

GROWING TOGETHER

Patient centred strategies for the development of LTV care

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HEALTHCARE

 **Resmed**


BREAS


East of England
Paediatric Critical Care
Operational Delivery Network
Collaborative working to deliver high quality care to our children and their families

SOUTH WEST

Paediatric Critical Care
OPERATIONAL DELIVERY NETWORK


The Yorkshire and Humber
Paediatric Critical Care
Operational Delivery Network


Thames Valley and Wessex
PAEDIATRIC CRITICAL CARE
Operational Delivery Network

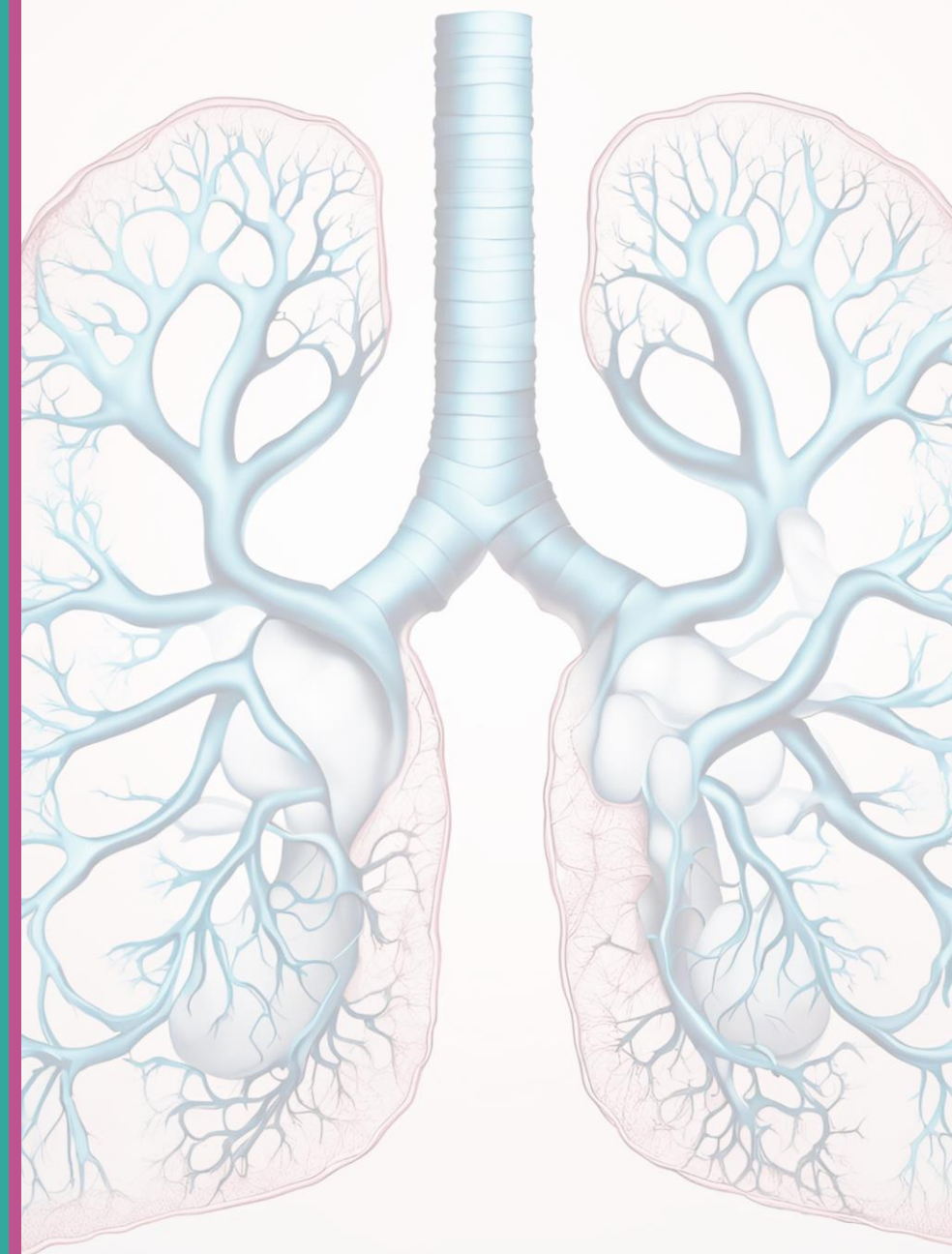
Pan Thames Paediatric LTV Programme

 North Thames Paediatric Network Connecting paediatric services	 South Thames Paediatric Network Transforming Healthcare for Children and Young People
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ODN SiC
LTV
NORTH WEST PCC




West Midlands
Children's Network





Patient Engagement, welfare and housing

ANNABEL COYLE-STEWART & EMMA ASHRAFI





Engagement - Aims of my work

Scoping what engagement work is currently happening for LTV families

Ensuring that patient voice is included in the work that the LTV programme is carrying out

Sharing my engagement skills across the North and South Thames Networks

Assessing what further support / resources / training is needed to help professionals undertake

engagement with families and patients





Why engage with patients and the public?



Improved quality and health outcomes

Engaging with patients and the public creates a better chance of ensuring services meet people's needs, improving their experience and outcomes. People have the knowledge, skills, experiences and connections services need to understand in order to support their health. Partnership working is more personalized



Better decision making

Decision-making is improved when insight from patients and the public is used alongside clinical information. Challenge from outside voices can promote innovative thinking which can lead to new solutions that would not have been considered had the decision only been made internally.



Accountability and transparency

Engaging more meaningfully with patients and their family helps to build public confidence and support that the service is responsive to their needs





Examples of engagement work



Digital Engagement



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Connecting paediatric services



South Thames Paediatric Network
Transforming Healthcare for Children and Young People



Are you a professional or family member supporting a child or young person on Long Term Ventilation?



Check out our new website

Get involved webpage - Look for gaps where you can link surveys, questionnaires, opportunities for story telling.

How You Can Get Involved

Help us improve and complete the below

(find a way for this to link to Microsoft forms)

A moment to share


Do you recall a specific stand out moment or time in your CYP's journey on LTV? We would like to hear it. Please reach out by filling this form.

Name


Email Address

Message


Remove accessibility barriers through Jargon Busters



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Jargon buster

We appreciate that the language used in the NHS can be complex. You may find this jargon buster helpful for understanding the terminology you may come across when engaging with the clinicians caring for your young person on LTV.



Abbreviation	Term	What does this mean
A&E / ED	Accident & Emergency / Emergency department	Is for serious injuries and life-threatening emergencies. It's also known as the emergency department or casualty.
ANP	Allied Health professional	Physiotherapists, Radiographers, Occupational Therapists, Dietitians, Operating Department Practitioners, Paramedics, Speech and Language Therapists, Art Therapists, Drama Therapists, Music Therapists, Osteopaths, Podiatrists, Prosthetists and Orthoptists
ANP	Advanced Nurse practitioner	A Nurse who has undergone extensive advanced training, who is deemed competent in practice using expert clinical knowledge and skills.
BPAP	Bi Positive airway pressure	(Bi means two) two levels of Positive Pressure Ventilation
BP	Blood Pressure	Blood pressure is the term used to describe the strength with which your blood pushes on the sides of your arteries as it's pumped around your body.
BiV	BiV Valve Mask	A device that can be used to manually deliver breaths, either with a mask over face or attached to a tracheostomy tube
CATS	Children's Acute Transport Service	A North Thames retrieval team that bring the skills and knowledge of an intensive care unit to local hospitals, stabilising children for and transferring to a Children's intensive care unit.
	Care Package	If a children or young person is eligible for continuing care, they receive an individualised care package. It is usually provided in the child's own home. This can be at any time of the day and tailored around the needs of the child or young person. Depending on area they live, these care packages can be provided by hospital at home team who are from the NHS or a private care agency funded by the NHS. Depending on clinical need this would either be a Nursing care package or Carer care package.
CCC	Children's Continuing Care	The Children and Young People's Continuing Care Team provides a service to children and young people who have very complex health needs, either due to congenital conditions, long-term, life-limiting, or life-threatening conditions, disability or the after-effects of serious illness or injury.
CCITCCN	Children's Community Nurse/ Children's	A children's community nursing team are experienced children's nurses who provide nursing care for children and young people to enable them to stay at home with their family, to prevent admission to hospital.



Social media platforms



@thames_south
@NTPaedsNetwork

For updates, news and upcoming events and developments within the Pan Thames LTV programme across the North and South Pediatric Networks.

Other engagement methods and work

Lived experience groups

A small group 6-12 people with experience of the topic in question
participants focus on a set of questions and have discussions on the topic

Surveys and interviews

Quick, fast, capture numbers
ideally ask no more than 5 questions on what works well and what can be improved
Put more emphasis on QUALITATIVE questioning. ie use more free text compared to likert scaling




WELLCHILD TRAVEL DOC


- Focus group devised of professions and a lived experience representative




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Long Term Ventilation Parent/Carer Survey

The Pan Thames paediatric long term ventilation (LTV) programme is commissioned by NHS England and is jointly managed by the South and North Thames Paediatric Operational Delivery Networks. Our mission is to transform service delivery of paediatric LTV services, (Tracheostomy and Non Invasive Ventilation) to reduce the time babies, children and young people on LTV spend in hospital and to maximize high-quality care at home.

We have identified our programmes aims and we would like to gather parent/carers feedback to help shape our teams work and to help us measure intended outcomes of our programme's work.

We will not be able to respond to any feedback on an individual basis. Therefore, please do not add any patient identifiable details and direct any further questions you have at your local LTV team. Your feedback will be kept anonymous and will be used to help improve LTV services.

LTV TRAINING VIDEOS

- Giving parents/carers a survey before and after a series of coproduced videos to support them in their LTV training package

HOSPITAL ADMISSION PROTOCOL

-View to interview families who have successfully experienced a funding package that allows carers to follow their children onto hospital wards

Welfare and Housing

Rights and entitlements

- Awareness
- Access

Reduce poverty
Promote financial stability
Uphold social justice



Challenges

Delays to discharge, due to:

- unsuitable housing
- lack of equipment or essential items
- impacted parental attendance at hospital

Housing
Finances

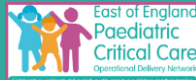
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Aims

- Reduce delays to discharge
- Reduce readmissions
- Address inequalities **CORE20 PLUS5**



Network facing, patient engaging

- Damp and Mould Resources



DAMP AND MOULD CHECKLIST



December 2023

Housing checklist to support
identification of housing and clinical
concerns related to mould and damp
exposure

*This resource has been developed through the collaboration of
London's Public Health System partners; the Mayor of London, Association of Directors of
Public Health (London), NHS England (London), Office for Health Improvement & Disparities,
UK Health Security Agency.*

Acknowledgements: Julie Billett, Shelley Aldred, Emer Forrest, Gladys Xavier, Georgie Herskovits, Christine Kirkpatrick, Philip Williams, Ian Diley, Nicky Brown, Lindsay-Jane Merrett, Emer O'Connell, Emma De Zoete, Josie Garrett, Sara Nelson, Anna Martinez, Jane Simmons, Rachel Knowles, Ingrid Barnes, Josephine Ozols-Riding, TechUK Damp and Mould Innovators Network, Association of London Environmental Health Practitioners, London Local Authority Chief Executives Group, London Directors of Housing and the Health and Housing Impact Network, UCL Centre for Access to Justice.

DAMP AND MOULD TOOLKIT

A comprehensive checklist for assessing housing and
clinical risks associated with exposure to damp and mould.



*This resource has been developed in response to the London
Damp and Mould Checklist and through the collaboration between
the Pan Thames Paediatric LTV Programme, Office for Health
Improvement and Disparities, the UK Health Security Agency and
London's Public Health System partners (the Mayor of London,
Association of Directors of Public Health (London) and NHS
England (London)).*

Network facing, patient engaging

- Damp and Mould Resources
- **Grants Search Tool**



ABOUT YOU

We need to ask you some basic questions as some grants are based on your location or age.

[Skip this page](#)

How old are you?

→ [Why do we need to know this?](#)

What is your postcode?

☐ I don't have a fixed address

☐ I don't live in the UK

☐ I don't want to say

→ [Why do we need to know this?](#)



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Next



Network facing, patient engaging

- Damp and Mould Resources
- Grants Search Tool
- **Benefits Calculator**

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ABOUT YOU

Everything you tell us is completely private and never shared with anyone, so please answer these questions correctly so that we can calculate the most accurate results for you.

Quick questions

What is your postcode?

☐ I am homeless and sleeping rough

→ [Why do we need to know this?](#)

Do you live with a partner?

Yes	No
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→ [What does this mean?](#)

What is your date of birth?

dd/mm/yyyy

→ [Why do we need to know this?](#)




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Network facing, patient engaging

- Damp and Mould Resources
- Grants Search Tool
- Benefits Calculator
- **Find a local advice service tool**



Your local guide to help with benefits, work, money, housing problems and more

A rightsnet service

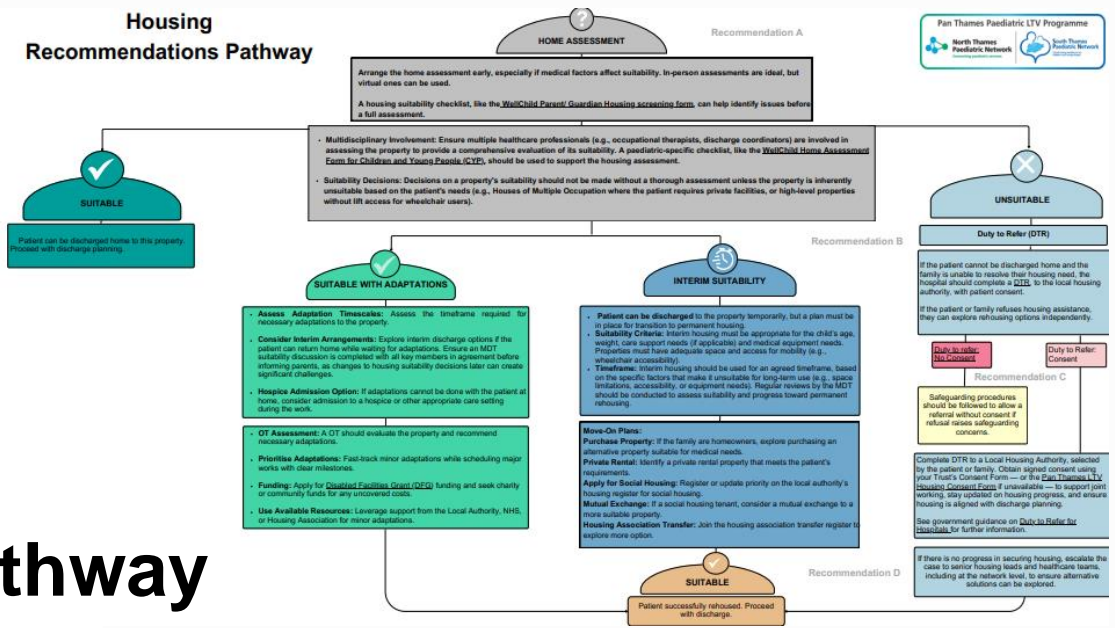
Network facing, patient engaging

- Damp and Mould Resources
- Grants Search Tool
- Benefits Calculator
- Find a local advice service tool
- **Charity eBook**



Network facing, patient engaging

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- Find a local advice service tool
- Charity eBook
- Housing Recommendations Pathway





Recent analysis and challenges

- Almost 50% of patients had unsuitable homes
- Of those without suitable homes who breached 90 days FFD, 50% of them repeatedly refused suitable offers of accommodation
- Not all homes were assessed for suitability

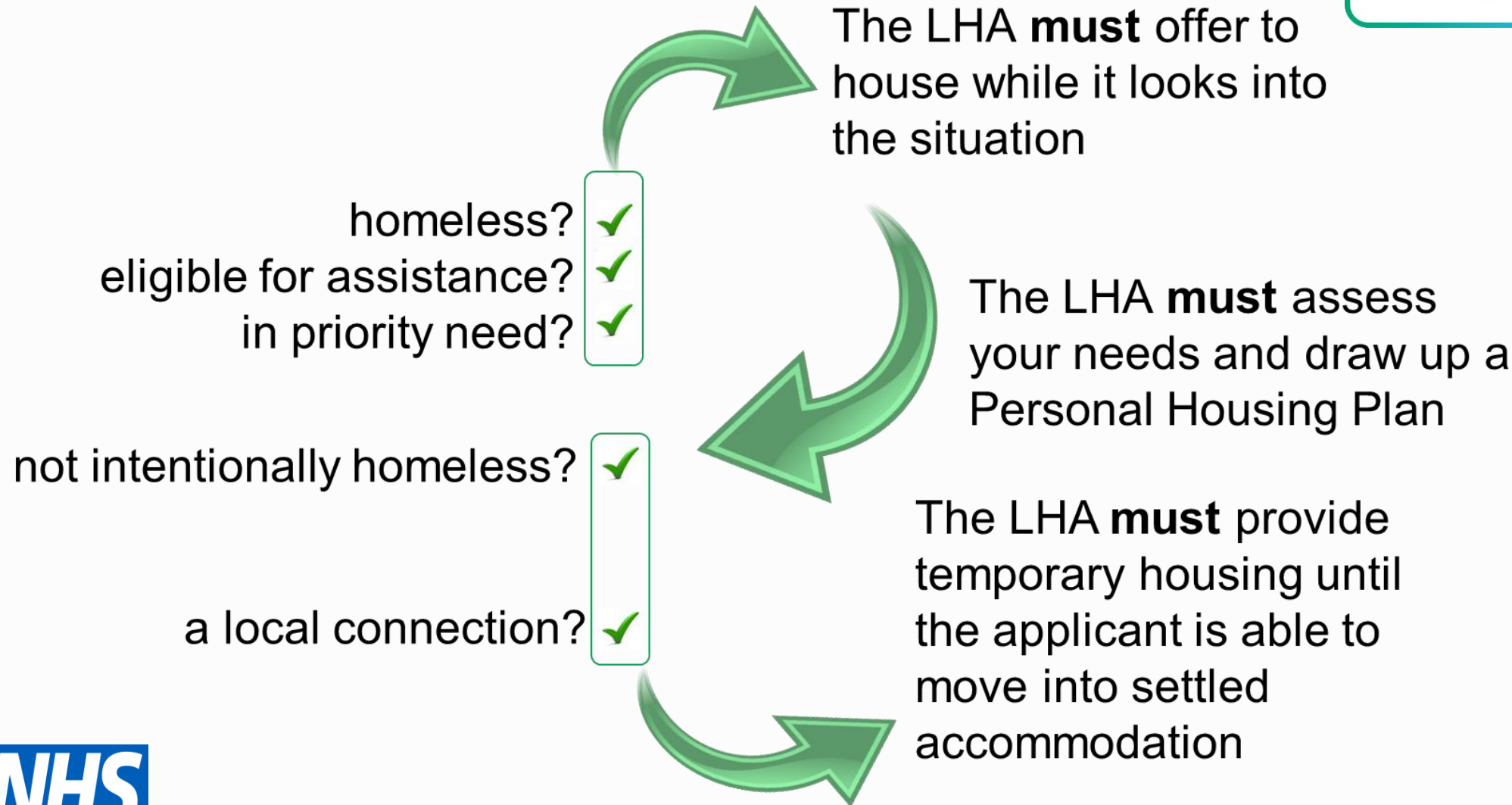




Housing proposal

- Make 'Duty to Refer' the default process for handling Pt's with unsuitable accommodation
- Ensure home assessments are carried out early, with clear intentions explained to families.
- Create a pathway for housing with agreed escalation
- Ensure hospital representation when LA's are reviewing their housing allocations policies





Our proposals

Make 'Duty to Refer' the default process for handling Pt's with unsuitable accommodation

The 'Duty to Refer' processes hospital inpatients with unsuitable accommodation as homeless – there is no right of refusal for suitable offers of accommodation made to relieve the family of homelessness



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Our proposals

Ensure home assessments are carried out early, with clear intentions explained to families.

- Early intervention
- Multidisciplinary agreement on suitability
- Expectation setting around home suitability



Our proposals

Create pathways with agreed escalation

- Resolution pathways for when Duty to Refer pathway is not resulting in timely rehousing, including clear escalation points within LHA
- Collaboration with Social Care to determine thresholds for escalation – e.g., completing a Duty to Refer without consent or when suitable offers of accommodation are being declined
- Involvement of Housing Professionals in discharge planning meetings





Our proposals

Input in changes to social housing allocations policies

- Feedback to LHA's on best practice policies
- Hospital staff should be involved in providing feedback when LHA's are running consultations on changing their housing policies:
- Hospital discharge specific priority
- Choice limitation for hospital discharge patients
- Enforce limit on no., of direct offer refusals





Plans for the future

- Bring the housing pathway proposal to health, housing and social care stakeholders to review
- Production of e-learning modules and a video for health care professionals
- Video for parents/primary care-givers
- Review of Housing Options booklet, designed to complement housing pathway





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