answered some of the questions you might have had on Long Term Ventilation and what it means for your child.

We understand this journey can be difficult, your LTV team is here to support you and address any concerns and questions you may have along the way.

Notes

Notes

Notes

References

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- Image: Breas NIPPY 4, **web** www.breas.com/products/nippy/nippy-4/
- Image: Flaticon.com'. This booklet has been designed using resources from Flaticon.com
- Image: shutterstock.com. Images from Shutterstock have been used in this booklet.

Acknowledgements

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Contact us

South Thames Paediatric Network - England.stpn@nhs.net
North Thames Paediatric Network - England.ntpn@nhs.net

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