University College London Hospitals
NHS Foundation Trust

British Association for Paediatric Tuberculosis: Strengthening networks to improve care

Jonathan Cohen

uclh

BAPT Inaugural Meeting
11 January 2018

IUATLD

PHE TB Delivery Board

National TB Office

British Paediatric Respiratory Society

National drug-resistant TB group

pTB.Net (European)

Paediatric TB meetings Eg. London, Solihull

CHIVA

National TB nurses group

WHO

TBCB England Regions Wales/Scotland/NI

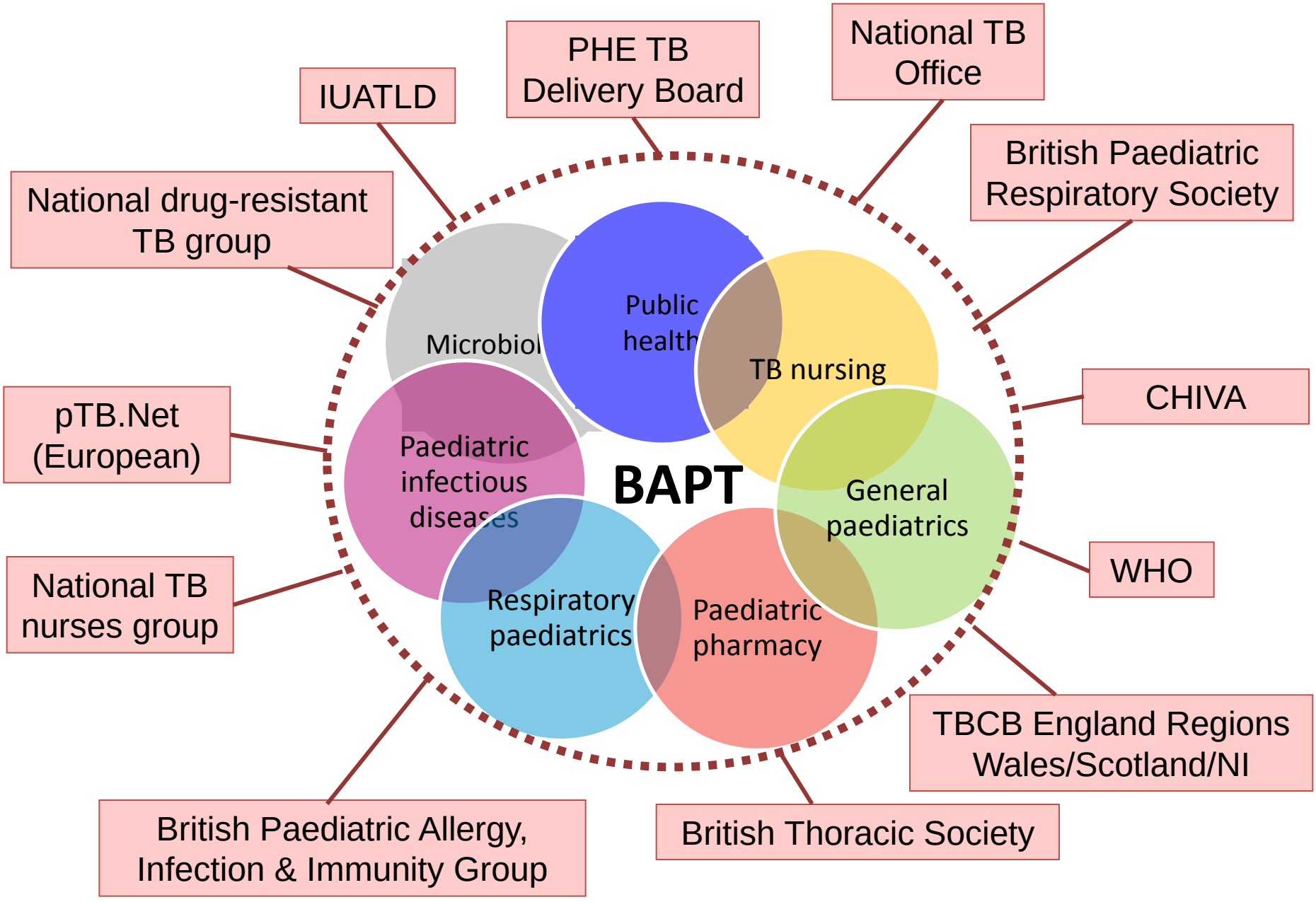
British Paediatric Allergy, Infection & Immunity Group

British Thoracic Society

British Association for Paediatric TB (BAPT)

- Multidisciplinary organisation to promote the health of children with latent tuberculosis (LTBI) and tuberculous disease (TB) in the UK.

- **Objectives**:
  - To advocate for excellence in the provision of clinical services
  - To advocate for equity of access
  - To promote evidence-based standards of care
  - To foster co-operation, friendship and mutual support between all those involved in the care of children with TB
  - To promote education and training in paediatric TB
  - To provide expert advice to clinicians and other bodies involved in the care of children with TB and LTBI
  - To promote and facilitate research into paediatric TB and its treatment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General paediatrics
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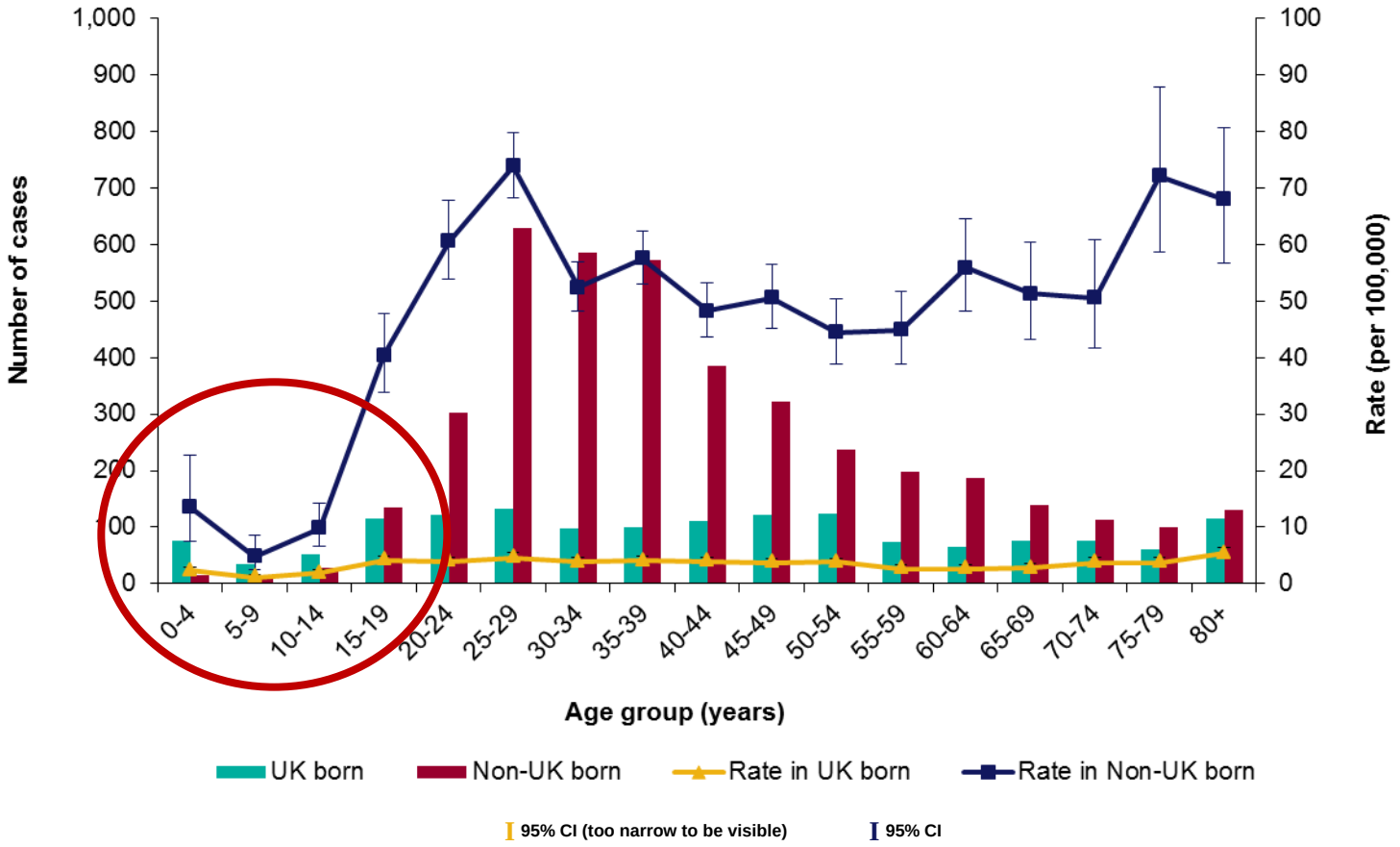
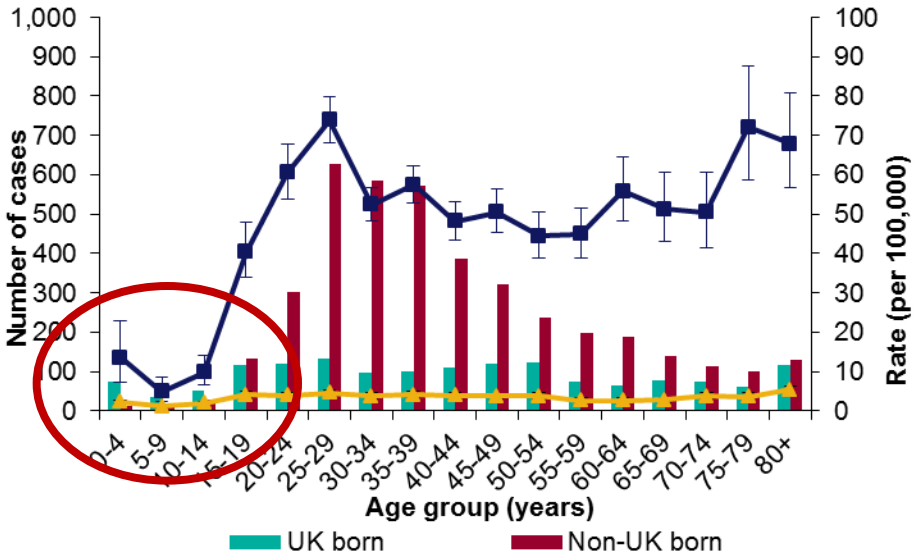
Advocacy

TB case notifications and rates by age group



Tuberculosis in England: 2016 report



Children with TB means:

- Active transmission in the community
- Highest risk of primary progressive disease
- Highest risk of disseminated TB / TBM

Guidance & Policy

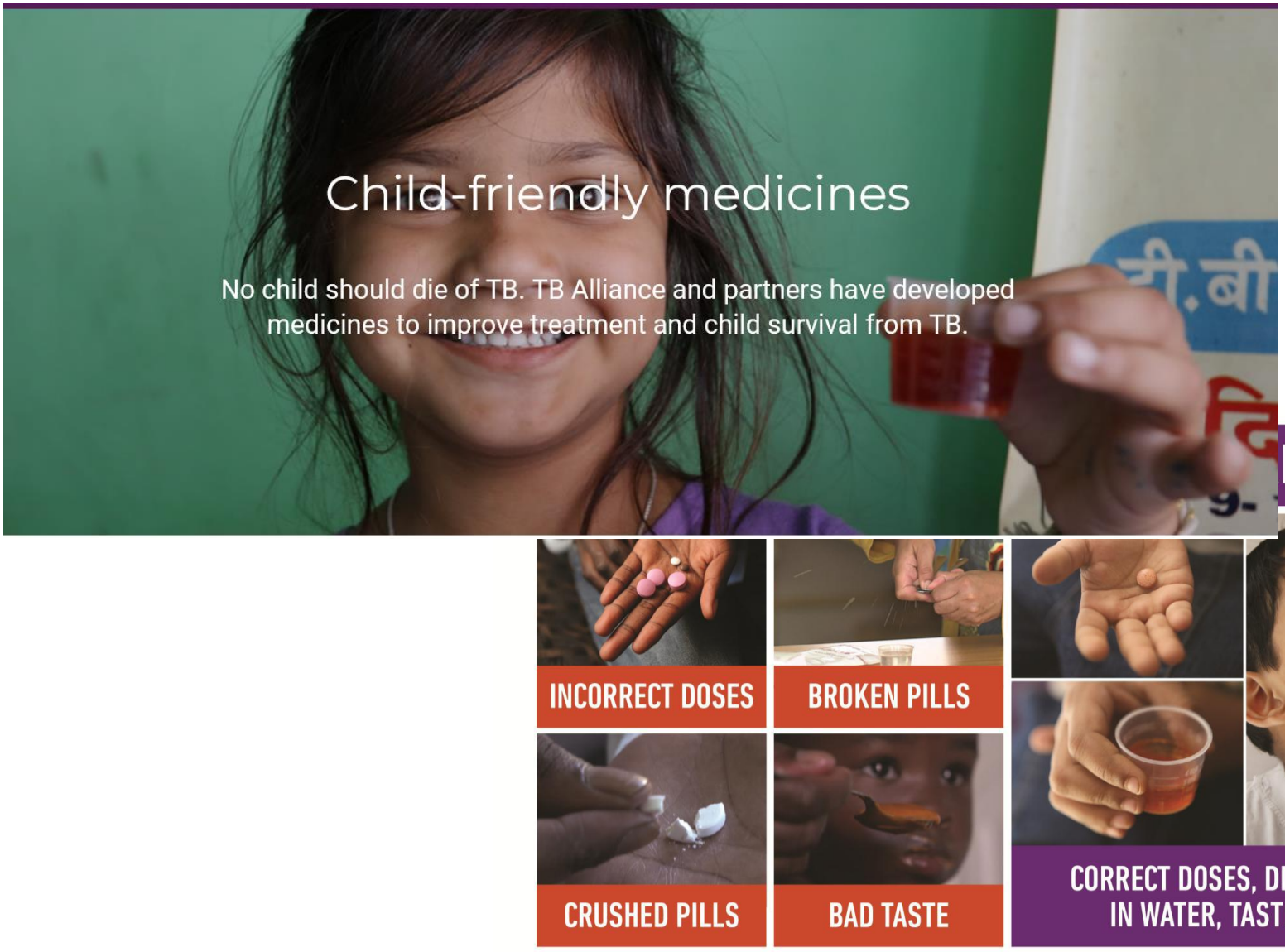
Dispersible Fixed Dose Combination Products for Children

Faye Chappell

Specialist Pharmacist Paediatric Infectious Disease

British Association for Paediatric Tuberculosis Inaugural Meeting

January 2018



Slide courtesy of Faye Chappell

Advantages

- More convenient for active pharmaceutical ingredients with insufficient stability in water
- Easily transportable, generate less handling and transportation costs for the same amount of active ingredient (less volume, less weight)
- Easier to produce, production costs are less, which makes them more affordable than standard liquid formulations
- Can be used in very young children (0 – 6 months)
- Easy to dispense
- Require minimal manipulation by health professionals and parents prior to use (reduced risk of errors)
- Require a small amount of water for administration
- Taste good!! (Confirmed)
- Can be dispersed in breast milk (ensure full dose taken)

Slide courtesy of Faye Chappell

Disadvantages

- Less physical resistance than regular tablets; more sensitive to moisture and may degrade at higher humidity conditions (blister packing)
- Tablets do not contain ethambutol
- Potential for under/over dose with FDC products – pyrazinamide in particular
- Potential for resistance with under dosing
- Lack of PK data – SHINE data not available until
- Product currently manufactured in India (Macleods Pharmaceuticals Ltd)
- Ethical concerns regarding diverting product away from developing countries should manufacturers struggle to meet the demand

Slide courtesy of Faye Chappell

MDR-TB Clinical Advice Service

British Thoracic Society

NIHR HPRU in Respiratory Infections

NHS National Institute for Health Research

Imperial College London

Public Health England

The BTS MDR Clinical Advice Service

Onn Min Kon

Imperial College Healthcare NHS Trust

Prophylaxis of MDR contacts?

Name of trial	Location	Population	Intervention and comparator	Months of treatment /follow-up	Clinical trials registry #
TB CHAMP	South Africa	Children <5 years	Levofloxacin vs. placebo	6 / 18	-
PHOENix	Various sites	All contacts (Adults and children)	Delamanid vs. isoniazid	6 / 22	-
V-QUIN	Vietnam	All contacts (Adults and children)	Levofloxacin vs. placebo	6 / 30	ACTRN12616000215426

Slide courtesy of Prof Onn Min Kon

Accessing new MDR drugs in children

Steve Welch

BAPT

11th January 2018

Building healthier lives

Heart of England NHS
NHS Foundation Trust

Cost for 24 weeks

- **Delamanid** **£17,570**
- **Bedaquiline** **£18,700**

Building healthier lives

Heart of England NHS
NHS Foundation Trust

Slide courtesy of Dr Steve Welch

Clinical Commissioning Policy: Bedaquiline and Delamanid for defined patients with MDR-TB and XDR-TB

Reference: NHS England F04/P/a

NHS England

July 2015

Building healthier lives

Heart of England NHS Foundation Trust

Slide courtesy of Dr Steve Welch

Clinical Commissioning Policy: Commissioning Medicines for Children in Specialised Services

First published: March 2017

NHS England

Reference: NHS England: 170001/P

Building healthier lives

Heart of England NHS
NHS Foundation Trust

Slide courtesy of Dr Steve Welch

Clinical Commissioning Policy: Commissioning Medicines for Children in Specialised Services

- This policy outlines that patients aged less than 18 years who meet the conditions set out in a NICE TA/HST or NHS England policy relating to adults will be able to receive the medicine without going through the IFR process, if they meet the criteria and conditions outlined within this document.

Criteria for commissioning

- 1 The medicine has a license for use in children and both the indication for use and the age of the child fall within those specified in the adult license
- **or**
- 2 The medicine is listed in the BNF for Children with a recommended dosage schedule relative to the age of the child
- **or**
- 3 The child is post pubescent.

Currently

- No paediatric licence
- No dosing in BNFc
- Only post-pubescent will qualify

Access

- Policy v IFR
- Doses into BNFc
- Children <6 Doses
  Formulations

Building healthier lives

Heart of England NHS
NHS Foundation Trust

Slide courtesy of Dr Steve Welch

IGRA vs TST – how to interpret screening tests?

Trade-off – sensitivity and specificity

Is it better to treat some children unnecessarily

OR

Fail to treat some children who may progress to disease

Slide courtesy of Dr Elizabeth Whittaker

Multi-centre audit of practice?

- Recording TST size in mm
- Comparing with IGRA results where available
- Information on contacts (EPTB, smear neg, smear pos etc)
- HIV, Hep B, C screening
- Number of children in clinic per year
- Cost-analysis ?
- Model cost of 10mm cut –off as comparison
- ? Missed patients – safety vs risk

Slide courtesy of Dr Elizabeth Whittaker

Supporting Clinical Research

Ptbnet is an international network of paediatricians promoting clinical orientated research in the field of childhood tuberculosis by sharing and developing ideas and research protocols.

The aims of the network are:

- to enhance the understanding of the pediatric aspects of active and latent tuberculosis
- to facilitate collaborative research studies for childhood TB in Europe
- to provide expert opinion through excellence in science and teaching
- to harmonise health care delivery/approaches within Europe
- to establish an evidence base for diagnosis and treatment of TB in children

UASC InfectNet:

Observational study of infection status of unaccompanied asylum seeking children and young people in the United Kingdom

27.10.2017

Protocol version 1.1

Training

Questions put to TB nurses at 2016 National TB Nurses Conference:

- Are you confident managing care for children with TB?
- Do you want further support?

TB NURSING

British Association for Paediatric Tuberculosis
Inaugural Meeting - 11th January 2018

Hanna Kaur - TB Lead Nurse Specialist
BIRMINGHAM & SOLIHULL TB SERVICE & RCN PUBLIC HEALTH FORUM
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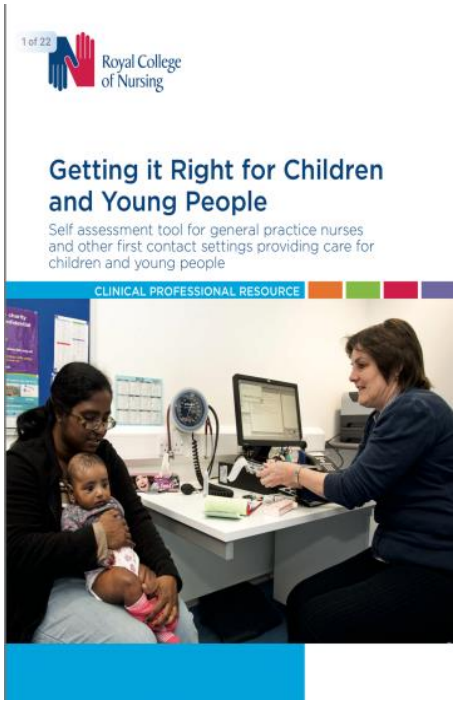
e-mail: hanna.kaur@heartofengland.nhs.uk / hanna.kaur@nhs.net

Getting in Right for Children and Young People / Tool

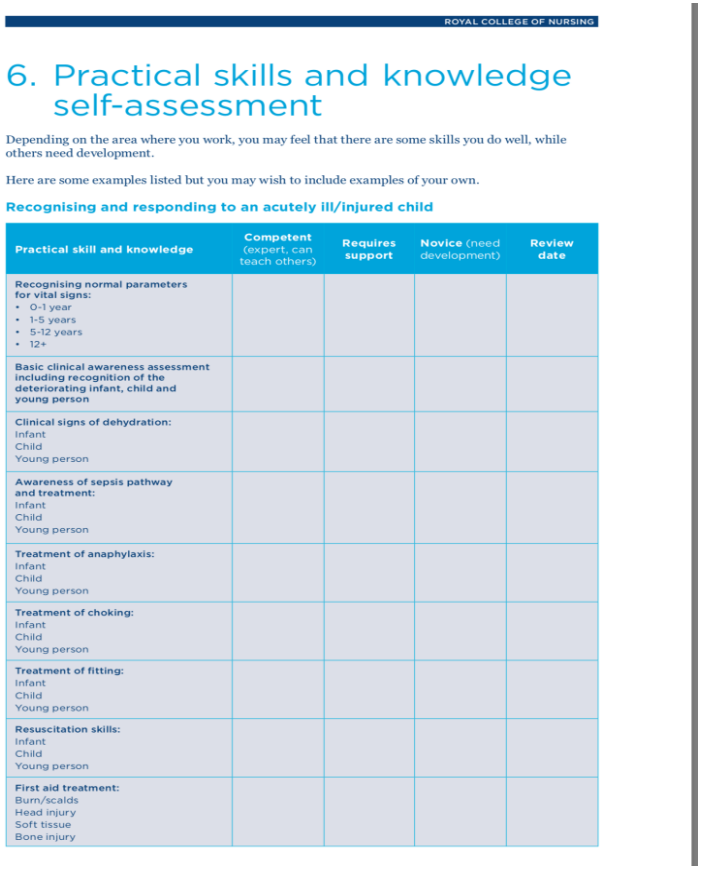
- Published December 2017 (revision)
- Self assessment tool for general practice nurses and '**other contact,**' setting
- This Toolkit will support registered nurses working out of hospital settings in providing care to children and young people



Slide courtesy of Hanna Kaur

Specific Skill to area e.g. TB Nursing

- Normal parameters (assessment / vital signs):
  - 0-1 year
  - 1-5 years
  - 5-12 years
  - 12 +
- Weighing
- Anaphylaxis
- BLS
- Safeguarding



ROYAL COLLEGE OF NURSING

6. Practical skills and knowledge self-assessment

Depending on the area where you work, you may feel that there are some skills you do well, while others need development.

Here are some examples listed but you may wish to include examples of your own.

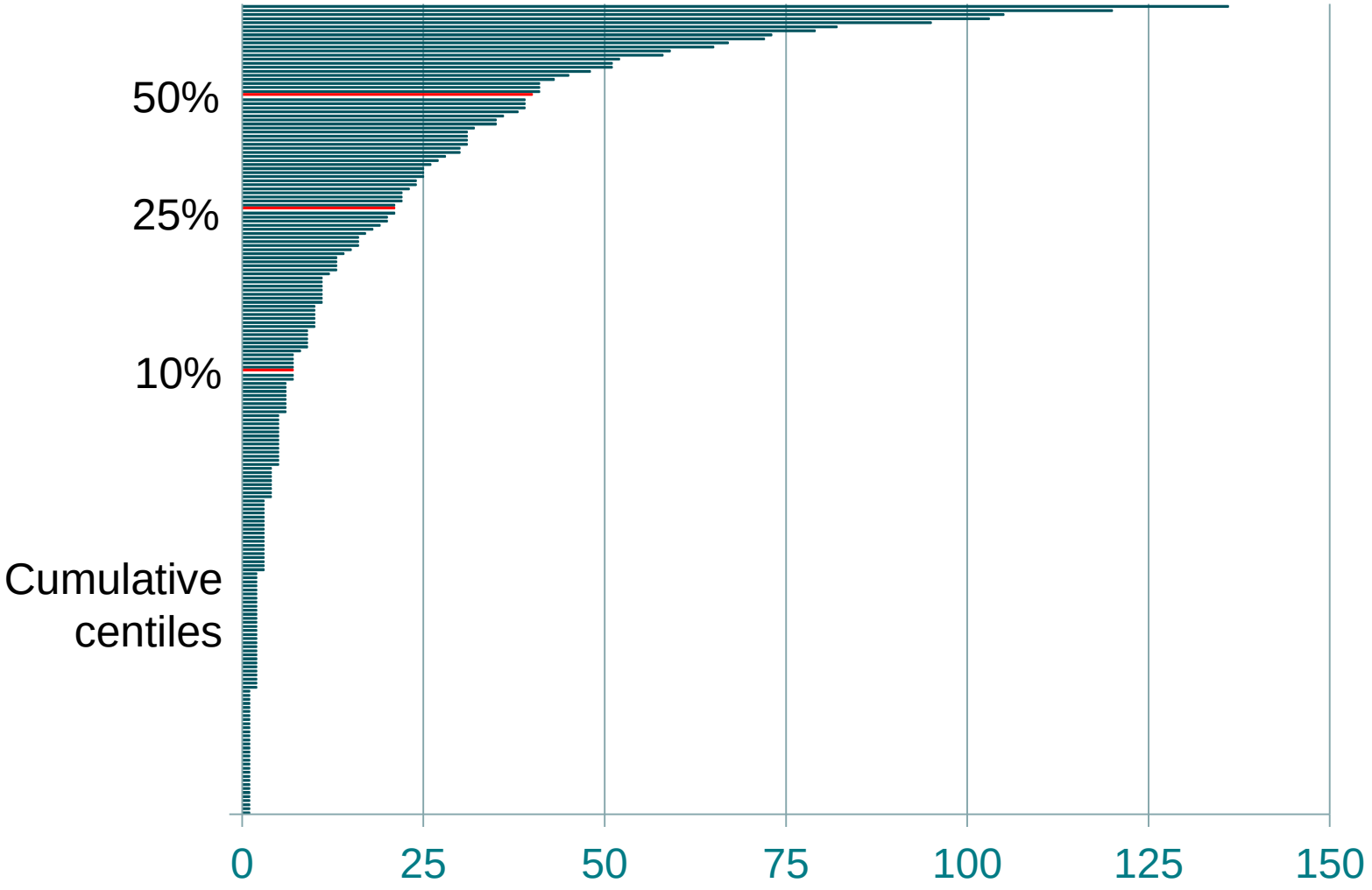
Recognising and responding to an acutely ill/injured child

Practical skill and knowledge	Competent (expert, can teach others)	Requires support	Novice (need development)	Review date
Recognising normal parameters for vital signs: • 0-1 year • 1-5 years • 5-12 years • 12+				
Basic clinical awareness assessment including recognition of the deteriorating infant, child and young person				
Clinical signs of dehydration: Infant Child Young person				
Awareness of sepsis pathway and treatment: Infant Child Young person				
Treatment of anaphylaxis: Infant Child Young person				
Treatment of choking: Infant Child Young person				
Treatment of fitting: Infant Child Young person				
Resuscitation skills: Infant Child Young person				
First aid treatment: Burn/scalds Head injury Soft tissue Bone injury				

Slide courtesy of Hanna Kaur

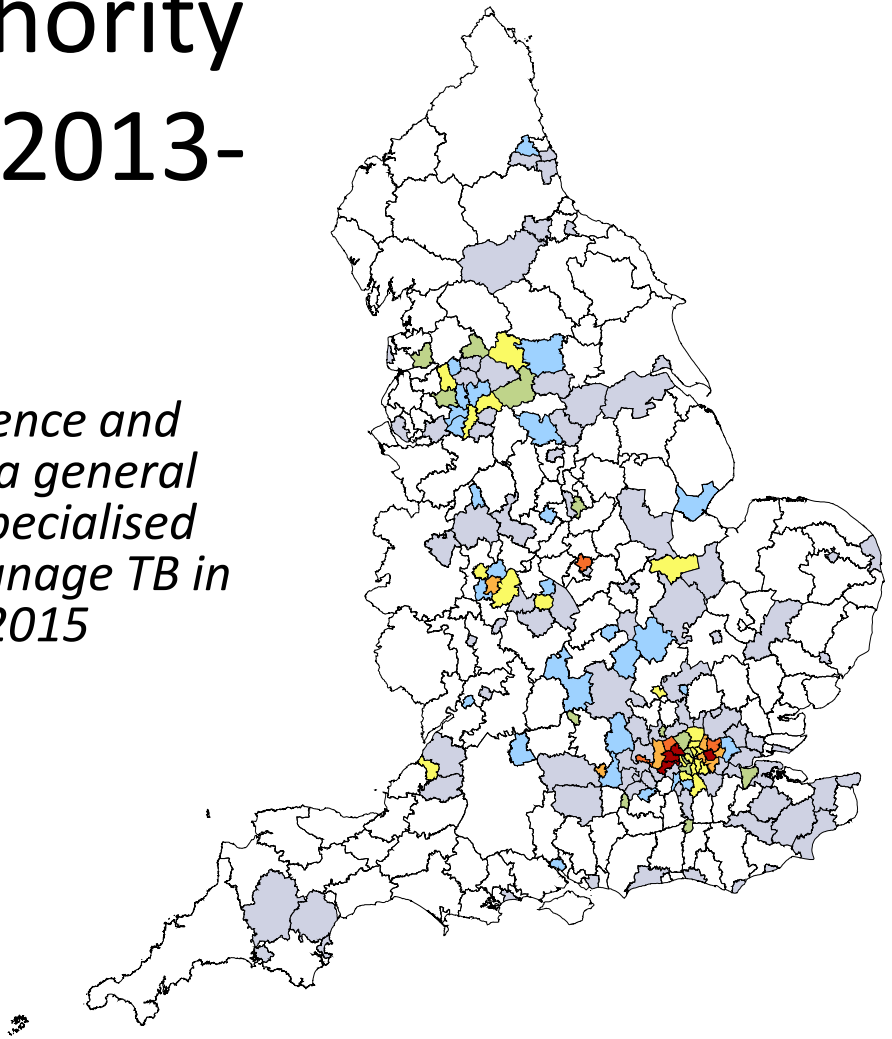
Networks and Support

Huge variation in numbers treated in 200 individual clinics



Three-year average TB rates by local authority district, England, 2013-2015

"either a paediatrician with experience and training in the treatment of TB, or a general paediatrician with advice from a specialised clinician should investigate and manage TB in children and young people" NICE 2015



Tuberculosis in England: 2016 report

North West Paediatric Networks

Developing a Paediatric TB network in the North West

Dr Fran Child

Consultant in Paediatric Respiratory Medicine

Royal Manchester Children's Hospital

NW TB Control Board

Manchester University Hospitals NHS

NHS Foundation Trust

Is cohort review the answer?

- Are all children in NW notified to ETS? ✓
- How many are getting good / suboptimal care?
  - Delays / samples / HIV tests / ECM ✓
  - Why no samples / what treatment / doses **x**
- Why do patterns of care vary?
  - Knowledge – patient / GP / DGH / tertiary care **x**
  - Resources **x**
- Where are we failing in prevention and why?
  - BCG **x**
  - Contact tracing – identification / treatment ✓
  - How much latent TB is out there? **x**
- Clinical outcomes **x**

Slide courtesy of Dr Fran Child

Why is it difficult to provide joined up care for children with TB?

Adult TB services

- Historically provided care for all ages groups
- More TB experience
- Links with public health
- TB nurses

Children's services

- Children should be cared for by paediatric staff in child-friendly setting
- Tertiary leadership for rare conditions
- Specialist investigations/GA available only in tertiary centres

Slide courtesy of Dr Fran Child

Paediatric TB Network

Tertiary Centre

2a centre

2b centre

Slide courtesy of Dr Fran Child

Paediatric TB network

Network administration

Send audit / outcome data

Tertiary centre

Send audit / outcome data

Inform

Investigate and manage at 2a centre with advice and support from tertiary centre as needed

refer

refer

Concern about latent or active TB

Potentially complex TB

Latent TB

Straightforward pulmonary or peripheral lymph node disease

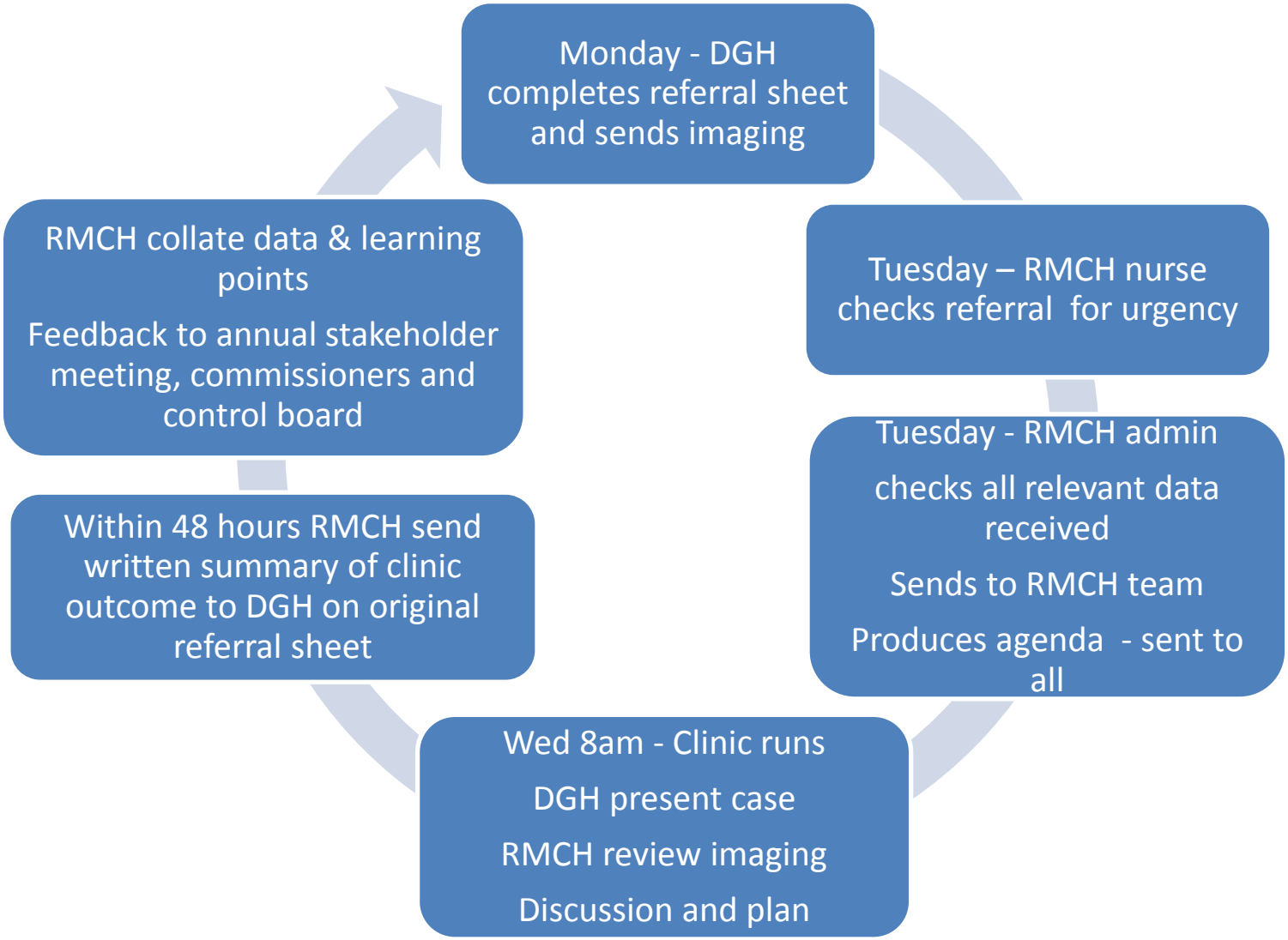
Level 2b centre

Level 2a centre

Child < 16yrs

Slide courtesy of Dr Fran Child

Virtual TB clinic – Wed 8-9am



Slide courtesy of Dr Fran Child

Regional paediatric TB networks

- How to move forwards….?

- Where are we now? How is care provided?
- What networks exist?

- Please reply to upcoming survey

- Share best practice…

BAPT activities for 2018

- Regional paediatric TB network meetings – encouraged annually
- Supporting regional networks:
  - Supplying paediatric clinic level data
  - Encouraging annual regional meetings
- Planning surveys of current practice
  - contact tracing (non-outbreak) and LTBI management
  - hepatitis (viral testing, LFT monitoring)
  - ethambutol and ophthalmology
- Guidelines committee to be established
- Developing QA/QC approval package for FDCs
- National annual BAPT meeting – Manchester (early 2019)