East of England
Clinical Senate

NHS England Midlands & East Specialised Commissioning

Report of the Clinical Senate Independent Review Panel

May 2015

May 2015

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1. CLINICAL SENATE CHAIR FOREWORD

The NHS needs to continually modernise and transform in order to deliver high quality care now and for future generations. Clinical senates have a unique role in supporting the NHS in enhancing quality and delivering sustainability by providing independent clinical leadership and advice.

We need to ensure that the right balance is achieved between providing accessible services for patients and carers and making sure they are provided with high quality care by appropriately trained and experienced staff.

We hope that by bringing an expert clinical voice we can contribute in a positive way to the future development of a paediatric rheumatology service in the East of England which although still in its early stages of development, aims to bring about significant improvement on the current level of provision for patients.

I am grateful to Dr Kate Armon, Consultant Paediatrician, Norfolk & Norwich University Hospital Foundation Trust, Dr Denise Williams, clinical director for the east of England Maternity, Newborn and Children and Young People Strategic Clinical Network and to the specialised commissioning team (SCT) of NHS England for inviting us to undertake the review at this early stage of the service development.

I thank all the members of the panel for giving up their considered and insightful contribution to this important piece of work and to the East of England clinical senate support team for coordinating the review and this report.

On behalf of the panel and the clinical senate, I wish all those involved in these service changes every success in achieving their ambitions to develop and implement the paediatric rheumatology service in the East of England.

Dr Bernard Brett,
Clinical Senate Chairman, chair of the clinical review panel

ADVICE REQUEST

2.1 The East of England clinical senate was advised by NHS England East Anglia Area Team interim Medical Director, Dr Melanie Clements, formerly Clinical Director for the East of England Maternity, Newborn, Children and Young People strategic clinical network, that a paediatric rheumatology service was in the early stages of development for the east of England and it might be suitable for a review by clinical senate.

2.2 Initial discussions were held with the specialised commissioning team and it was agreed to carry out an early stage review of the operational model against the national service specification.

2.3 The review panel was asked to specifically to look at the early outline proposal for the development of a Paediatric Rheumatology service jointly by the Norfolk and Norwich NHS Foundation Trust and Cambridge Hospitals NHS Foundation Trust in the East of England against the NHS England service specification for Paediatric Medicine: Rheumatology E03/S/b.

2.4 East of England Clinical Senate was asked to review the documentation and evidence provided and consider:

a) The extent to which the preferred option currently meets the criteria set out in the national service specification;

b) The extent to which the preferred option is supported by evidence in relation to the joint proposal; and

c) The extent to which the preferred option offered an appropriate way forward in light of the above and which areas of the proposal would need to be developed further over time to enable to the providers to deliver a service specification compliant service.

2.5 The scope of the review did not include the east of England clinical senate making any comment on the alternative operational models, even if its view was that the current operational model did not fully comply with the national service specification.

2.6 Nor did the scope of review consider any financial implications, either negative or positive.

2.7 The evidence and information provided for the clinical review panel was provided by the specialised commissioning team with the support of the two trusts.

3. METHODOLOGY & GOVERNANCE

3.1 The scope of the review was discussed with the specialised commissioning team to identify the most appropriate skills mix and expertise for the review panel and also the approach to be taken.

3.2 As there were no local experts and the majority of the panel would need to be identified from other parts of the UK, it was agreed that a desktop review of the evidence followed by a clinical review panel to be held by teleconference was the most appropriate approach.

3.3 Terms of Reference for the review were drafted with specialised commissioning and agreed and signed by Ruth Ashmore, Interim Associate Director for Specialised Commissioning, NHS England and Dr Bernard Brett, Chairman of East of England clinical senate and council appointed Chairman of this review panel.

3.4 Senate Council support team identified clinical review panel members (see Appendix 2 for panel members) from the east of England senate council and assembly. Experts were identified from outside the east of England and invited.

3.5 A pre-panel telephone conference with panel members was held one week before the panel day to identify the key lines of enquiry for the panel day in order that focus could be kept to the Terms of Reference of the review.

3.6 The key lines of enquiry were finalised and produced with the agenda (see Appendix 4) for the panel day, and circulated to the panel members and specialised commissioning team

3.7 The clinical review panel took place between 14.00hrs and 16.00 hrs on 18th May 2015. The panel was held by teleconference. Specialised Commissioning explained the context and background of the service, its development and current position. The panel followed up with questions to the team. Finally the specialised commissioning team left the teleconference and the panel had a full discussion and considered its recommendations following the identified key lines of enquiry.

3.8 A draft report was circulated to panel members and the specialised commissioning team for matters of accuracy.

3.9 This, final report, was submitted to the meeting of the East of England clinical senate council held 18th June 2015 who agreed that the clinical review panel met and fulfilled the Terms of Reference of the review.

3.10 This report is now submitted to the sponsoring organisation, NHS England Midlands and East Specialised Commissioning team.

3.11 On a date agreed with Specialised Commissioning team, the east of England clinical senate will publish this report on its website as agreed in the review Terms of Reference.

4 REVIEW FINDINGS & RECOMMENDATIONS

4.1 The panel had been asked to look at the early outline proposal for the development of a Paediatric Rheumatology service jointly by the Norfolk and Norwich NHS Foundation Trust and Cambridge Hospitals NHS Foundation Trust in the East of England against the NHS England service specification for Paediatric Medicine: Rheumatology E03/S/b. Initially this had been laid out in three separate questions:

a. The extent to which the preferred option currently meets the criteria set out in the national service specification;

b. The extent to which the preferred option is supported by evidence in relation to the joint proposal; and

c. The extent to which the preferred option offers an appropriate way forward in light of the above and which areas of the proposal will need to be developed further over time to enable to the providers to deliver a service specification compliant service.

4.2 The panel had developed key lines of enquiry to elicit further information in order to formulate its response and recommendations but as the panel discussion took place, it became clear that the responses to the questions were interdependent and separating out the responses and recommendations in line with the three questions was the most appropriate way to produce a meaningful report for the sponsoring organisation.

The following recommendations then simultaneously cover and respond to the three questions.

General Comment

4.3 The panel agreed that from the evidence provided, the need for a well-planned paediatric rheumatology service in the east of England was clear. East of England patients were currently under-served with different access to existing services depending upon geography, and available services falling well below those described in the national service specification. The proposed new service, although falling short of delivering all elements of the national service specification, was likely to be a substantial improvement for many patients on the existing arrangements. The panel agreed that this proposal was a very positive step in the right direction.

4.4 The panel commended the team on its work so far, particularly Dr Kate Armon for her work and tenacity in developing this and working to improve the paediatric rheumatology service for patients in the east of England.

Key findings:

4.5 Although the panel recognised that there was still some way to go before the operational model was fully compliant with the national service specification, it considered that the proposal had demonstrated some appropriate first steps and should continue to be progressed. The panel considered that in order to ensure a safe clinical approach to the development of the service, a robust phased approach to meet full compliance was required, and should include all aspects of the service (see recommendation one below).

4.6 The panel considered that there needed to be more clarity on plans for level one and level two centres, and that the existing arrangements with Great Ormond Street Hospital for children NHS Foundation Trust and Nottingham University Hospitals NHS Trust continue and develop (see recommendation 3). The panel was unclear where the clinical governance arrangements for

the consultant were intended to sit and considered that maintaining links with existing service providers would be beneficial to the staff.

4.7 From the evidence provided and hearing of the personal experience of a panel member who had worked under the same conditions, the panel considered that one consultant working single handed from two hubs would be challenging and were concerned about the sustainability and resilience of the service and the impact on the staff and patients.

4.8 The panel agreed that the commissioners should ensure the current service continued and remained in place whilst developing the service to be a service specification compliant one – this would include those services provided by other tertiary centres and those currently provided by other regional providers. This would enable the service to grow manageably without a rapid change of referral patterns. The panel agreed that whilst there was an ambition to proactively offer services that would encourage the repatriation of patients currently being treated at other centres, it would be preferable to ensure that the service was fully compliant and resilient first. The panel was of the opinion that as the service developed it would build its own reputation and the demand was likely to increase significantly with informed patient choice leading to changes in patient pathways.

4.9 The panel had reservations about the level and quality of data provided and available whilst recognising it was beyond the immediate control of the presenting team. The panel considered that without sufficient robust data and information, the scale of the task of developing the service could not be accurately understood. It recognised that there are significant issues with coding for paediatric rheumatology patients with many patients who were referred for medical conditions other than JIA or MSK probably not being coded under one of the many rheumatology codes and, in addition, with many patients being seen in more general paediatric and adult clinics, these patients would often be captured under non-paediatric rheumatology codes. The panel felt that a better understanding would be beneficial to the development of the service.

4.10 The panel acknowledged that there had been some engagement with service users and understood the level of engagement reflected the early stage of the proposal.

4.11 The panel sought further clarity for the arrangement of preparation, dispense, storage and disposals of drugs, particularly high risk biological medicines.

4.12 The panel sought assurance around accessibility and arrangements for inter-dependent services. It was noted that with the exception of renal and surgical cardiology, most other interdependent services were available in the east of England, mostly in Addenbrookes hospital.

Recommendation 1

4.13 The commissioners will need to ensure that the providers develop a robust business case with operational plan for the commissioners to consider. The plan for meeting full compliance with the national service specification should include workforce, training, location, sustainability, data capture and information sharing, arrangements for access to and availability of inter-dependent services and arrangement for networking and support with other paediatric rheumatology providers. This could be over a three to five year period but needed to be laid out clearly including milestones, timelines and regular reviews to ensure a safe clinical improvement in the service. Commissioners' will need to consider if the provider's plan to meet the service specification is viable.

Recommendation 2

4.14 The commissioners should give consideration to the sustainability of proposed Consultant staffing, i.e. having a single consultant working from two hubs. Preferred options right from the start could include a single consultant working from one hub or two consultants working from both hubs. The panel recommended that at least three consultants with appropriate and proportionate number of specialist nurses and allied health professionals in accordance with the national service specification should be in place by year three.

Recommendation 3

4.15 Links with GOSH and Nottingham hospitals need to be maintained now and in future and the panel recommended that the commissioners explore the willingness and capacity of both hospitals to support the east of England service as it develops and grows. This could include shared Consultant appointments. This approach would strengthen clinical governance

arrangements for the east of England Consultants and should include matters such as training for all service staff. In line with the phased approach to development of the service, there should be a clear plan of continued engagement with GOSH and Nottingham hospitals for the foreseeable future and certainly during the period of development of the east of England service.

Recommendation 4

4.16 The commissioners should ensure that pharmaceutical arrangements were included in the business case and operational model including consideration whether it was preferable to have one or two main bases for the storage, preparation, distribution of pharmaceutical agents.

Recommendation 5

4.17 The panel recommends that the commissioners could consider a more rigorous approach to data analysis and evidence to support the development of the service and recommended that resource be identified and allocated to undertaking a review of coding and provision of other data to support the development of the service now and into the future. The panel recognised that there is a dependency upon Trusts' being compliant with ICD codes.

Recommendation 6

4.18 The panel acknowledged that there had been some engagement with service users and families and recommended that this continued with further and more in depth engagement as the service developed. The service user engagement should be part of the phased plan for development.

Recommendation 7

4.19 The commissioners should commission to the service specification which includes the wider multi-disciplinary team to support the service and should include the detail of that in the phased plan. It may be helpful to discuss training and development for all medical staff, nursing and allied health care professionals and other staff for this service with Health Education England.

Recommendation 8

4.20 Finally, the commissioners should ensure that the service that is currently in place remains so and is not de-commissioned until any elements can be fully and sustainably provided by the new service. The commissioners should allow the 'new' service to develop according to the phased programme.

East of England Clinical Senate

Independent clinical review panel for NHS England, Midlands & East Specialised Commissioning on

Paediatric Rheumatology.

18th May 2015

Terms of Reference

CLINICAL REVIEW: TERMS OF REFERENCE

Title: **Paediatric Rheumatology**

Sponsoring Organisation: **NHS England Midlands & East Specialised Commissioning**

Clinical senate: East of England

Terms of reference agreed by: **Dr Bernard Brett**

on behalf of east of England clinical senate and Ruth Ashmore

on behalf of sponsoring organisation NHS England Midlands & East Specialised Commissioning

Date: 15th May 2015

Clinical review team members

Dr Bernard Brett	Chairman of Review Panel Chairman east of England clinical senate council Deputy Responsible Officer and Consultant Gastroenterologist James Paget Hospital NHS Trust
Dr Eileen Baildam	Consultant Paediatric Rheumatologist, Alder Hey Hospital, Honorary Senior Lecturer at the University of Liverpool
Dr Anurag Bharadwaj	Consultant Rheumatologist Basildon & Thurrock University Hospitals NHS Foundation Trust
Fan Iek Cheng	Senior specialist pharmacist, Great Ormond Street Hospital
Erica Crust	Ward Manager Jungle children's Assessment Unit and Rainforest Children's Outpatients Dept & Paediatric Rheumatology Nurse
Joanna Douglas	Chief Executive, Allied Health Professionals Suffolk (CIC)
Dr Peter Powell	Consultant Paediatrician, West Suffolk Hospital NHS FT
Dr Daniel Fishman	Consultant Physician and Rheumatologist Luton & Dunstable NHS Foundation Trust (desktop review and pre panel call)

Aims and objectives of the clinical review

The review will specifically look at the early outline proposal for the development of a Paediatric Rheumatology service jointly by the Norfolk and Norwich NHS Foundation Trust and Cambridge Hospitals NHS Foundation Trust in the East of England against the NHS England service specification for Paediatric Medicine: Rheumatology E03/S/b.

Scope of the review

The East of England Clinical Senate is asked to review the documentation and evidence and consider:

a) The extent to which the preferred option currently meets the criteria set out in the national service specification;

b) The extent to which the preferred option is supported by evidence in relation to the joint proposal; and

c) The extent to which the preferred option offers an appropriate way forward in light of the above and which areas of the proposal will need to be developed further over time to enable to the providers to deliver a service specification compliant service.

When reviewing the case for change and options appraisal the clinical review panel (the panel) should **consider whether these proposals have the potential to deliver real benefits to patients. The panel should also identify any significant risks to patient care in these proposals.** The panel should consider benefits and risks in terms of:

- Clinical effectiveness
- Patient Safety and management of risks
- Patient experience, including access to services
- Patient reported outcomes.

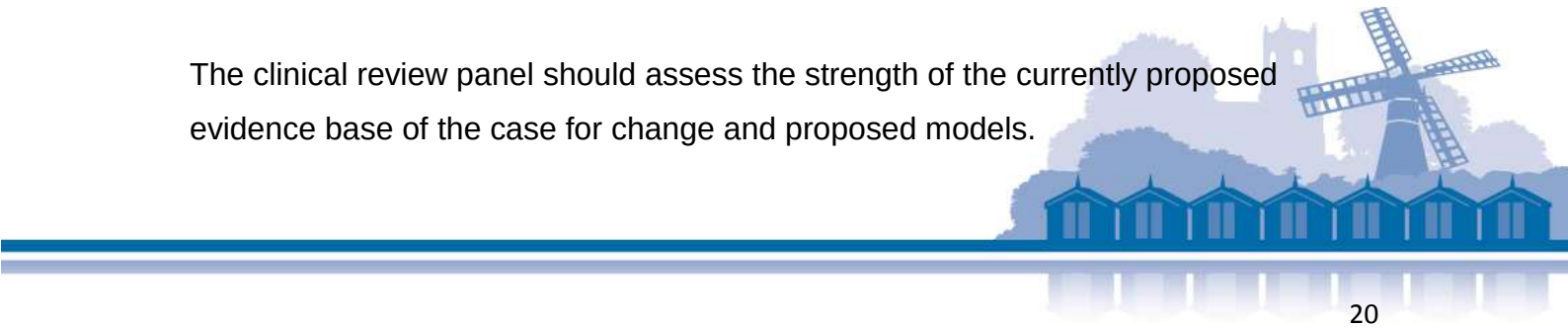
The clinical review panel is not expected to advise or make comment upon any issues other than clinical (e.g. financial elements of risk in the proposals, patient

engagement, GP support or the approach to consultation). However, if the panel felt that there was an overriding risk this should be highlighted in the panel report.

Questions that may help the panel in assessing the benefit and risk of the proposals include (but are not limited to):

- Is there evidence that the proposals will improve the quality, safety and sustainability of care? (e.g., sustainability of cover, clinical expertise)
- Do the proposals set out an appropriate plan for the service to be able to meet national specifications and standards
- Do the proposals reflect up to date clinical guidelines and national and international best practice e.g. Royal College reports?
- Will the proposals reflect further the delivery of the NHS Outcomes Framework?
- Do the proposals uphold and enhance the rights and pledges in the NHS Constitution?
- Will these proposals meet the current and future healthcare needs of their patients within the given timeframe of the planning framework (i.e. five years)?
- Is there an analysis of the clinical risks in the proposals, and is there an adequate plan to mitigate identified risks?
- Do the proposals demonstrate good alignment with the development of other health and care services, including national policy and planning guidance?
- Do the proposals support better integration of services from the patient perspective?
- Do the proposals consider issues of patient access and transport? Is a potential increase in travel times for patients outweighed by the clinical benefits?
- Will the proposals help to reduce health inequalities?
- Does the options appraisal consider a networked approach - cooperation and collaboration with other sites and/or organisations?

The clinical review panel should assess the strength of the currently proposed evidence base of the case for change and proposed models.



Timeline

The review panel will be held on 18th May 2015. This will be conducted by teleconference.

Reporting arrangements

The clinical review team will report to the clinical senate council which will ensure the report meets the agreed terms of reference, agree the report and be accountable for the advice contained in the final report.

Methodology

The review will be undertaken by a combination of desk top review of documentation and a review panel which will be held by teleconference.

Report

A draft report will be made to the sponsoring organisation within six working days of the clinical review panel for fact checking prior to publication.

Comments/ correction must be received from the sponsoring organisation within five working days.

Final report will be submitted to clinical senate council to ensure it has met the agreed terms of reference and to agree the report.

The final report will be submitted to the sponsoring organisation no later than 1st July 2015.

Communication and media handling

Communications will be managed by the sponsoring organisation. Clinical senate will publish the report once the service change proposal has completed the full NHS England process. This will be agreed with the sponsoring organisation.

Resources

The east of England clinical senate will provide administrative support to the review team, including setting up the meetings and other duties as appropriate.

The clinical review team may request any additional existing documentary evidence from the sponsoring organisation. Any requests will be appropriate to the review, reasonable and manageable.

Accountability and Governance

The clinical review team is part of the east of England clinical senate accountability and governance structure.

The east of England clinical senate is a non statutory advisory body and will submit the report to the sponsoring organisation.

The sponsoring organisation remains accountable for decision making but the review report may wish to draw attention to any risks that the sponsoring organisation may wish to fully consider and address before progressing the proposals.

Functions, responsibilities and roles

The **sponsoring organisation** will

i. provide the clinical review panel with the case for change, options appraisal and relevant background and current information, identifying relevant best practice and guidance. Background information may include, but is not limited to:

- relevant public health data including population projections, health inequalities, specific health needs
- activity date (current and planned)
- internal and external reviews and audits,
- relevant impact assessments (e.g. equality, time assessments),
- relevant workforce information (current and planned)
- evidence of alignment with national, regional and local strategies and guidance (e.g. NHS Constitution and outcomes framework, Joint Strategic Needs Assessments, CCG two and five year plans and commissioning intentions).

The sponsoring organisation will provide any other additional background information requested by the clinical review team.

ii. respond within the agreed timescale to the draft report on matter of factual inaccuracy.

iii. undertake not to attempt to unduly influence any members of the clinical review team during the review.

Clinical senate council and the sponsoring organisation will

i. agree the terms of reference for the clinical review, including scope, timelines, methodology and reporting arrangements.

Clinical senate council will

i. appoint a clinical review team, this may be formed by members of the senate, external experts, and / or others with relevant expertise. It will appoint a chair or lead member.

ii. endorse the terms of reference, timetable and methodology for the review

iii. consider the review recommendations and report (and may wish to make further recommendations)

iv. provide suitable support to the team and

v. submit the final report to the sponsoring organisation

Clinical review team will

i. undertake its review in line the methodology agreed in the terms of reference
ii. follow the report template and provide the sponsoring organisation with a draft report to check for factual inaccuracies.
iii. submit the draft report to clinical senate council for comments and will consider any such comments and incorporate relevant amendments to the report. The team will subsequently submit final draft of the report to the clinical senate Council.
iv. keep accurate notes of meetings.

Clinical review team members will undertake to

i. Declare any conflicts of interest and sign a confidentiality agreement prior to having sight of the full evidence and information
ii. commit fully to the review and attend all briefings, meetings, interviews, panels etc that are part of the review (as defined in methodology).
iii. contribute fully to the process and review report
iv. ensure that the report accurately represents the consensus of opinion of the clinical review team
v. comply with a confidentiality agreement and not discuss the scope of the review nor the content of the draft or final report with anyone not immediately involved in it. Additionally they will declare, to the chair or lead member of the clinical review team and the clinical senate manager, any conflict of interest that may materialise during the review.

Summary of process

Stage 1

- Sponsoring organisation (SO) requests clinical review of Senate as part of NHS England assurance process 1
- Senate office 2 review nature and scope of proposals to ensure appropriate for review

Stage 2

- Senate office and SO agree early stage Terms of Reference, in particular agreeing the timeline & methodology
- Senate council appoints Lead member / chair of clinical review team

Stage 3

- Senate office, Senate Chair and clinical review team chair identify and invite clinical review team members
- Clinical review team members declare any interests, these are considered by Senate and CRT chairs
- Clinical review team members confirmed, confidentiality agreements signed

Stage 4

- Terms of reference agreed and signed
- SO provides clinical review team with case for change, options appraisal and supporting information and evidence
- Clinical review commences, in accordance with the agreed terms of reference & methodology

Stage 5

- On completion of the clinical review, report drafted by CRT and provided to the SO to check for factual accuracy
- Any factual inaccuracies amended, draft report submitted to and considered by Clinical senate council
- Senate council ensures clinical review and report fulfils the agreed terms of reference

Stage 6

- Any final amendments made > Clinical senate Council endorses report & formally submits to sponsoring organisation
- Sponsoring organisation submits report to NHS England assurance checkpoint
- Publication of report on agreed date

In attendance at the panel:

PANEL

Dr Bernard Brett , Review Panel chair
Chairman east of England clinical senate council
Deputy Responsible Officer and Consultant Gastroenterologist
James Paget Hospital NHS Trust
Dr Bernard Brett is a consultant in Gastroenterology and General Internal Medicine based at the James Paget University Hospitals NHS Foundation Trust. His clinical interests include Bowel Cancer Screening (he has been an accredited bowel cancer screening colonoscopist for the last 7 years), Therapeutic Endoscopy and ERCP. Bernard has held several senior management posts including that of Medical Director, Responsible Officer, Deputy Medical Director, Divisional Director, Director of Patient Flow and Appraisal lead.

Dr Eileen Baildam
Consultant Paediatric Rheumatologist, Alder Hey Hospital,
Honorary Senior Lecturer at the University of Liverpool
Eileen Baildam has been a Consultant Paediatric Rheumatologist at Alder Hey Children's Hospital, since 2006. Dr Baildam is Co-Director of the UK's only Experimental Arthritis Treatment Centre and Deputy Chair of the National Institute for Health Research / Children's Paediatric Rheumatology Clinical Studies Group. She is a founder and a PI of the Childhood Arthritis Prospective Study which has recruited 1400 patients with newly diagnosed JIA for long-term follow up. She is on the research steering committee for the UK's Extended Biologics registry.

Dr Anurag Bharadwaj
Consultant Rheumatologist, Basildon & Thurrock University Hospitals NHS FT
Dr Bharadwaj worked as a Consultant Rheumatology (Associate Professor, Medicine and Head, Unit of Rheumatology) until 2003 in a university hospital in India. He did his training as Registrar in Rheumatology (FTTA, Eastern Deanery), completed his postgraduate training in Internal Medicine(1994) and Clinical Immunology-Rheumatology (1998) in India and has been working as a Consultant Rheumatologist in the UK since August 2008.

Iek Cheng
Iek Cheng is a Senior Specialist Paediatric Pharmacist with a special interest in immunology and rheumatology. She joined the rheumatology team at Great Ormond Street Hospital NHS Foundation Trust in 2014.

Revd Erica Crust
Erica is paediatric Sister managing the Rainforest Children's Outpatient and Nurse led unit. Paediatric Rheumatology Nurse at Peterborough and Stamford NHS Trust, shared care with Queens Medical Centre Nottingham)
Previous experience includes the Paediatric acute assessment unit, Paediatric day surgery and Paediatric Inpatient services, Adult Accident and Emergency

Dept and Renal Transplant and Dialysis.

Joanna Douglas
Chief Executive, Allied Health Professionals Suffolk (CIC)
Jo Douglas is a chartered physiotherapist with many years of senior management experience across the health environment. Jo worked with the leadership team to develop Allied Health Professionals Suffolk as a social enterprise in 2011.

Dr Peter Powell
Consultant Paediatrician, West Suffolk Hospital NHS FT
Dr Peter Powell trained at Cambridge and the London Hospital with training posts in London and the North West of England. Peter joined West Suffolk Hospital in 2010 from a Consultant post in Bolton and was recently appointed as the Clinical Director for Maternity and Children's services.

Dr Daniel Fishman
Consultant Physician and Rheumatologist
Luton & Dunstable NHS Foundation Trust (desktop review and comments only)

Dr Fishman qualified from St Mary's Hospital, Paddington, where he also worked as an SHO. His rheumatology training began at Northwick Park Hospital and continued at UCL/The Middlesex. Here he completed a PhD in paediatric rheumatology, funded by an Arthritis Research Council Clinical Research Fellowship. He then went on to the Royal London Hospital and finally Whipps Cross Hospital where he finished his rheumatology and general medical training. Prior to taking up his permanent post, he worked for one year as a Locum consultant at Chase Farm Hospital, Enfield and Kings College Hospital, Dulwich.

CLINICAL SENATE SUPPORT TEAM

Sue Edwards, East of England Clinical Senate Manager, NHS England Midlands & East

SPONSORING ORGANISATION

Dr Kate Armon, Consultant Paediatrician (Paediatric Rheumatology) Norfolk & Norwich University Hospital NHS FT

Rush Ashmore, Associate Director, NHS England Midlands & East Specialised Commissioning

Daniel Eve, Service Specialist, Specialised Commissioning NHS England Midlands and East

Dr Denise Williams, Interim Clinical Director for the Midwifery, Newborn, Children & Young People Strategic Clinical network, Consultant Paediatric Oncologist, Cambridge University Hospitals NHS FT

Appendix 3: Declarations of Interest

Name	Personal pecuniary interest	Personal family interest	Non-personal pecuniary interest	Personal non-pecuniary interest
	None	None	None	None
	None	None	None	None
	None	None	None	None
	None	None	None	None
	None	None	None	None
	None	None	None	None
	None	None	None	None
	None	None	None	None
	None	None	None	None
	None	None	None	None
	None	None	None	None

Appendix 4: Key lines of enquiry

Key Lines of Enquiry **At this stage of development of the service, the panel does not expect fully developed answers to all KLOEs** **Key lines of Enquiry – (at this stage of development the panel does not expect fully developed answers to all KLOEs)**
Interdependencies with other associated medical specialities services and networks – including imaging, orthopaedics, anaesthetics, ICU, renal, neurology, psychiatry and psychology. Current provision within Hubs and within region. Current arrangements with other Units. Planned changes to service provision
Clarity on level 1 & level 2 services: The number of envisaged units, the designation of units, the intended workforce arrangements for recruitment, support and training particularly consultants and specialist nurses, their location and likelihood of recruitment - information on thresholds of transfer – information sharing Location / designation of service (in relation to above): Is this one service with two hubs (shared care) or two 'half' services What are the referral routes, how do they operate with each other How are they configured (the geography), travelling time for patients What is the treatment pathway for patients, can they attend either centre (shared information?) Outreach services and clinics
Pharmacy Arrangements for storage, preparation, transport, disposals and dispensing of high risk drugs. Current numbers of patients on biological medicine and predicted numbers. The likely impact of NHS England commissioning guidance in relation to biological therapies What are the planned arrangements for supporting home care

	Key Lines of Enquiry (continued)
	Workforce planning: more clarity on staffing, workforce development, training. By spreading the workforce over more sites would this reduce availability? Are the consultant and specialist nurse numbers adequate for the volume of patients? Cross cover arrangements. Plans for recruiting specialist staff to the service
	Demographic and activity data Patient travel times to Hubs, to current referral routes, to level 2 units. **Patient flows:** Understanding of current patient flows, particularly Essex and into London, how the proposed service might attract patients from current tertiary centres outside of area. What is the predicted change? Is there registry data – are the number of cases what one would expect when compared to other regions – evidence for under-diagnosis and under treatment (drivers for change above and beyond service specification).
	IT – information sharing between hubs and from level 1 and 2 centres to Hubs

Appendix 5: Summary of documents provided by the Specialised Commissioning as evidence to the panel

a. NHS Standard contract Paediatric medicine: Rheumatology **(**Particulars, Schedule 2 – The Services – A Service Specifications) (NHS England 2013)

b. Core Competencies for Paediatric Rheumatology Clinical Nurse Specialists and Advanced Nurse Practitioners: Administering Disease Modifying Anti Rheumatic Drugs and Biological Therapies to Children & Young People with Rheumatological Conditions, (The British Society for Paediatric and Adolescent Rheumatology (BSPAR) 2014)

c. AHP competencies (BSPAR 2014)

d. East of England Paediatric Rheumatology Operational Model

e. Travel information: Methodology used for MKSM travel times, Journey Times

f. Supporting information from Dr Kate Armon:
    a. Audit of EoE against ARMA soc vs national data
    b. Audit JIA case note summary
    c. Summary ARMA audit
    d. BSR Poster, patient questionnaire