Update on the New Congenital Heart Review Process

Author: Alison Poole Sponsor: Mark Wightman Trust Board 2.2.17 **paper F**

Executive Summary

Context

This paper provides the Trust Board with an update on the Congenital Heart Disease (CHD) Review, the key actions for immediate attention, and associated risks.

Questions

1. **What has happened in the EMCHC campaign since the last Trust Board update**
   - *1.1.* **CQC inspection results** rate EMCHC as Good overall and Outstanding for effectiveness
   - *1.2.* **Surgical appointments –** Both surgeons have accepted their appointments, and subject to usual HR checks the new substantive consultant will start on June 1st 2017.
   - *1.3.* **Public Consultation-** We have had no formal confirmation of the dates for the public consultation. However NHS England have issued more detail regarding the consultation process in a letter to the Chair of the Lincolnshire OSC
   - *1.4.* **Overview and Scrutiny Committees –** The Trust attended OSC meetings at Lincolnshire and Derbyshire, full support was offered and a close working relationship will continue throughout the consultation process
   - *1.5.* **All Party Parliamentary Group on cardiac health–** Dr Aidan Bolger, Mark Wightman and Alison Poole attended a meeting at Portcullis House on Wednesday 18th January. The committee will be inviting NHS England to attend a future meeting, and it was agreed that a cross party joint initiative should be explored to challenge the value of the current review process.
   - *1.6.* **East Midlands MP support** – Mr Will Huxter NHS England attended a meeting with East Midlands MPs on Wednesday 25th February. We have been asked to respond to feedback from the meeting.
   - *1.7.* **Leicester Council support -** We have had confirmation from Leicester County Council that they have made financial provision should it be needed to challenge any decisions from the public consultation.
   - *1.8.* **Latest communications to NHSE–** We still have not had any response to our letter from the 20th December sent to Mr Will Huxter NHS England asking for a formal response to our latest self-assessment.
   - *1.9.* **Stakeholder meetings –** meetings are planned monthly and dates have been circulated. Staff update meetings have now been established monthly , and ward level staff meetings are in place for a more informal discussion with staff

1.10. **Network engagement –** Good progress has been made in discussions at Exec and clinical level with the wider network. A meeting is being planned; to which all network Trusts will be invited

1.11. **Petition update –** The online petition closed on the 22nd January and achieved 48,796 signatures .The offline version has over 78,000 signatures. The joint petition is being presented to Liz Kendall MP on February 6th 2017.

2. **What is the planned over the next month?**

2.1. A continued approach to engage with the Network to enhance the cardiac referral pathway

2.2. Close liaison with the East Midlands OSC to inform and update

2.3. Response to the letters from NHS England to East Midlands MPs and the Lincolnshire OSC

2.4. Continued discussions with The Royal Brompton Hospital

2.5. Continuation of stakeholder engagement and preparation of potential responses to the public consultation

3. **What are the risks to the campaign?**

3.1. The revised self-assessment submission is still subject to review by the assessing panel; the outcome of which will determine the next steps in the process. There does not appear to be any movement in opinion of NHS England despite numerous submissions from EMCHC indicating our compliance to the standards.

Conclusion

4 The Trust Board are requested to :

4.1 Note the content of the paper and

4.2 Provide comments and guidance of any areas deemed appropriate

For Reference

1. The following **objectives** were considered when preparing this report:

Safe, high quality, patient centred healthcare	[Yes]
Effective, integrated emergency care	[Yes]
Consistently meeting national access standards	[Yes]
Integrated care in partnership with others	[Yes]
Enhanced delivery in research, innovation &ed'	[Yes]
A caring, professional, engaged workforce	[Yes]
Clinically sustainable services with excellent facilities	[Yes]
Financially sustainable NHS organisation	[Yes]
Enabled by excellent IM&T	[Not applicable]

2. This matter relates to the following **governance** initiatives:

a. Organisational Risk Register [Yes]

If YES please give details of risk ID, risk title and current / target risk ratings.

Datix Risk ID	Operational Risk Title(s) – add new line for each operational risk	Current Rating	Target Rating	CMG
2940	There is a risk that paediatric cardiac surgery will cease to be commissioned in Leicester with consequences for intensive care and other specialist paediatric services	15	0	Women's and Children

If NO, why not? E.g. Current Risk Rating is LOW

b. Board Assurance Framework [Yes /No /Not applicable]

If YES please give details of risk No., risk title and current / target risk ratings.

Principal Risk	Principal Risk Title	Current Rating	Target Rating
No.	There is a risk …		

3. Related **Patient and Public Involvement** actions taken, or to be taken
4. Results of any **Equality Impact Assessment**, relating to this matter:
5. Scheduled date for the **next paper** on this topic: December
6. Executive Summaries should not exceed **1 page**. [My paper does not comply]
7. Papers should not exceed **7 pages.** [My paper does comply]

Update Paper on New Congenital Heart Disease Review

Prepared by Alison Poole Date: 26th January 2017

1. Context:

1.1. This paper provides the Trust Board with an update on the Congenital Heart Disease (CHD) Review, the key actions for immediate attention, and associated risks.

2. Questions: What has happened in the EMCHC campaign since the last Trust Board?

2.1. **CQC inspection results** – We are particularly pleased that the CQC judged our East Midlands Congenital Heart Centre to be "Good" overall, with 4 domains "Good" and 1 "Outstanding".

2.2. **Surgical appointments –** Both surgeons have accepted their appointments, and subject to usual HR checks the new substantive consultant will start on June 1st 2017.

2.3. **Public Consultation-** We have had no formal confirmation of the dates for the public consultation. However, in a letter to the Chair of the Lincolnshire OSC, NHS England have confirmed that ;

- The consultation will run in excess of 12 weeks
- Events will be arranged across the whole country and full details will be released at the beginning of the consultation
- In the Midlands there will be a number of events in Lincoln, Northampton, Leicester, Norwich, Nottingham and Papworth
- The events will be ticketed events and will also be available by webinar
- There will be events run by charities and voluntary groups, written literature and a hub on NHS England website
- Clearance has been provided by the Department of Health to run consultation during the Local Council period of purdah (due to the local elections)

2.4. **Overview and Scrutiny Committees** –

- **The Lincolnshire OSC committee** was held on the 18th January and the Trust was invited to attend and was represented by Dr BuLock and Mr Jon Currington. The committee had received correspondence from NHS England in response to the questions raised in the meeting on the 21st December and asked the Trust representatives to respond to key aspects of the letter. Following the meeting a request was received for the Trust to formally respond to the points raised by NHS England which will be completed as soon as possible. Cllr Talbot , the Chair of Lincolnshire OSC has written to the Secretary of State for Health asking him to reconsider the decision to run consultation during purdah as it will inevitably impact the quality of the Committee's engagement and communication and make it more difficult for the OSC to formulate it's response to the consultation.

- **Derbyshire OSC committee** was held on the 23rd January 2017 and the Trust was invited to attend, represented by Dr Simon Robinson and Alison Poole. A detailed presentation outlining the background to the campaign and current situation, and the committee asked some very relevant questions. The Chair assured the Trust of the support of the Derbyshire OSC and asked for updates when relevant.

2.5. **All Party Parliamentary Group on cardiac health**– Dr Aidan Bolger, Mark Wightman and Alison Poole attended a meeting at Portcullis House on Wednesday 18th January. The meeting was chaired by Stuart Andrew MP, and attended by a number of MPs and Peers. The Trust and the Royal Brompton Hospital presented the current situation in relation to the NHS England proposed decommissioning of Level 1 services. Following both presentations there was an opportunity for debate and questions, and considerable support for the retention of services in both centres. The committee will be inviting NHS England to attend a future meeting, and it was agreed that a cross party joint initiative should be explored to challenge the value of the current review process.

2.6. **East Midlands MP support** – Mr Will Huxter from NHS England attended a meeting with East Midlands MPs on Wednesday 25th February. We have been asked to respond to feedback from the meeting.

2.7. **Leicester Council support -** We have had confirmation from Leicester County Council that they have made financial provision should it be needed to challenge any decisions from the public consultation. This matches the amount set aside by Leicester City Council. Both councils are planning activity outside the Trust in support of the campaign.

2.8. **Latest communications to NHSE–** We still have not had any response to our letter from the 20th December sent to Mr Will Huxter NHS England asking for a formal response to our latest self-assessment.

2.9. **Stakeholder meetings –** meetings are planned monthly and dates have been circulated. Staff update meetings have now been established monthly , and ward level staff meetings are in place for a more informal discussion with staff

2.10. **Network engagement –** Good progress has been made in discussions at Exec and clinical level with the wider network. A meeting is being planned; to which all network Trusts will be invited. The aim of the meeting is to discuss the mutual benefits of widening the Cardiac referral network.

2.11. Petition update – The online petition closed on the 22nd January and achieved 48,796 signatures .The offline version has over 78,000 signatures. The joint petition is being presented to Liz Kendall MP on February 6th 2017.

3. Activity planned over the next month;

3.1. Attendance at OSC meetings in Lincolnshire and Northamptonshire – details being finalised.

3.2. Development of Network meeting to discuss the wider cardiac referral network. All Network Trusts will be invited

3.3. Formal response to the NHS England letters to the Lincolnshire OSC and the East Midlands MPs.

3.4. Preparation of evidence in advance of the consultation which will be tailored once the full consultation questions are made public

3.5. Collaboration with the Royal Brompton Trust to pursue support from MPs and Peers

3.6. Information and stakeholder contact lists continue to be prepared in advance of the consultation

3.7. 100 short Bio case studies of patients who have attended EMCHC ward 30, PICU and ECMO continue to be prepared. These will be shared by social media channels every day of the public consultation phase to drive awareness of the consultation.

4. The key issues and risks associated with this;

4.1. The revised self-assessment submission is still subject to review by the assessing panel, the outcome of which will determine the next steps in the process.

5. Conclusion The Trust Board are asked to;

5.1. Note the content of the paper

5.2. Provide comments and guidance of any areas deemed appropriate

University Hospitals of Leicester NHS
NHS Trust

Caring at its best

University Hospitals of Leicester

All-Party Parliamentary Group for Heart Disease

Wednesday 18th January 2017

Portcullis House , Westminster

2017
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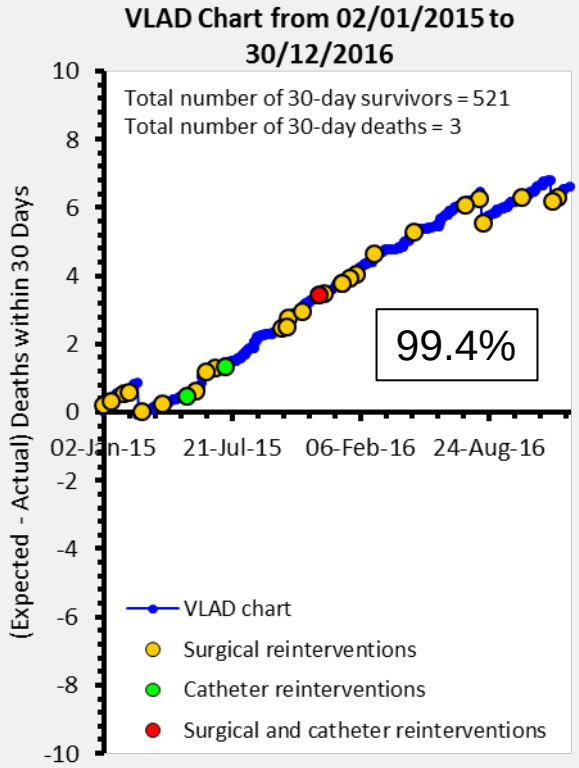
East Midlands Congenital Heart Centre

Better than expected surgical survival

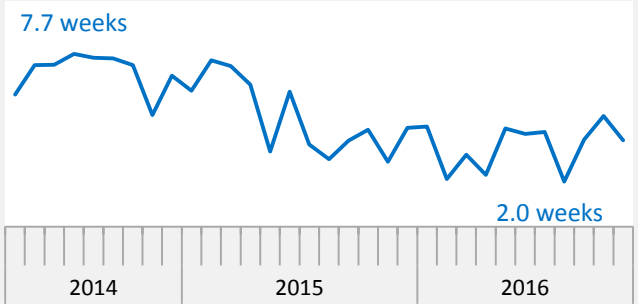
Risk-adjusted survival following paediatric surgery is statistically better than expected for the previous 2 years.



National average (PRAiS 2012-15) = 98%

4 weeks

average waiting time for paediatric surgery in 2016



Lower rates of:

- Surgical cancellations
- Complications
- Catheter re-interventions

Specialised Services Quality Dashboards NHS England

Statistically lower rates compared with other Level 1 congenital heart centres in Q1 of 2016-17 according to our Specialised Quality Dashboards.

99%

Recommendation rate from our Friends and Family test

434 /436 respondents would recommend our services to their family and friends.

(Jan 16 – Nov 16),

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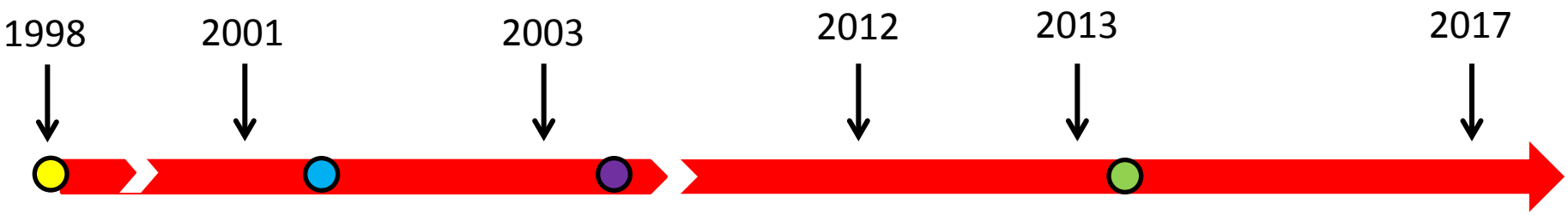
Timeline of Reviews



Bristol Inquiry	**Munro Report**	**Safe & Sustainable**	**IRP**	**New CHD Review**
198 recommendations 2 surgeons 40-50 open heart ops	Standards 300 unit ops "participate in"	4 surgeons 400 ops	4 surgeons	4 surgeons 500 ops

- Dobson
- Milburn
- Smith
- Hunt

East Midlands Congenital Heart Centre

A profession transformed

Mortality

Mortality

1991 → **2001** → **2012-15** → **2015-16**

1991	2001	2012-15	2015-16
Bristol 28%	Bristol 3%		
National 14%	National 4%		National 2%
Leicester 13%	Leicester 7%		Leicester 0.6%

17 centres

(UK & RoI)

→

Cardiff to Bristol, 1999
Edinburgh to Glasgow, 2001
Harefield to Royal Brompton, 2001
Oxford to Southampton, 2010
Belfast to Dublin, 2016

→

12 centres

Occasional practice: 190 cases to 5 cases,1991 to 2001
All CHD centres relocated or upgraded to children's facilities

Regulation Governance Audit

→

NCDHA Revalidation National standards
Technology Knowledge
CRG NSFs Appraisal Education
PSA NICE CQC CQIN HEE

→

Regulation Governance Audit

The Report of the Independent Review of Children's Cardiac Services in Bristol

Eleanor Grey QC, Professor Sir Ian Kennedy

June 2016

"There is a fundamental difference between the circumstances revealed by the Bristol Public Inquiry…and the situation now"

The work of the National Congenital Heart Disease Audit "should ensure that such a situation would now not go undetected".

East Midlands Congenital Heart Centre

UHL compliance with 14 key standards

Criteria		Compliance
1.1	Surgery and catheter procedures to take place in a Specialist Surgical Centre	Compliant
1.2	Network MDT discussions for rare, complex and innovative procedures	Compliant
1.3	Age-appropriate care environments	Compliant
2.1	Surgeons to be primary operator in 125 procedures each year (3-year average), 4 surgeons by 2021	Plan not approved
2.2	Cardiologist to be primary operator for 50 procedures each year (lead cardiologist = 100) each year (3-year average)	Plan
3.1	Surgical rotas should be no more than 1 in 3	Compliant
3.2	Interventional cardiologist rotas should be no more than 1 in 3	Compliant
3.3	Cardiologist rotas should be no more than 1 in 4	Compliant
3.4	A consultant ward round occurs daily	Compliant
3.5	Patients and their families can access support and advice at any time	Compliant
3.6	Network medical staff can access expert CHD advice at any time	Compliant
4.1	Co-location of key specialities and facilities (call-to-bedside within 30 mins)	Plan
4.2	Key specialities to function as a multidisciplinary team	Compliant
5.1	Participate in national audits, use current risk adjustment models and learn from adverse incidents	Compliant

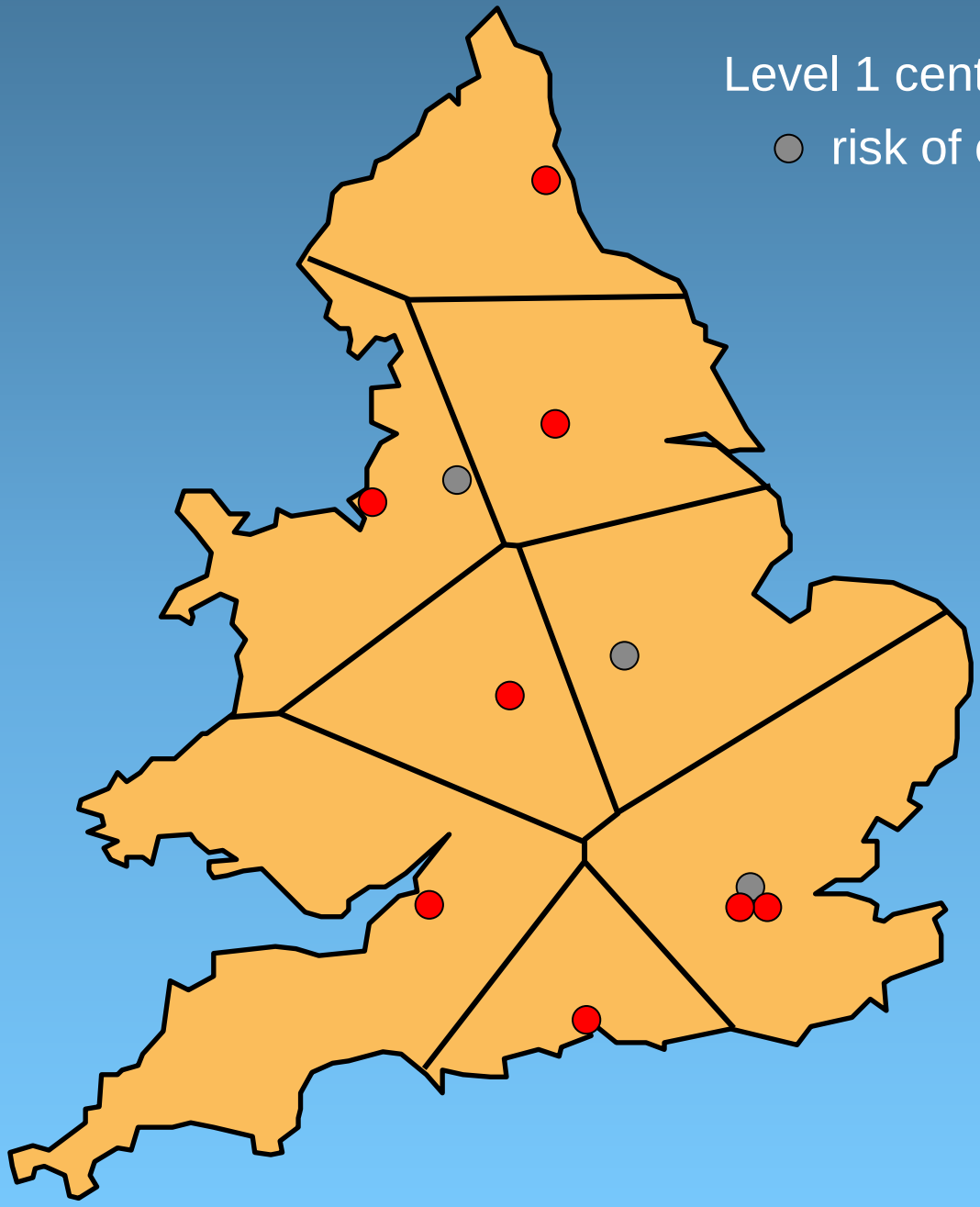
NHS England's numbers game

Case numbers – 3 Surgeons

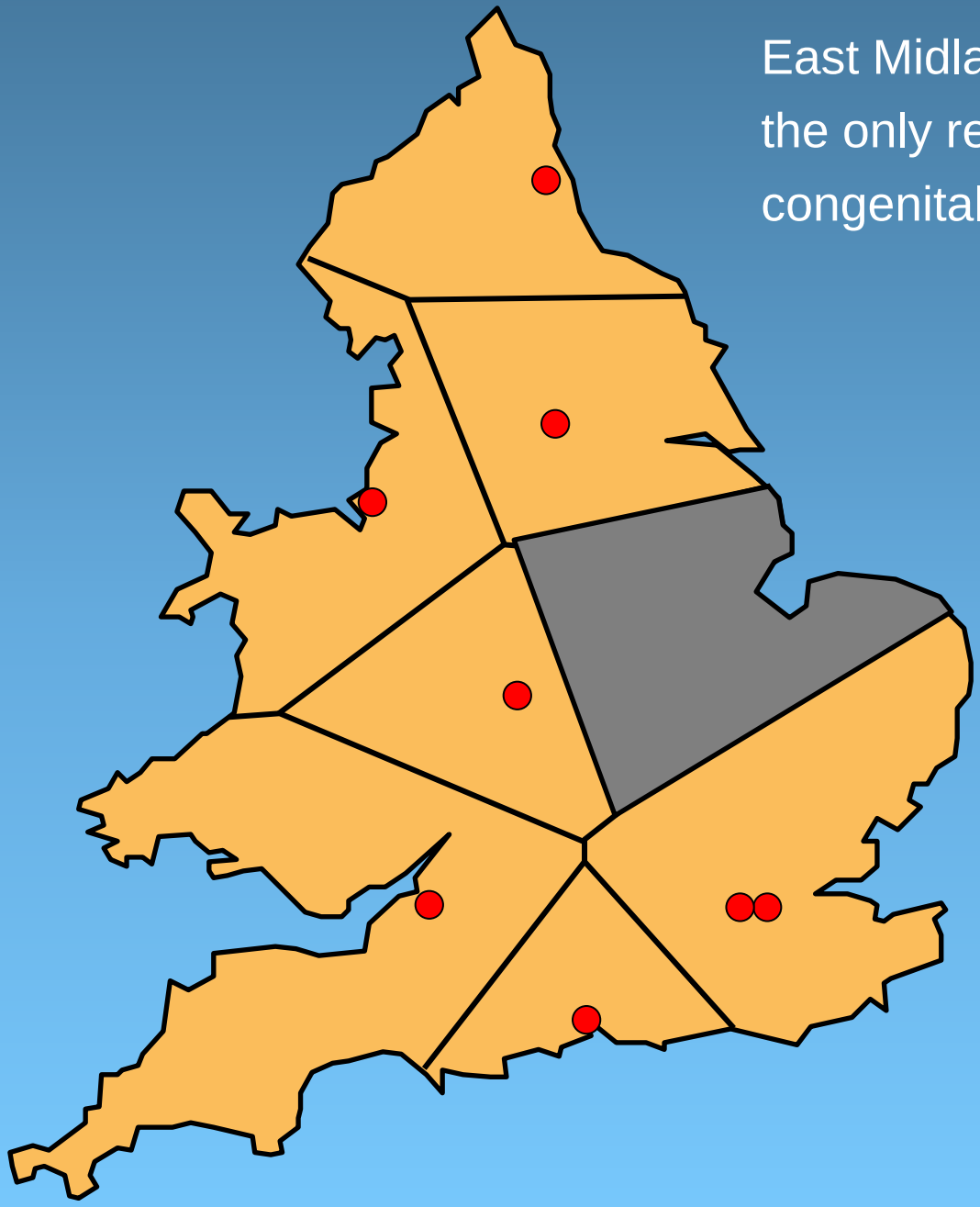
- Standard 2.1 requires each surgeon to perform 125 cases pa and the unit to achieve 375 cases per year, averaged over three years
- NHSE are counting this retrospectively rather than from standards implementation in April 2016 thereby predetermining the outcome
- If counted from this year onwards (as intended), we expect to be compliant with this standard by March 2019 as required

Case numbers – 4 Surgeons

- by 2021 teams should have 4 surgeons all performing 125 cases pa i.e. a total of 500 cases
- We have submitted a network development plan that clearly demonstrates how we can meet this standard
- NHSE have refused to consider our proposal as a potential solution


Level 1 centres in England
risk of closure

East Midlands would be the only region without a congenital heart centre



Likely patient impacts …

2500 PICU bed days to be re-provided….?where

1000 Congenital cardiac inpatient episodes per year

1000 Fetal cardiac outpatient appointments per year

474 Paediatric & Neonatal ECMO bed days

Increased pressure on remaining surgical waiting lists

400 Cardiac catheter procedures per year

375 Congenital Cardiac Surgeries

Destabilisation of National PICU capacity

40 Mobile ECMO transports

12+ Specialist Services

Severe compromise of education, training & research

Transition period

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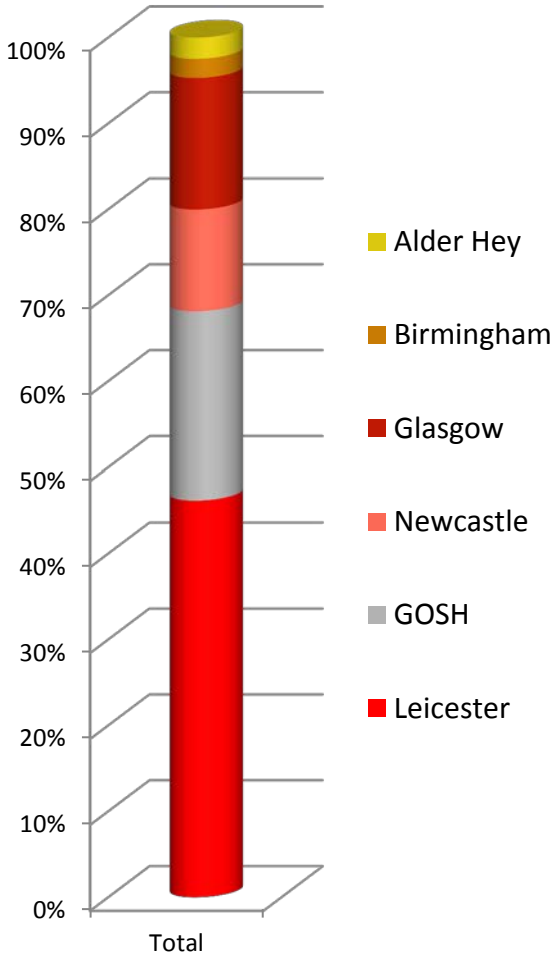
Likely patient impacts …

- Travel times
- Cost
- Ease of access
- Increased waiting lists
- Disruption of patient-clinician relationships
- Uncertainty and anxiety

→ Healthcare inequality

Given the harm, costs and illogicality of NHSE's proposal, we shouldn't be asking whether Birmingham Children's Hospital can accommodate patients from the East Midlands but rather, *should it*.

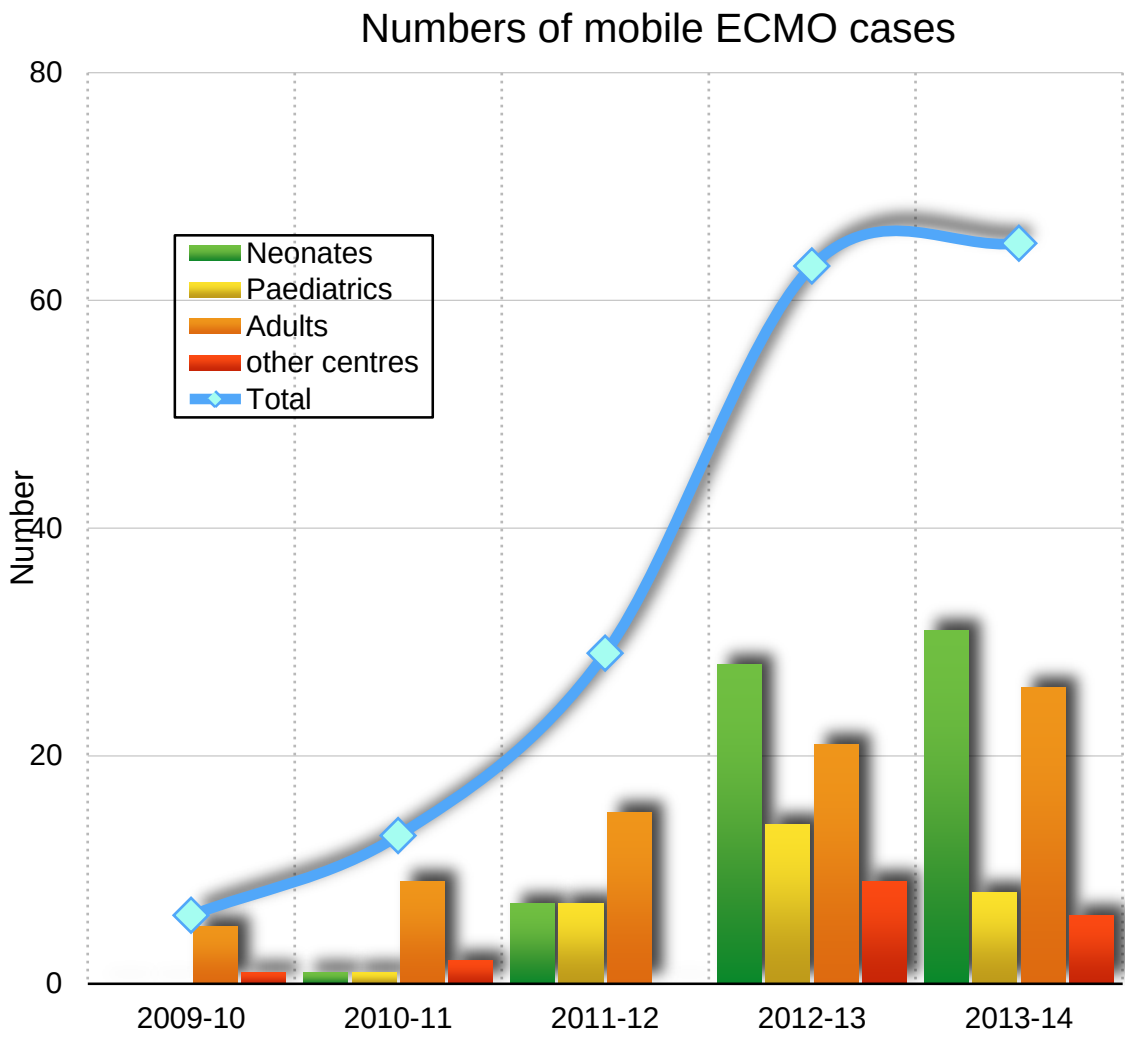
ECMO Activity



World Leading ECMO Centre

- ECMO Commenced in 1989 funded by our Heart Link Charity
- Second centre globally to treat more than 2000 patients
- Accounts for nearly 50% of UK Respiratory Paediatric activity
- Only UK 24/7 mobile service

Combined UK Respiratory Neonatal & Paediatric Data (2012-2015)



The EMCHC ECMO team dominate the provision across Paediatrics and Adults – the other centres do not have the expertise to manage the additional demand if EMCHC were to close .

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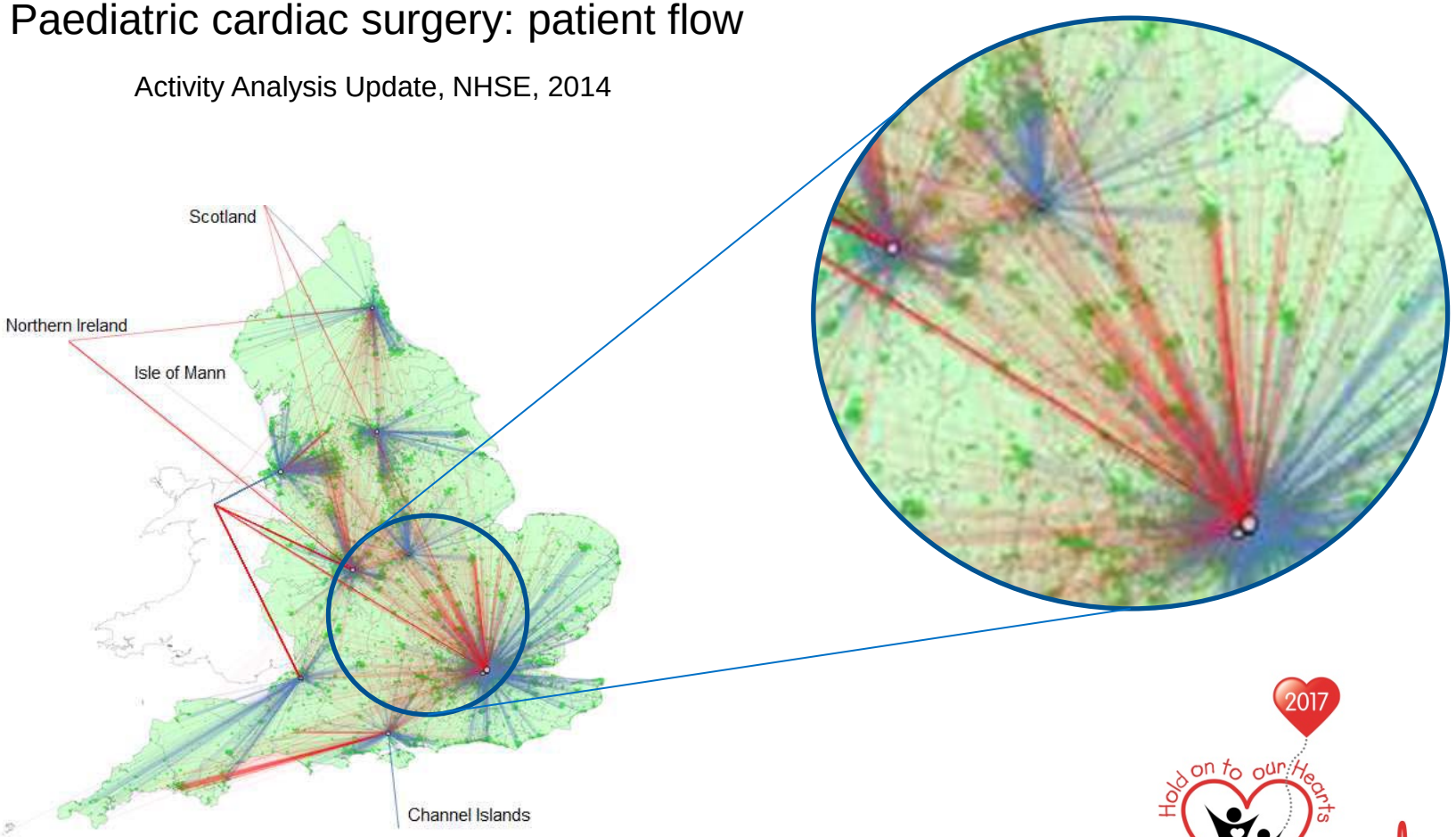
The simple solution:
East Midlands patients treated closest to home

Paediatric cardiac surgery: patient flow

Activity Analysis Update, NHSE, 2014



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East Midlands Congenital Heart Centre

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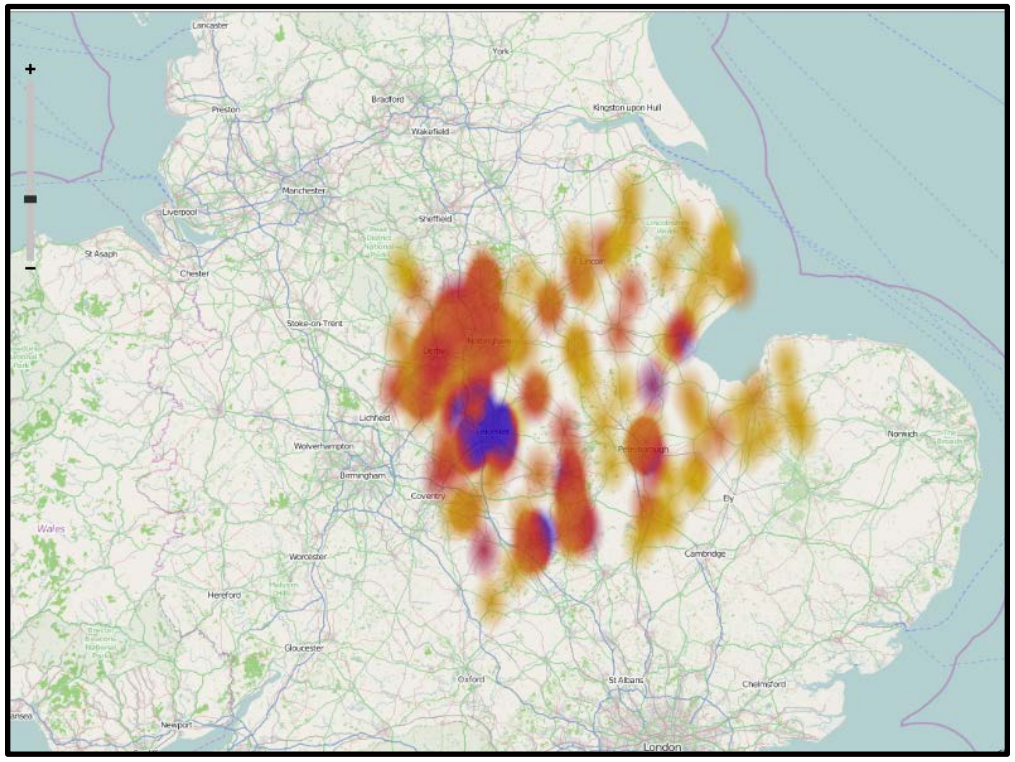

NICOR data 2014-16: 502 operations per year

2017

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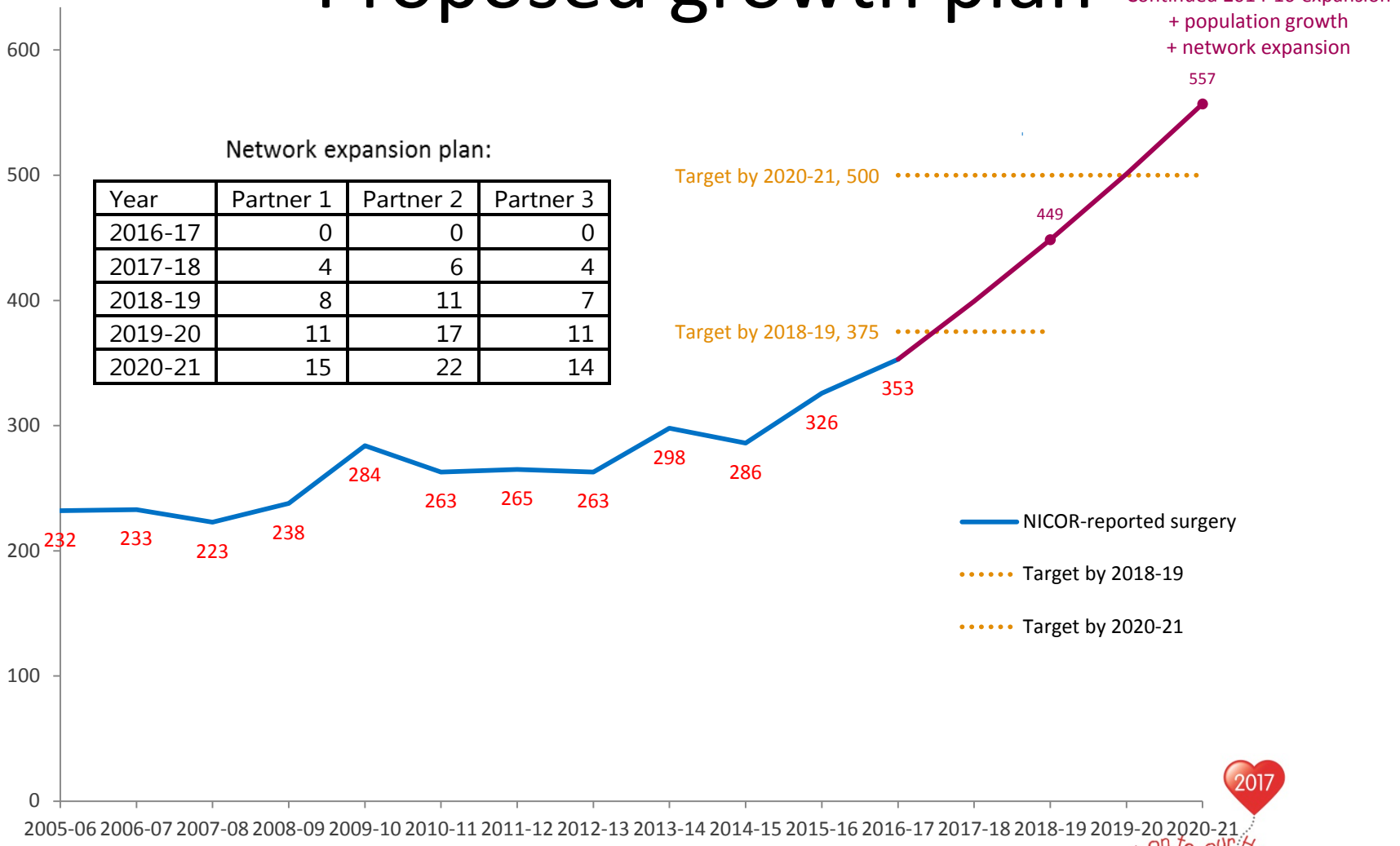
Proposed growth plan

Network expansion plan:

Year	Partner 1	Partner 2	Partner 3
2016-17	0	0	0
2017-18	4	6	4
2018-19	8	11	7
2019-20	11	17	11
2020-21	15	22	14



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Summary

- UK CHD surgery already transformed and results now world leading, including in Leicester
- Current process disproportionate, costly and disruptive
- NHS time & resources could be focussed where there is pressing clinical need
- Geographical balance of CHD provision severely threatened by NHSE plans and specifically to the detriment of the East Midlands population
- Any concerns about centre size resolved by adopting our simple proposal to allow East Midlands patients to stay in their region for treatment
- Our proposal should be supported by NHSE, not ignored