



The NW Paediatric TB Network

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#Our family caring for yours

NW Paediatric TB network



What is it?

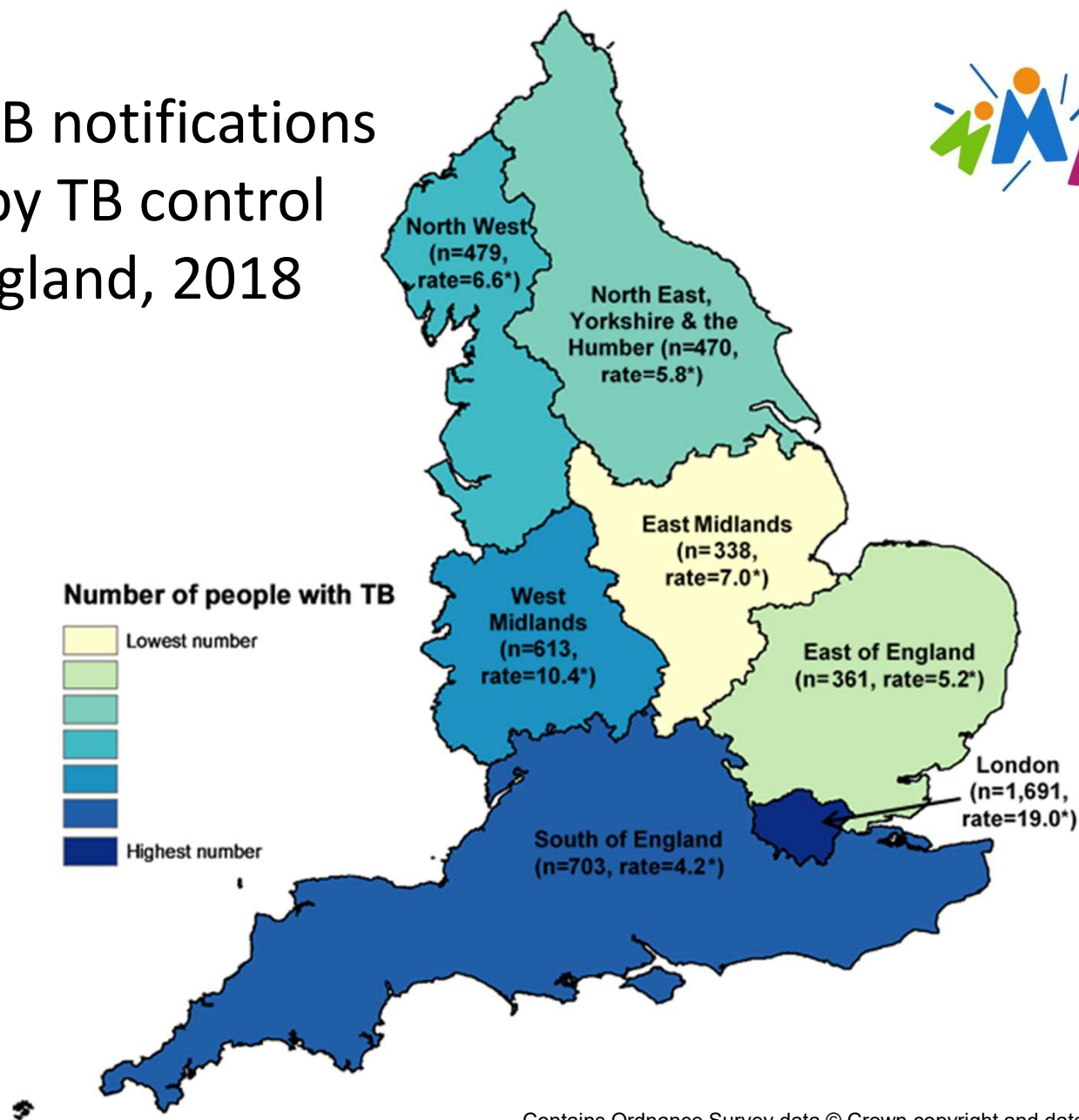
Why did we set it up?

How does it work?

What is its impact?

What have we learnt?

Number of TB notifications and rates by TB control board, England, 2018



* per 100,000 population

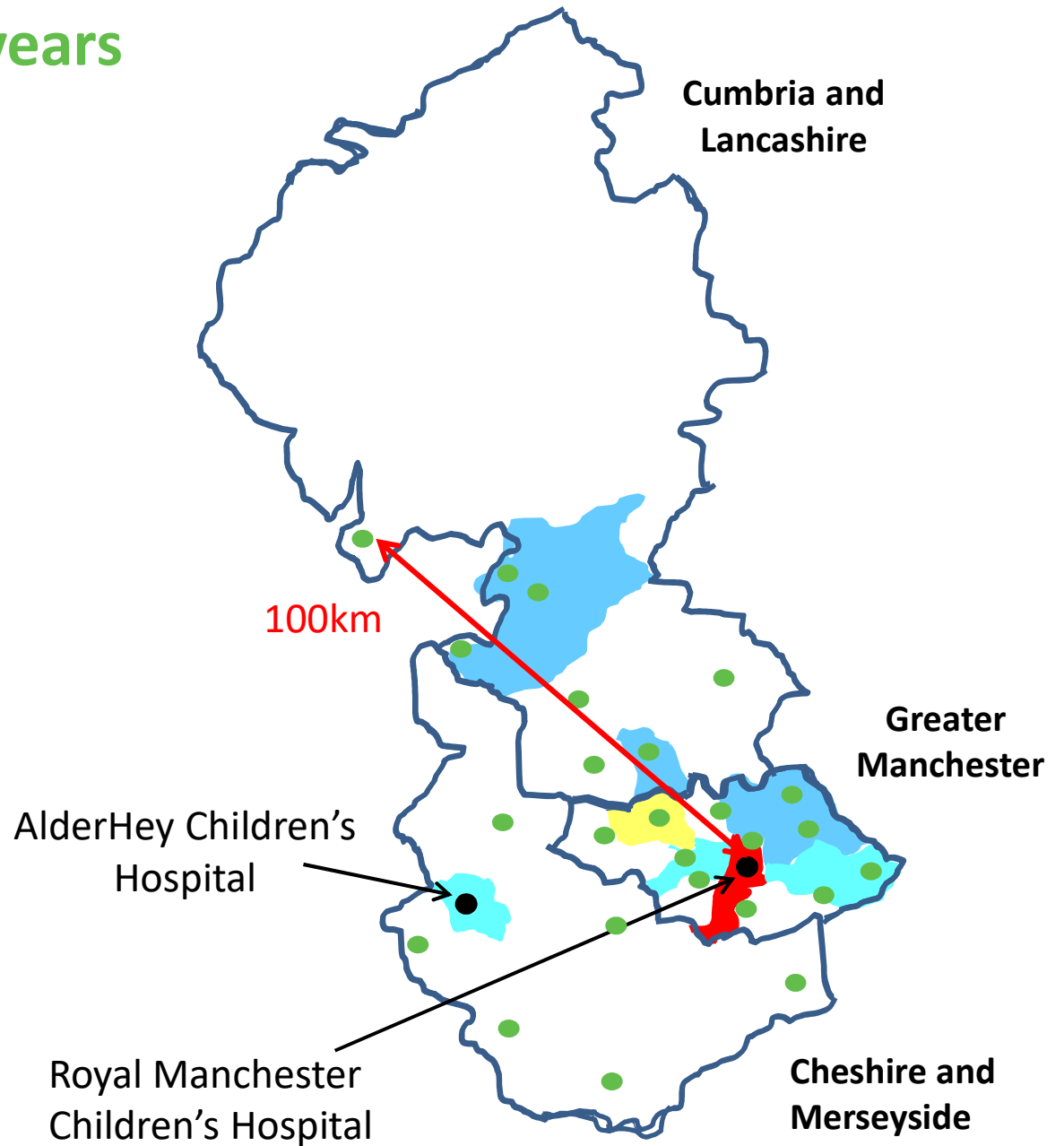
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Annual TB Notifications by CCG in Northwest 2009-14

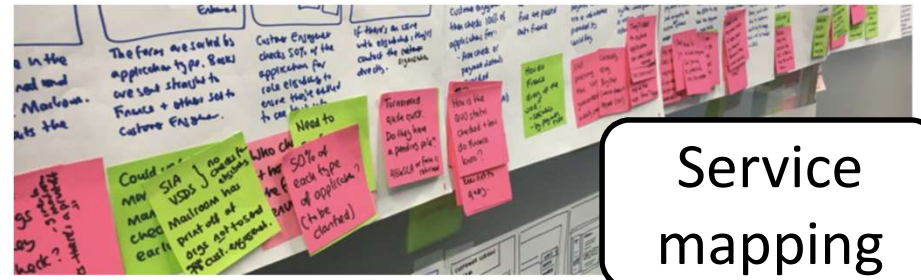
Children aged < 16 years

Total cases = 40-70/yr

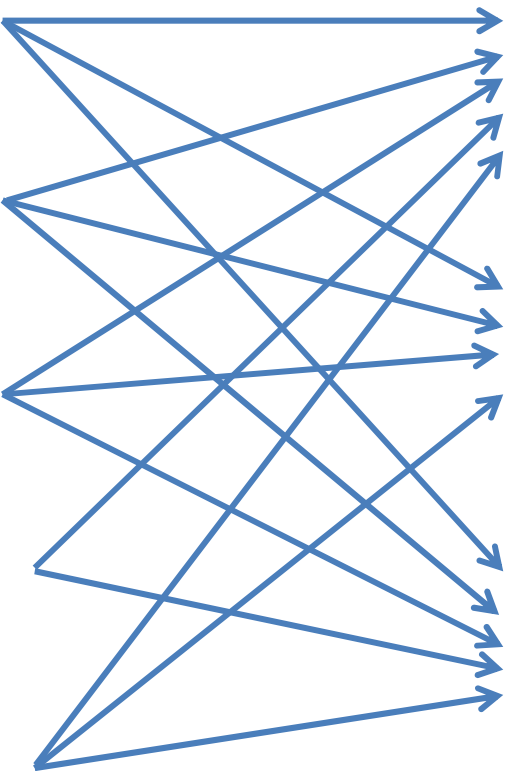
- 25 DGH
- 2 Tertiary Centres



AUDIT



- Variable patterns and standards of care
- Incomplete assessment and follow-up
- Delays in diagnosis and treatment
- 30% cases potentially preventable
- Patients travelling long distance
- Poor information governance



- Training & Experience
- Timely access to investigations
- Gaps in service
- Cohort Audit
Paediatricians don't go

Agreed Principles



Care in line with National guidelines

Consistently high standards

Rapidly and readily accessible / close to home

Multidisciplinary expertise

Access to specialist investigations and support

No service gaps / Surge capacity

Regular regional review of performance and outcome

Link to adult services important

DGH Type 1



- Lots of LTBI and TB cases
- Good clinician expertise
- Can manage LTBI and most pulmonary and lymph node TB without support
- Need support with
 - Difficult / high risk cases
 - Tertiary expertise
 - Investigations

DGH Type 2



- Very few cases
- Little clinician expertise
- Need support with
 - diagnosis, investigation and management
 - LTBI and TB disease
- Different models depending on distance from tertiary centre

Paediatric TB network

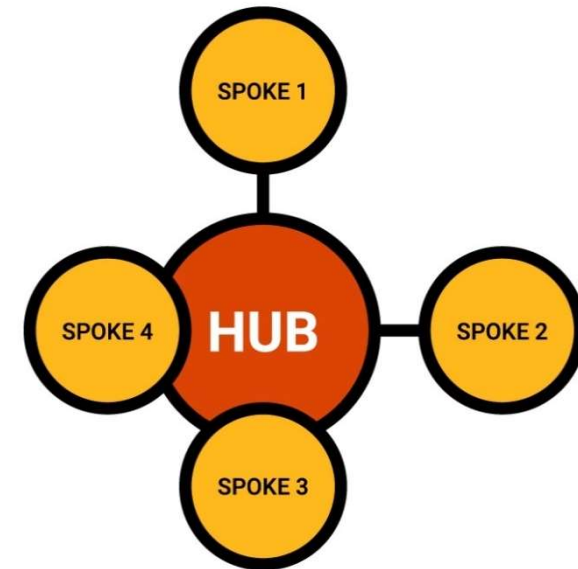


Focus

- Maintain local expertise
- Care close to home

Mechanism

- Tertiary clinical support
- Regional data collection and analysis
- Feedback and education



Practical implementation



Virtual TB clinic



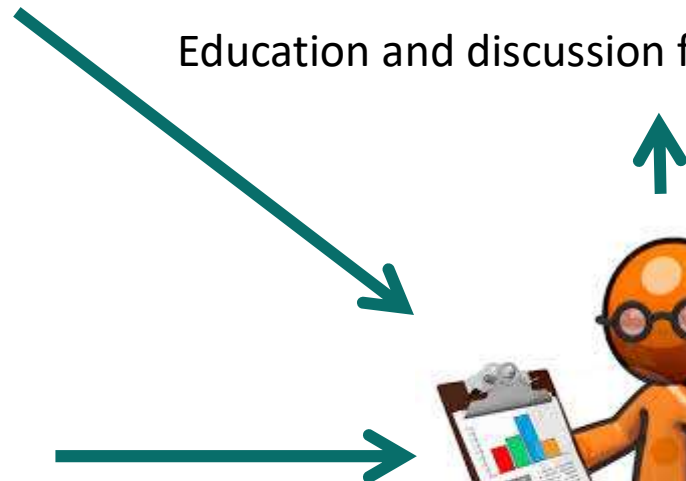
Education and discussion forum

Regional TB Audit Presentation Form (v20)		
1. Patient details		
Date form completed:	Case manager: #CaseManager#	
Clinic: #Clinic#	PHC Centre: #PHC#	
ETS no: #id#	Date of notification: #CaseReportDate#	Patient occupation: #Occupation#
Age: #Age#	Sex: #Sex#	Ethnic group: #EthnicGroup#
UK born: #UKborn#	Country of birth: #BirthCountry#	Entered UK [year]: #UKEntryYear#
Date of symptom onset: #SymptomOnset#	Date of first contact with health service while symptomatic, if known:	Referred to TB service by: Select response
Date 1 st seen by team initiating treatment:	Date 1 st seen by TB nurse:	Date treatment commenced: #StartOfTreatment#
2. Clinical details		
Site of disease: Click here to enter site of disease.	Pulmonary infection: #SitePulmonary#	Previous BCG: #BcgVaccinated#
Spontaneous sputum smear status: Select response	Other respiratory samples: Select type	Smear status (other than spontaneous sputum): Click here to enter smear status
CXR / chest CT at diagnosis: Select response	Culture at any site: Select response	Culture sensitivities: Select response
PCR resistance done: Select response	Histological diagnosis: <input type="checkbox"/>	Empirical/clinical diagnosis: <input type="checkbox"/>
HIV test offered: #HivTesting#	Outcome of HIV test: Select response	Year of test:
3. Risk factors requiring Enhanced Case Management		
Standardized Risk Assessment completed: <input type="checkbox"/>	Enhanced Case Management: Select response (see guidance notes)	
Problem alcohol use: #AlcoholUse#	Unstable housing: #Homeless#	Problem drug use: #DrugUse#
Previous TB diagnosis: #PreviouslyDiagnosed#	Imprisonment: #Prison#	Mental health: <input type="checkbox"/>
Clinically complex: <input type="checkbox"/>	MDR: <input type="checkbox"/>	Loaded onto BTS MDR website: <input type="checkbox"/>
Non-adherence: <input type="checkbox"/>	Gypsy / traveller: <input type="checkbox"/>	Hard to reach group: <input type="checkbox"/>
Language barrier: <input type="checkbox"/>	Child/adult protection issues: <input type="checkbox"/>	
Other: Click here to enter details.		
4. Treatment plan		
Self administered treatment: <input type="checkbox"/> (including treatment administered by parent/carer/family member)	Treatment as inpatient: <input type="checkbox"/>	
Weekly supervised: <input type="checkbox"/>	Tablet count: <input type="checkbox"/>	Urine test: <input type="checkbox"/>
DOT required: <input type="checkbox"/>	DOT from start of treatment: <input type="checkbox"/>	% doses observed: <input type="checkbox"/>
DOT offered: <input type="checkbox"/>	If not from the start, DOT started: <input type="checkbox"/>	% doses self-administered: <input type="checkbox"/>
DOT refused: <input type="checkbox"/>	No. of weeks on DOT: <input type="checkbox"/>	% doses missed: <input type="checkbox"/>
5. Treatment outcome at time of cohort		
Post-mortem diagnosis: #PostMortemDiagnosis#	Completed treatment: Select response	
If treatment not completed:		
if still on TB medications: no. of completed weeks treatment and total planned treatment period equals Select response (time from treatment start date)		
Died prior to completion of treatment: <input type="checkbox"/> Planned exit from UK (with full or partial meds): <input type="checkbox"/> Transferred to another TB service within UK: <input type="checkbox"/>		
Lost to follow up: <input type="checkbox"/> If lost to FU, actions taken, click here to enter details.		
Other: Click here to enter details.		

Enhanced cohort review



Analysis



Virtual TB clinic

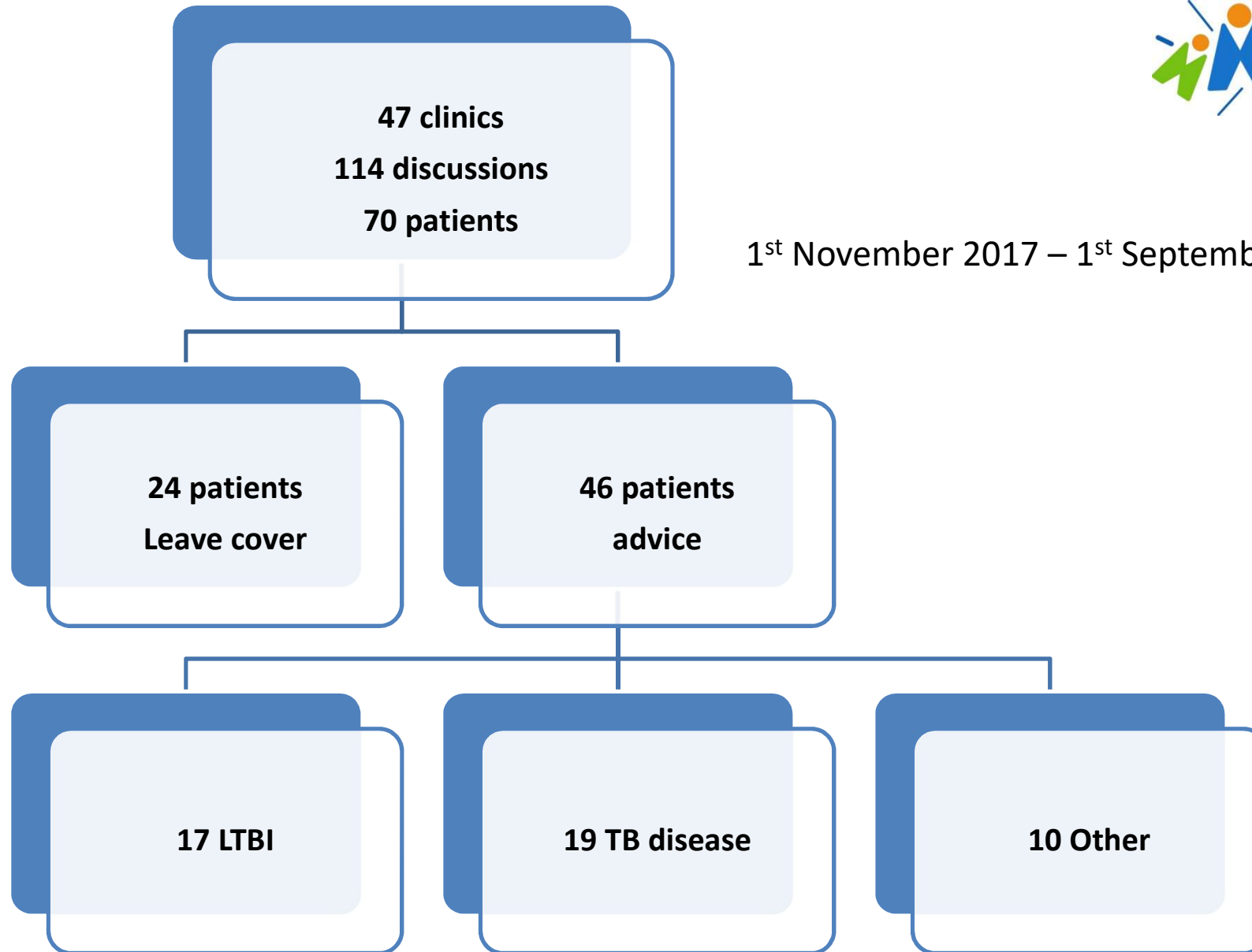


- Weekly teleconference (non urgent cases only)
- RMCH team
 - Paediatrician with TB experience
 - TB nurse
 - Paediatric radiologist
 - Administrator
- DGH teams
 - Paediatricians
 - TB nurses
- Paperwork





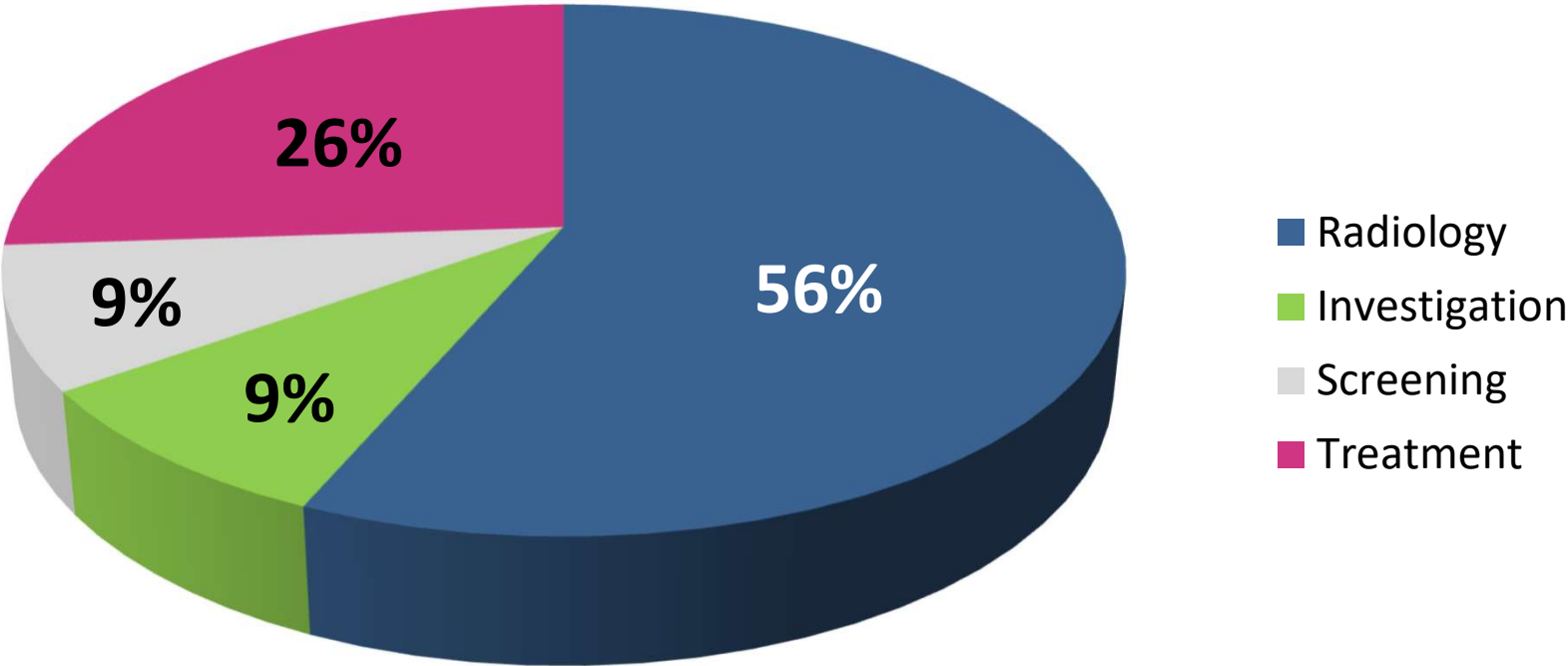
1st November 2017 – 1st September 2019



Primary reason advice sought



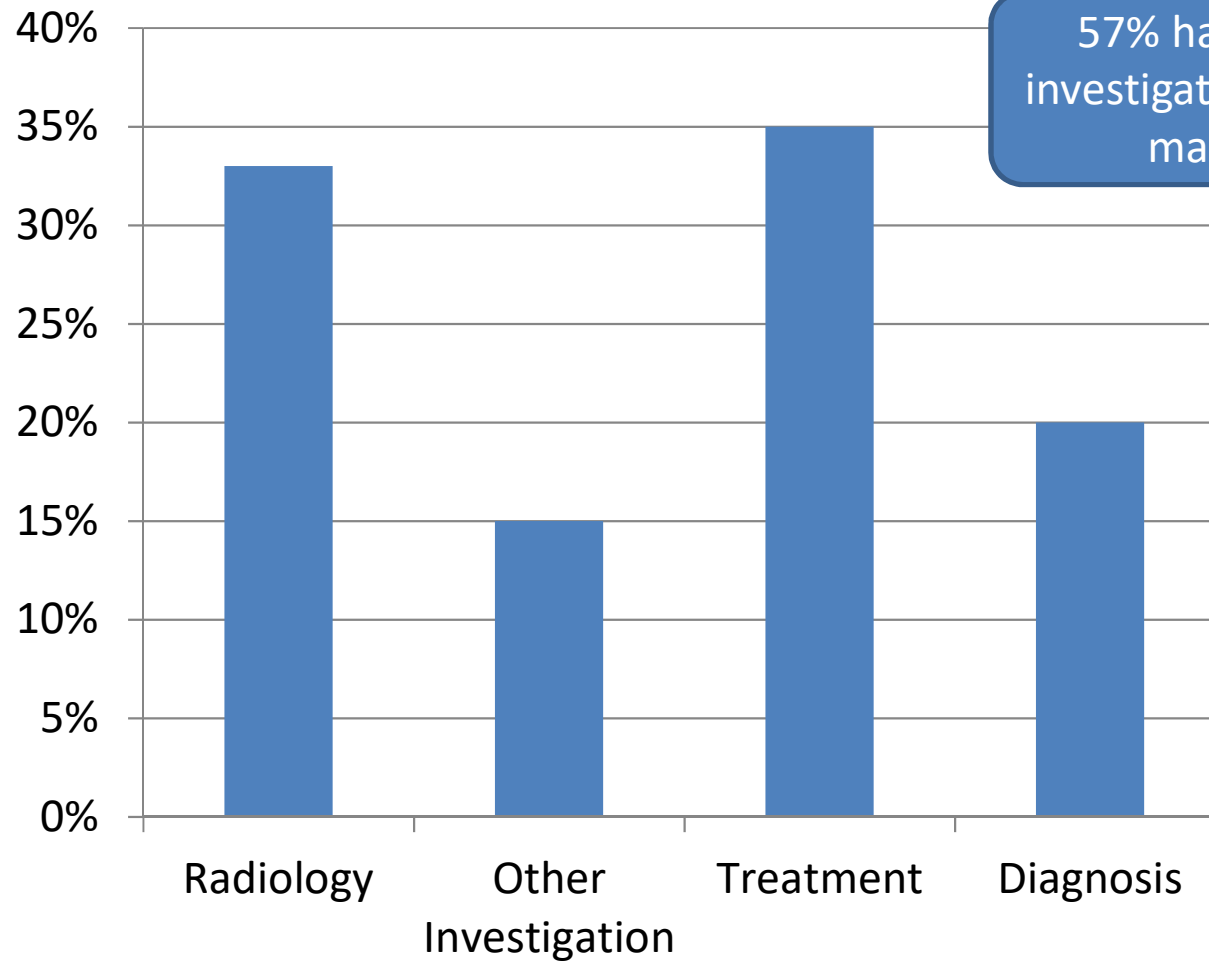
(n= 46)



Changes made



N=46



57% had a change in investigation, diagnosis or management

Changes to diagnosis



4 patients LTBI → TB disease

n=9 (20%)

1 patient TB disease → LTBI

4 patients suspected TB → Alternative diagnosis

Other outcomes



- 53% care closer to home
- Filled gaps in service – reduced diagnostic delay
- Earlier imaging / sample collection at tertiary centre
- Co-ordination of large cross site screening exercise
- Adult physicians seeing children without paediatric input
- Contacts < age 2 years not given chemoprophylaxis
- Fear of safeguarding referral / impact on relationship with wider family

Paediatric cohort review



- Enhanced data collection
 - Was this case preventable?
 - Clinical outcomes
- Annual paediatric cohort review
 - Good attendance from paediatricians
 - All paediatric cases in region in 12 month period
 - External chair
 - TB nurses present (can be daunting / repetitive)
 - Selected detailed case presentations
 - Data analysis and feedback

Feedback and Education



- Focus on general themes from virtual clinic and cohort audit
 - Safeguarding
 - Diagnostic delay
 - Radiology
 - Where do teens fit in?
 - Large screening exercises
- General education & national updates

Funding and Governance



- Current funding is from GM, block contract, sessional funding for virtual clinic and 1PA for running network. Reviewed annually
- Ongoing funding depends on our ability to evidence that all children are getting good care and where this is not the case we have systems to address this

Our experience



- Engagement is key
 - Good engagement from most
 - Some clinicians feel threatened / resist engagement
- Important to have clear lines of responsibility
- Tendency to accept the status quo
 - Delays in CXR reporting / slow access to CT
 - *Can't* get microbiology samples
 - *Too difficult* to give DOT
- Oversight of the bigger picture helps improve services

Network governance



- How do we provide commissioners with the data they require?
- How do we ensure data is collected?
- How do we raise concerns?
- Do we have a responsibility for holding individual services to account?

What if:

- Clinical agreement is not reached in virtual clinic?
- Virtual clinic plan agreed but not followed? Who is responsible? How do we / should we monitor that?
- Radiology reports from local and tertiary team differ significantly?
- Information governance breaches – insecure data transfer
- Agreed network standards are broken?
 - Where children with TB should be cared for

Network Governance



- Who is responsible for each patient?
 - Gaps – tertiary team until handback
 - Advice – DGH team
- Radiology discrepancy meetings
- Escalation of concerns
 - Local resolution
 - PHE teams
 - Cohort review mechanism

Conclusions



- A paediatric TB network can
 - Improve patient care closer to home
 - Support small local services / solo clinicians
 - Increase networking, expertise & shared focussed learning
 - Identify wider service delivery issues and support their resolution
- It requires support from all involved
 - Collaboration and shared planning / decision making
 - Agreed governance structures
 - Data collection and analysis services
 - Time

Virtual TB clinic – Thurs 8-9am

