Summary – Supporting ILD pathway transformation in the North West

28 April 2025

This event was co-developed by Boehringer Ingelheim and the NHS Confederation ICS Network, with Boehringer Ingelheim co-organising the event, including the development of the agenda and identifying attendees. Boehringer Ingelheim was responsible for funding the event. This summary was prepared by NHS Confederation, with input from Boehringer.

Overview

From April 2024, the budgets for the commissioning of 59 specialised services were delegated to Integrated Care Boards (ICBs) in the East of England, the Midlands and the North West. The delegation of these services has been rolled out to remaining ICBs in April 2025. Delegated specialised commissioning offers an opportunity for ICBs to redesign services end to end. The NHS Confederation and Boehringer Ingelheim published a report on the vision for delegated specialised commissioning, the opportunity to improve access to and integrate care, in February 2025.

One of the services delegated in 2025 is interstitial lung disease (ILD). This virtual workshop, hosted and delivered jointly by the NHS Confederation's ICS Network and Boehringer Ingelheim, explored the opportunity for reimagining specialised services through the lens of the ILD care pathway.

Chaired by Fiona Edwards, attendees heard from two clinicians on the development of their ILD pathways, followed by a discussion. This briefing provides a summary of the session, including the key slides shared by the speakers.

Case studies

Case study 1 ILD service – Wrightington, Wigan and Leigh
Presented by Dr Abdul Ashish, Consultant Respiratory Physician and Deputy Medical Director, Wrightington, Wigan and Leigh NHS Foundation Trust • The ILD dedicated service was started in 2011 and initially involved a weekly clinic with specialist nurses. • The service then developed to include a joint clinic with the rheumatology team, a patient support group, a joint ILD palliative clinic and a carers group. • Referrals come in from advice and guidance, incidental findings from hospital, A&E, direct GP referrals and lung cancer screeneing. They are triaged by the consultant and Advanced Nurse Practioners into different pathways according to their need and complexity. • The service manages about 300 patients. A range of clinics helps manage patients across a fairly small team.

- Working with the community palliative team has helped reduced the amount of patients with ILD dying in hospital and the establishment of a community ILD team helps patients at the end of life manage their conditions closer to home where possible.

- The services have reduced waiting times for appointments from 8-10 months to a few weeks by collaborating across primary and secondary care and delivering virtual MDTs.

- The service is aspiring to be a tier 2 prescribing centre in order to reduce waiting times for patients at the end of their life, improve their prioritisation and research and secure an ILD nurse consultant.

Case study 2 The Morecambe Bay Respiratory Network

Presented by Dr Timothy Gatheral PhD FRCP, Consultant Respiratory Physician, University Hospitals of Morecambe Bay NHS Foundation Trust and Senior Clinical Lecturer, Lancaster Medical School, Lancaster University

- Coming into post in 2014, Dr Gatheral built an ILD service in Morecambe, where previously patients had to rely on services in Manchester. This includes a networked element with remote MDTs and a joint rheumatology clinic.

- In 2016, they established a respiratory network that includes not only ILD but also asthma, COPD and bronchiectasis. The aim of this primary care integrated respiratory service is to improve care for respiratory patients, including by shifting more care closer to home.

- Developing this network has changed the mindset and ways of working in the area. This is particularly important as it can be challenging to recruit to this remote, coastal area,and a range of professionals are necessary to run these services.

- The network joins up primary, community and secondary care and harnesses the expertise of teams across the area. A more joined-up approach is particularly important for ILD patients who require input at the early diagnostic stage and need quality information as they wait for appointments towards the end of life.

- Funding was diverted from the ICB to primary care so they could offer an enhanced respiratory diagnostic and management services. Primary care were granted direct access to CT scanning and blood tests and supported by secondary care.

- The network also delivers a monthly integrated respiratory MDT meeting to discuss more complex cases.

- Evaluation shows a decrease in hospital admissions for core respiratory admissions in the GP practices involved in the networks and a reduction in referrals to secondary care.

- The speaker reflected that were delivering integrated care is complex and bringing partners along is key.

Discussion

- **Service specification for lung disease.** Attendees discussed what changes to the service specification for lung disease might better support their work. They raised:
    - increasing access to prescribing for smaller centres
    - improving awareness among GPs to support early diagnosis,
    - palliative and psychological support as standardised best practice
    - expanding capacity through ILD nurse capacity.

- **Sustainability of leadership.** Attendees highlighted the challenge of sustaining change and innovation in service delivery over the long term. Transformation of services often relies on passionate and dedicated clinicians, but without long-term funding and the right infrastructure, it risks not being sustainable as it relies on a small group of individuals.

- **Building collaboration with general practice.** One of the speakers described how they had built relationships between secondary and primary care. This was developed by identifying a common problem and understanding the needs of individual GP practices. Breaking down hierarchial structures and developing new ways of working across different professions also unlocked better collaboration.

- **OneVoice LD pathway.** Attendees discussed the benefits of including the principles of the OneVoice ILD pathway within the new service specifications, allowing for localised approaches to a more integrated or tiered approach. Some attendees felt that a balance should be struck between minimising the risk of potential variation and allowing systems to deliver services adapted to their local populations.

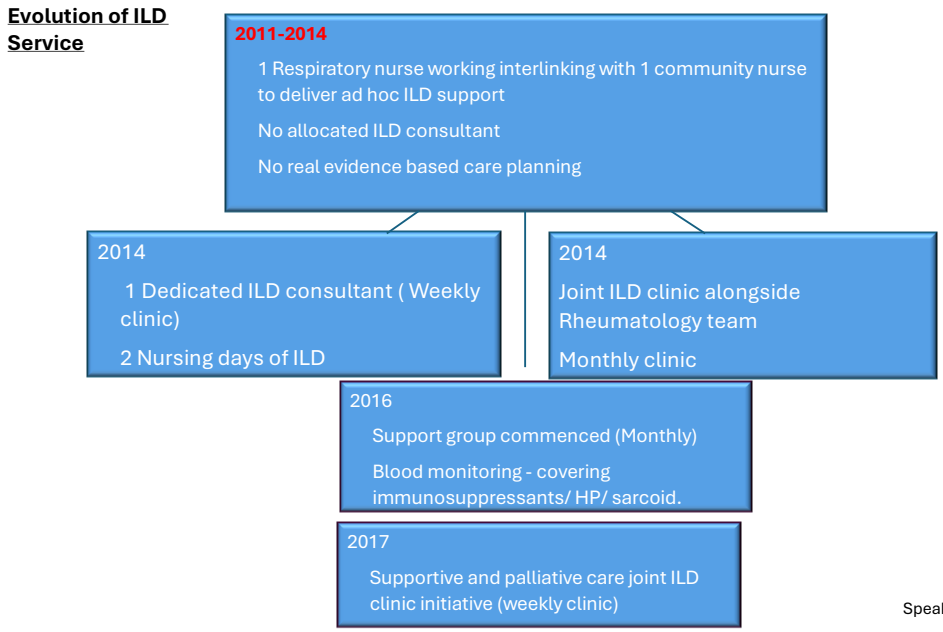
    - The pathway can also support commissioners who may lack expertise in ILD.

- **Integration and left-shift.** Managing demand and reducing waiting times for patients with ILD will only be possible through tertiary, secondary and primary care providers working together. ICBs have a key role to play in shifting small amounts of resources to allow this to happen.

For more information, please contact skeena.williamson@nhsconfed.org

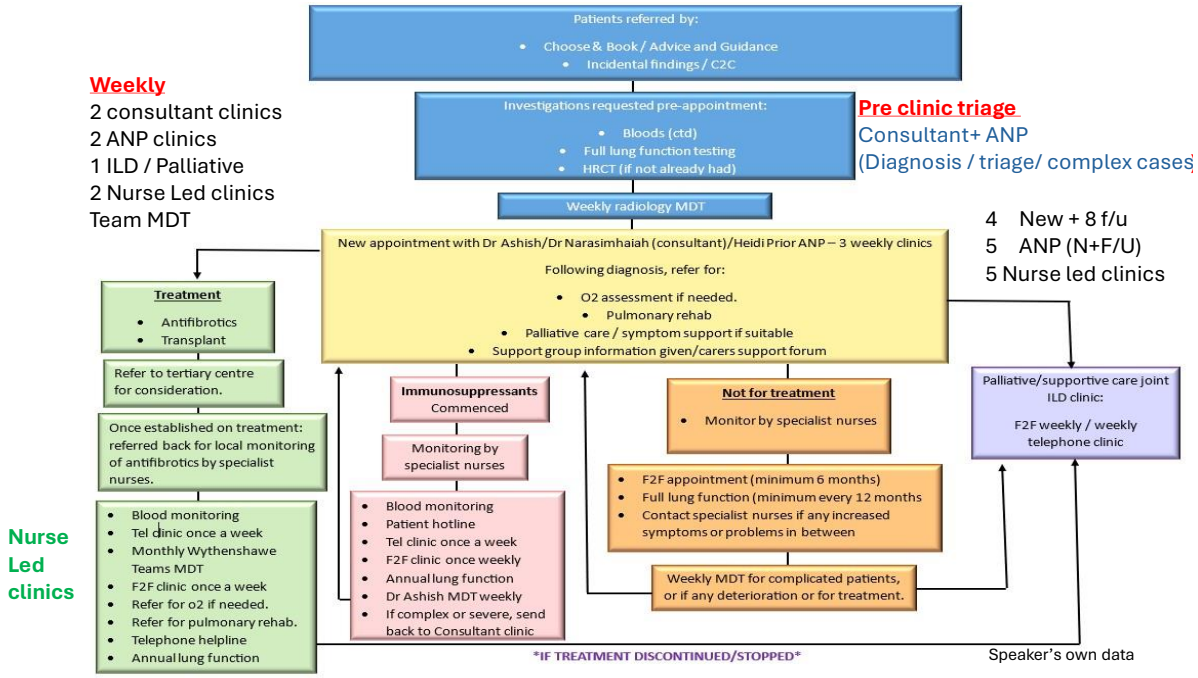
Appendix 1 – Presentation slides ILD service – Wrightington, Wigan and Leigh (produced by Dr Abdul Ashish)

Slide 1



Speaker's own data

Slide 2



Speaker's own data

Slide 3

Current service @ WWL (300 pts)

ILD NURSE:

Total patients under service to date 150 (ILD)

Patients on Antifibrotics – 44

Transfer back to WWL— Blood monitoring + monthly MDT with MFT

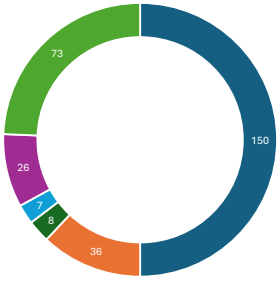
Patients on immunosuppressants – 26 (shared care arrangements existent with GP's)

Psychological + symptom support –68

In patient assessment from the ILD nurses and Palliative care team

In-reach services (Mon-fri)

ANP+ ILD nursing team



Joint ILD and Rheumatology clinic 100 (ILD +CTD, approx)

Monthly clinic

8 patients

Whole spectrum of CTD / ILD

Attended by trainees /Sp nurses

All immunosuppression including MAB/ Ritux/ Cylco

Monitored / managed by rheumatology team

Speaker's own data

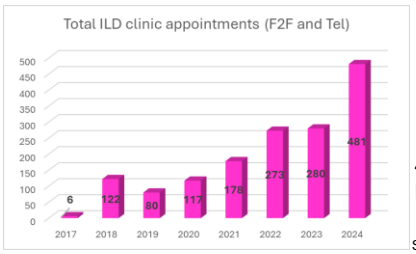
Slide 4

The supportive and palliative care + Joint ILD clinic

- **Since 2017.**
- Year on year increase in case load.
- 68 active patients on case load who have access to a 7-day telephone support line (9-5)
- All patients struggling with symptoms referred
- Seen within 4 weeks
- S/B palliative nurses

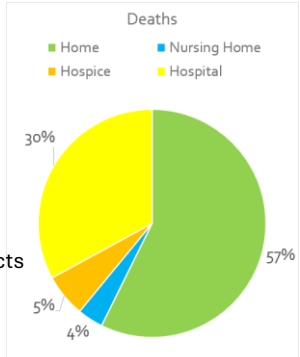
Step down to community palliative team:

- WHISPAR referral form sent to the hospice.
- Daily MDT (WHISPAR meeting) to discuss referrals made.
- These are then allocated to relevant team (community palliative care nurses or palliative district nurses) .



480 pt contacts In 2024

Speaker's own data



Early advanced care planning and discussions

Preferred place of death this has shown that

66% of our patient die out of hospital.

88% in hospital deaths in 2016

Slide 5

Community support interlink (MDT working)

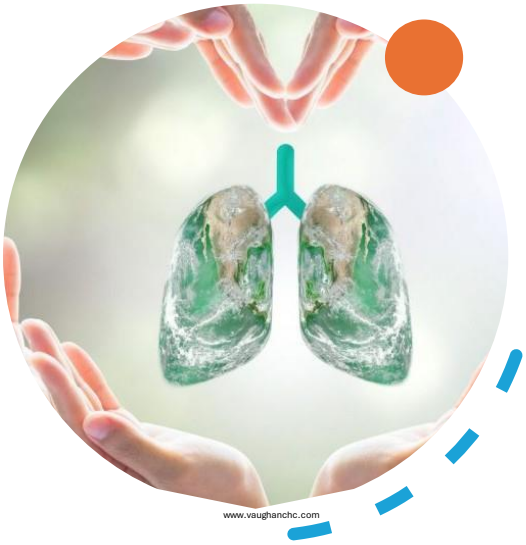
Community respiratory team including Matron/Respiratory nurses

Access to community occupational therapy team who will attend and support patients within their own home

April 2024 - Community MDT (supported by acute clinicians) – bi-monthly ANP led (50 patients discussed to date)

Nov 2024 - Carers Forum– ANP led (developing service) (supported by the supportive palliative care team) x 3

April 2025 – Discussions being held with community dietitian to support specifically ILD patients



Speaker's own data

Slide 6

Collaborative working with all partners to develop and streamline patient service (OP+ Acute setting)

Virtual MDT with MFT , Feb 2025 weekly. (SOP/ joint proforma)

Patients once approved by MDT can have direct prescription for Antifibrotics

Reducing waiting time from up to 6 months to few weeks.

Research opportunities

Baseline audits to improve care– working alongside CCOT

Alert system for admission

Earlier review of ILD patients

Support medical teams with early recognition of deterioration of this complex group of patients

Education

Speaker's own data

Slide 7

Future

- Aspiring tier 2 , prescribing centre
- Working with CRG lead to commence this ASAP
- Waiting well / prioritisation for ILD cases – Remote monitoring
- More research active / early case finding
- ILD nurse consultant

Appendix 2 – Presentation slides Morecambe Bay Respiratory Network (produced by Dr Timothy Gatheral)

Slide 1

The Morecambe Bay Respiratory Network

The MBRN is a comprehensive, end-to-end, integrated care model for patients with suspected or confirmed Chronic Respiratory Disease in Morecambe Bay

The MBRN is a healthcare ecosystem which has been built up since 2016 bringing together a multidisciplinary team across primary, community, secondary and voluntary care sectors

The MBRN is obsessed with moving more care into the community, focusing on earlier intervention and support to keep citizens living well

The MBRN has fostered innovative care across primary, secondary and community care which extends far beyond its original KPIs to improve the respiratory health in our population

The MBRN has been able to support wider population health measures by providing a cohesive approach for partner organisations to liaise and work with

MORECAMBE BAY RESPIRATORY NETWORK

MBRN Objectives

1. Deliver Respiratory care in Morecambe Bay with a community-based MDT model.
2. We will contribute to population health measures by increasing access to respiratory healthcare services for patients who struggle to use traditional services. Working with system partners we will support efforts to reduce harmful effects of smoking and air pollution.
3. Improve the quality and timeliness of diagnosis in Asthma, COPD, Bronchiectasis and ILD
4. Improve the quality and impact of routine management in Asthma, COPD, Bronchiectasis and ILD.
5. Improved access to respiratory therapies such as Pulmonary Rehabilitation, Respiratory Physiotherapy, Occupational Therapy and behaviour change techniques.
6. Reduce our Non-Elective admissions for patients with chronic respiratory disease
7. Improve access to specialist support at the end of life for patients with respiratory illness or symptoms

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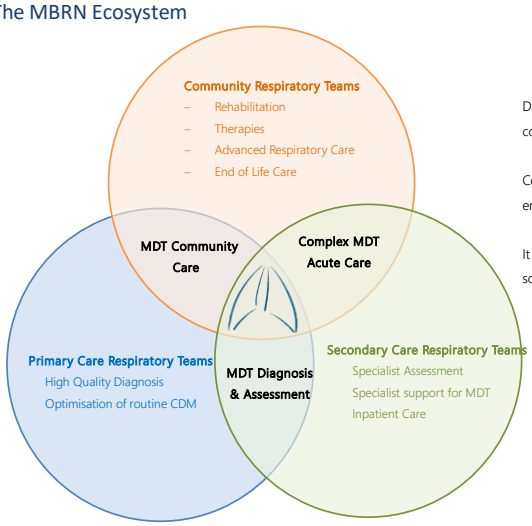
Slide 2

The MBRN Ecosystem



MORECAMBE BAY RESPIRATORY NETWORK

Developing the model has been about developing our teams and colleagues across primary, community and secondary care into an ecosystem with a shared vision that make their work easier.

Core to this are our MDTs across Morecambe Bay and establishing a common set of objectives, enabled by the funding we have obtained and the metrics we have developed

It has been important to us that the colleagues enjoy the work and feel part of a supportive network, some of their comments on the MBRN are here:

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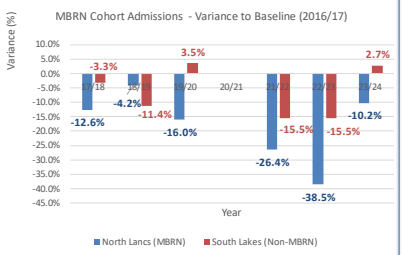
Slide 3

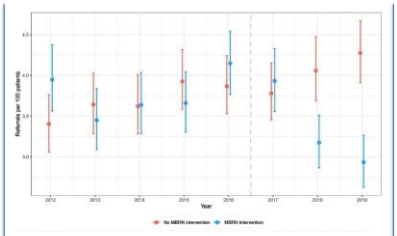
MBRN - Successes

MORECAMBE BAY RESPIRATORY NETWORK

System Benefits - Admissions

- Patients registered with MBRN practices showed a reduction in admissions for COPD, Bronchiectasis, ILD and Asthma





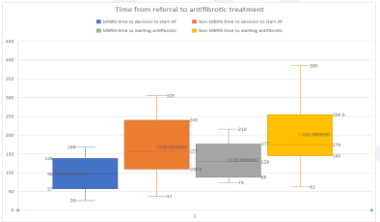
Reproduced with permission from Mountain, R., Knight, J., Heys, K. et al. Spatio-temporal modelling of referrals to outpatient respiratory clinics in the integrated care system of the Morecambe Bay area, England. BMC Health Serv Res 24, 229 (2024).

System Benefits - Referrals

- MBRN Practices refer less to secondary care, providing the specialist review in-house with direct access to testing

System Benefits – Earlier access to specialist therapies

- Patients from MBRN Practices who would be eligible for specialist medications in ILD get diagnosed earlier and start therapy earlier



Plum C, Gatheral T et al. Poster presentation summer British Thoracic Society Meeting 2024

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Slide 4

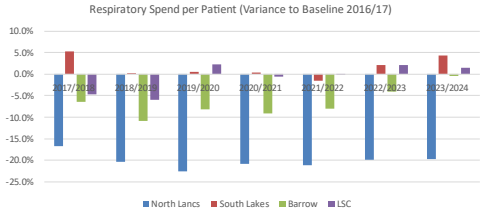
MBRN - Successes

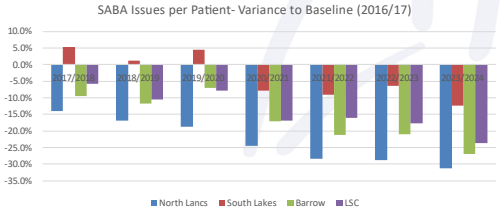
MBRN Education Programme – Our Integrated Education Programme is now well established. Bringing together teams from across Morecambe Bay and from Primary, Secondary and Community Teams we deliver an integrated education programme via a day-long conferences each year. We have always received overwhelming positive feedback for these days

Breathe Easy Groups – Supporting patient support groups is an important part of our pathway. Working with our Integrated Care Communities we have been able to support the development of breathe easy groups across Morecambe Bay

Medications

- MBRN Practices in North Lancs (longest funding) and Barrow (shorter funding) have shown reduction in SABA (reliever inhaler) use less if better controlled and has high CO2 emissions) compared to South Lake (no MBRN funding) and the wider ICB (LSC)
- MBRN practices also shown bigger reduction in overall respiratory medication spend





Slide 5

MBRN – Left Shift in Respiratory Care

Our experience of the past eight years has taught us much about integrating care and how we might fulfil the ask by Lord Darzi to 'left shift' care:

- You cannot left-shift care without partners working together with a joint vision and standards – **Integration is foundational**
- Moving care into the community needs education, support and development of new ways of working - **It takes time to implement**
- Our ambition is to **Left shift all aspects of care** from diagnosis to chronic disease management to complex and EoL respiratory support

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