



Young Hearts

Registered charity no 1107986

March 2011

Children's Heart Surgery Closure Big Threat to Oxford John Radcliffe Children's Hospital

Safe & Sustainable National review of paediatric cardiac surgery Is this a plan for a child to die for?

Who is conducting the review? The NHS Management Board and the NHS Medical Director Sir Bruce Keogh, has instructed The National Specialised Commissioning Group (NSCG) to examine the way that children's heart surgery and interventional cardiology services are provided in the UK.

Current situation The UK has 11 centres (hospitals) conducting children's heart surgery. This programme plans to close Leeds, Leicester, Royal Brompton London, Oxford and Southampton. The patients from these already safe centres will have to travel considerable distances to a 'bigger' centre for surgery. (Bigger centres will increase the number of patients (cases) with more surgeons operating in each centre.

Oxford Radcliffe Hospital NHS Trust and Southampton University Hospital On 1 March 2011, Safe and Sustainable, a government appointed review published a consultation document to close 4 or 5 of the 11 Children's Heart Surgery Centres in England. The Oxford Radcliffe Hospitals NHS Trust also announced a Joint Strategic Partnership with Southampton to continue to provide children's heart surgery services at the John Radcliffe Hospital in Oxford and Southampton University Hospital and provide a service for the South of England.

Services for Oxford children have been provided by Southampton following the temporary suspension of the Oxford Unit in March 2010 but are now ready to re-open following an independent review published in July 2010 which found no clinical concerns about surgical practice in the unit and said that it needed to join forces with another unit to increase the number of surgeons available to at least 4/5 working across both units. The Trust will publish detailed plans showing how this will be achieved at the end of March 2011

The Safe & Sustainable review published 4 different options for re-configuring the service none of which include Oxford and only one option (Option B) which includes retaining a service in Southampton. This means if Option B is not chosen the 150 plus children from Oxfordshire and surrounding counties referred by heart specialists at CHOX for heart surgery each year will have to travel to Bristol Children's Hospital or to Great Ormond Street or the Evelina Children's Hospital at St Thomas' Hospital in London for treatment.

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Safe & Sustainable publicly stated none of the current 11 units, including Oxford, are unsafe and all have excellent outcomes. It's concern is that in future this safety record may not be sustainable for a number of reasons such as the shortage of paediatric cardiac surgeons coming through the training schemes / and the need to ensure all rotas are compliant with the European Working Time Directive (compliance with which is now being less vigorously pursued in the NHS).

Safe & Sustainable plan to spend £60 million closing 4 or 5 units to create 6 or 7 larger units on the grounds that the new service will be safer and parents may have to travel further but it will be worth it? As parents of children with congenital heart defects it is important to understand how these changes could affect you and what you can do to ensure that your child receives the best service and one that suits you as parents and your family.

Public Outcry - Children's Heart Surgery Closure Threatens Future Viability of Oxford Children's Hospital

Jude Kelly (Chair YH) – DAUGHTER IN A&E /HOSC/ MP's/TRAVEL

It's not just children with congenital heart disease that need surgery. Our daughter had a virus that attacked her heart and we arrived in an ambulance at the JR's A&E as an emergency. In December 2010 she had an interventional catheter by Dr Wilson, at Southampton. I don't think it is fair for children to have to travel 3hrs to Bristol. We have to protect our YH members and do all we can to safeguard the future of our children. Nicola Blackwood, Conservative MP for Oxford West has been very supportive and arranged for YH's to meet with Simon Burns, Health Minister. On behalf of YH, I attended a meeting in Oxford with 15 councillors who represent HOSC (Oxfordshire's Health Overview Scrutiny Committee) and Jeremy Glyde of Safe & Sustainable. The Vice Chair, Suzanne Pressel was outraged that Safe & Sustainable have dropped Oxford and later went on Radio Oxford to voice her concerns.

YH members are upset, concerned and angry and believe that 'Safe & Sustainable' is 'Unsafe and not Sustainable' and fear raid on other children's hospital services

Maria Crocker – LOCAL SERVICE VITAL FOR SON

My son was diagnosed with a congenital heart defect at 6 weeks old and at 8 yrs with Aspergus Syndrome. We have been struggling for a long time to get David comfortable to go to the hospital which he now knows, and the way that it is set up. When I first found out about safe and sustainable I started a face book campaign to generate awareness. I believe in the John Radcliffe Hospital and that it should be allowed to continue with surgery. It is important for me and my family that there is a local service where David is able to have his operation close to his friends and family.

Fiona Spensley – UNDER NEW SAFE & SUSTAINABLE PLANS MY DAUGHTER WOULD BE DEAD

My daughter Soph Barton was a normal healthy 15yr old who was admitted to The Horton Hospital (Banbury) and then transferred to the JR Oxford intensive care with suspected meningitis. In fact it was a bacterial infection (which could happen to any child) which had seated itself in her heart. It was only apparent that she had a major heart problem (it destroyed the mitral valve and the back of the left ventricle) when she had a cardiac arrest in the hospital. Professor Westaby saved her life with a series of operations and a heart pump which allowed her heart time to heal. I am eternally grateful both to him and

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to YH who donated the pump. Under the new Safe & Sustainable plans Soph would be dead. She would still have been transferred to the JR, given her initial diagnosis, and by the time she collapsed it would have been too late to transfer her to another hospital. We have asked, but the Safe and Sustainable team do not know how many patients, like Soph, would never make it to surgery – they focus on congenital problems, planned operations and surgical outcomes. Patients with heart problems are vulnerable and especially so when they suffer other medical conditions. The JR, at least, has a heli-pad for emergency transfers (as does Southampton), but a helicopter could not land at Bristol or Great Ormond Street!

Yvonne Thomas – TRANSITION FROM PAEDIATRIC TO ADOLESCENCE, REOPERATIONS, WORRY OF SMOOTH TRANSITION ELSEWHERE

I gave birth to my son at the John Radcliffe and he spent the first six months in hospital where he was diagnosed with Truncus Arteriosus. He has subsequently gone through three open heart surgeries and recently had an interventional catheter by Dr Wilson. I am deeply concerned that the Safe & Sustainable steering group do not consider sufficiently these patients who need transition and ongoing care. I believe they have not considered the non cardiac care and services needed by cardiac children. As a consequence of his surgery he has had other non cardiac problems but his local centre has the facilities for children and adolescents with these problems. In the John Radcliffe the surgeons and whole care team have been the ideal people to perform his second and third operations as redo procedures on my son are very challenging. The risk of reoperation a 2nd and 3rd time and the new surgery would have been much greater and immense and more stressful for him and my family in a different centre. The risks would be much greater for my son and other children that need ongoing 2nd and 3rd reoperations of moving to another centre. Currently we have a safe service in all 11 UK centres and over 92% of families apparently are satisfied with this. They talk about sustainability; we do not have clear evidence that what we are moving to is BETTER OR SAFER.

The transition of my son through adolescence has been vital. The immediate adjacency to adult cardiac services is highly desirable to allow easy involvement of relevant professional groups, good communication and smooth transition of care and ongoing multidisciplinary involvement in decision making and management. With the help of all the team and Dr Ormerod this has been very smooth – would it be so smooth elsewhere?

Bill Homewood – THE REPORT, SAFE & SUSTAINABLE and SERIOUS CONFLICT OF INTEREST

Professor Westaby saved our daughter's life by doing emergency surgery at 7mths. We are told she would not have survived a transfer. Oxford has always provided the best surgery and care for her staged ops and we see no reason for going elsewhere. In March 2010, Katy had an interventional cath by Dr Wilson and was the last child to be operated on before the JR was suspended, following 4 deaths on children operated on by Mr Salih. It is sheer madness that he was allowed to join another hospital and continue to practice whilst the report was carried out and that children are still denied being operated on by Prof Westaby a whole year later.

The report: As one of five parents, we found 7 fundamental errors in the report and a major conflict of interest. We are so incensed that we have written to the 'General Medical Council' 1) Mr Bill Brawn was a key person in the report 2) Mr Brawn sits on the 'Safe & Sustainable' committee that have dropped Oxford 3) Mr Salih was Mr Brawn's registrar in Birmingham, before Mr Salih came to Oxford.

Tara Hart – SCBU CARDIOLOGIST IN OXFORD SAVED DAUGHTER'S LIFE – SURGERY IN SOUTHAMPTON

Ten years ago my twin girls were born six weeks early. Jessica weighed 4lbs and would not be with us now if under the new Safe & Sustainable proposals she had been transferred to another hospital. For two days she struggled to survive, with Transposition of the great arteries. To keep her alive until she was strong and big enough for open heart surgery she required an immediate and urgent procedure called a balloon septostomy which was done in SCBU as she was too poorly to be moved. Under the new proposals she would not have even had the septostomy surgery that took place in Oxford, which kept her going for four weeks. She then transferred for open heart surgery to Southampton General Hospital. This hospital is also under threat of closure. Our experience in Southampton was very good.

If Oxford patients are moved to Bristol or London there is the extra costs of travelling, where to stay and loss of earnings which believe me take their toll on everyone in what is already an extremely upsetting and stressful time. Aftercare, follow up appointments and consistency of monitoring the child's progress when a unit is unfamiliar with your child is a big issue too. Having a two year old son as well as the twins, my family network was very important and being away from home made it difficult to draw on any help and support that would be available if treated locally. As a parent of a heart child and being co-founder for the Oxfordshire charity Young Hearts I have considerable contact with other parents and they are all extremely concerned about their children's future and other heart babies to come. I know we would all travel to the ends of the earth for our children but in a large number of cases this is not an option, especially if the child needs urgent life saving surgery and is too sick to be transferred to a new super unit. I know a number of members of our charity who have been to various meetings with the Children's Heart Federation and steering groups to seek answers but unfortunately nothing has been forthcoming to put our minds at rest. The paediatric cardiac consultants at the John Radcliffe Hospital are also sharing our concerns about the repercussions of these new proposals.

Kim Homewood – BIRTH & ADOLESCENCE CRUCIAL – I WANT A HOSPITAL COVERING ALL AGE GROUPS

I gave birth at the John Radcliffe (JR) Oxford and spent 5 weeks in SCBU where our daughter Katy was diagnosed with Tetralogy of Fallot. Over the past 12yrs she has an emergency operation, open-heart surgery and stents. I cannot speak highly enough of the entire clinical team who saved her life. To prepare for her last op, Katy made weekly visits to the clinical psychiatrist at the JR Oxford. If she had been under Bristol this would have been very expensive travelling back and forth, but more importantly she would have missed a whole day a week off school. Before her last op, she was very tired, her immune system was not as strong and travelling as a sick child in winter was stressful. We are fortunate to have a car, but I know of some parents who rely on public transport. Imagine getting home after an op on the bus or train.

It is illogical to separate infants and children from teenagers and adults with the same problems. I want a hospital catering for ALL age groups. The next stage in Katy's life is crucial and involves the transition from paediatric care to services for adolescents. The JR Oxford has one of the best and oldest GUCH practices in the UK which is very comforting as Dr. Oliver Ormerod (adolescence) has already met Katy several times over the past few years, so she already knows and trusts him and Dr Archer (Paediatric Cardiologist) fully understands the importance of a 'smooth transition' so has been planning this for some time.

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My biggest worry right now and the question I will ask Safe & Sustainable is, *'If Oxford paediatric cardiac surgery does not re-open then paediatric cardiac catheter including interventions will stop. Will adolescence/adult congenital interventions and cardiac surgery decrease and will this also stop in Oxford?'* Therefore, it is vital for it to remain not only for my daughter but for everyone who needs a local service. When Katy decides in the future to have a family, she will be able to have an assisted birth with Dr Ormerod present to ensure her safety throughout her pregnancy and delivery. As I see it, the maternity facilities are one of Oxford's greatest assets.

I have no faith in Safe & Sustainable and feel that the whole thing has been rigged from the start. Their proposals are without evidence and are not economically sound. I accept that Southampton and Oxford working together would be a better option than Bristol and therefore look forward to reading Professor Ted Baker's (Medical Director of ORH Trust JR) and the Southampton University Hospital's proposal for this new South of England centre.

One Mum says - ON-SITE MATERNITY IS ESSENTIAL - MOTHER'S AND BABIES SHOULD NOT BE SEPARATED AT BIRTH

Had I had a caesarean birth at the JR under the new S&S proposal, my baby would have been taken to Bristol or Birmingham (who do not have on-site maternity) and I would not have seen my baby for a week! That can't be right – It is vital for Mother's to bond with their babies and breast milk is recommended for heart babies. Furthermore, if my baby had heart surgery without me in the same hospital I would have been devastated and probably had a breakdown as my nerves were already shattered from hearing my child had a heart condition.

Sandra Childs - CHILDREN DENIED ACCESS TO MEDICAL EQUIPMENT AND SURGEON

Cardiac Nurses are highly unlikely to re-locate to the larger centres. What a waste of skills. It seems crazy that in Oxford there are currently two highly trained ECMO nurses who are specialists in working with Professor Westaby on the circulatory pump that saved Fiona's daughter Sophhy. Because the JR is still closed for surgery they are unable to do their highly skilled job. It is madness that children are denied the right to be saved by this very specialised pump that YH purchased and at the time the NHS refused to buy. We believe that children within the 6 counties that the JR serves should not be denied access to Professor Westaby, one of the best surgeons in the world or indeed the YH pump. Finally, can anyone tell me why Safe & Sustainable for the past 10yrs have not sorted out the training of new surgeons with only 2 training places a year – one at GOS and one at Birmingham Children's Hospital ?

Vincent Kehoe - MASSIVE COSTS - HOW MANY MORE LIVES WILL BE SAVED MINISTER?

If this was business, there would need to be some hard information on costs and benefits before engaging in a multi-million pound re-organisation apparently costing up to £60 million. The key question, to which we get no answer, is how many more lives will be saved? Safe & Sustainable acknowledge that we already have good surgical outcomes, but this re-organisation could actually make things worse. The Oxford experience already shows that key personnel will not relocate to other centres, the children of Oxford (and the UK) have lost Prof Westaby (operating now only on adults) and Dr Neil Wilson, Interventional cardiologist (moving to USA for a year) both world leaders. When I met with the Health Minister, Simon Burns I challenged: "When Parliament asks you Minister, how many more lives will be saved by S&S closing Oxford and other centres, you had better have the answers."

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Caroline Langridge – SAFE & SUSTAINABLE PLANNING £60 MILLION SPEND UP OF HARD UP NHS MONEY

I was previously a Non Executive Director on the ORH Trust, where I took a special interest in Children's Heart Surgery. On 25th February 2011, NHS Chief, Sir David Nicholson who will be head of the Specialist Commissioning Board, was commenting about private sector take-overs, mergers and community based care. He told the BBC the combination of reforms and squeeze on spending meant some hospitals would find the future difficult. Yet, the very team he is responsible for, Safe & Sustainable, is recommending spending in the region of £60 million plus to build the bigger heart centres. It is my belief that for around £4million, existing centres could recruit an extra paediatric heart surgeon(s) plus 2/3 other extra members of the team to meet the new S&S standards for 24/7 care. This would eliminate the need to spend £60million on an unnecessarily grandiose and expensive programme where patients have to travel miles and miles for the privilege. This matters at a time of deep cuts in public expenditure with continuing austerity likely over the next 5/10 years. We believe the initiative is more orientated towards fulfilling the European working time directive than caring for the children.

It will be interesting to see the plan that ORHT roll out for the re-opening or merging of Oxford with Southampton. We will be meeting Professor Ted Baker, Medical Director of the ORH soon to get more details of the Trust's plans. It is also interesting to note that £14m was generously contributed by the public towards the £30 million costs of building the Oxford Children's Hospital and circa £30 million of public money was spent on building the new Oxford Heart Centre which provides services for adults including adults with congenital heart services.

Robert Bell – SAFE AND SUSTAINABLE DECISION PERVERSE, ILL CONCEIVED AND ALMOST NAIVE

It is not just Young Hearts who are baffled by Safe & Sustainable's thinking. Robert Bell, Chief Executive Royal Brompton Hospital, London gave BBC interview

When Fergus Walsh, BBC News interviewed Robert Bell on 16.2.11 about Safe & Sustainable's suggestion of closing children's heart surgery at his hospital, he said 'Our position is that it is a decision that is perverse, ill conceived and almost bordering on naive.' It also threatens the continuation of the RBH's surgery for children with cystic fibrosis – some 300 cases a year –as without children's heart surgery; the RBH's Paediatric Intensive care Unit would no longer be viable.

Fergus went on to say, using the Safe & Sustainable current review, it appears that The Royal Brompton and Harefield Trust is one of the most vulnerable to the closures despite it being the largest specialist heart and lung centre in the UK and an acknowledged centre of excellent in Europe. It meets the 4 surgeons' quota and does 450+ ops per year.

VANISHING SOON!

Oxford Children's heart surgery AND related surgery

Imagine arriving at the JR Oxford with no comprehensive service in place. What is in place now WILL NOT BE THERE if children's heart surgery stops. Join the fight against 'Safe & Sustainable' proposals which will close our regional services at Oxford and Southampton

- **Heart Children with NO LOCAL surgery forced to travel to Bristol/London** - Parents and their child will have to travel for up to 3 hours at their own expense instead of having access to local treatment. This will cause particular problems for those families with more than 1 child as judging by our members' experience they may find it difficult to be with their heart child in hospital and still care for other family members left at home
- **Children taken to Accident & Emergency who need heart/lung machine may risk death in transfer** Children will have to travel for up to 3 hours by blue light ambulance to access treatment. Some children will not be able to cope with this and may die in transit or become too weak to cope with heart surgery at a distant location. We have asked S&S to tell us how many children are likely to die as a result of their plans but they refuse to tell us saying it is impossible to give a definitive answer. They accuse us of scaremongering yet their plans focus on elective children's heart surgery and take little account of the needs of children with acquired heart disease needing urgent care. Unlike S&S a number of Young Hearts parents have direct personal experience of their child needing emergency cardiac surgery and only surviving because IMMEDIATE help was available at the John Radcliffe
- **Healthy child falls into river – arrives A&E but with no heart/lung machine will be transferred to Bristol or London** - Because Oxford will no longer do any children's heart surgery there will be no perfusionist to work the paediatric heart and lung machine. Your child will be transported by ambulance to Bristol or London. A helicopter might be available but there is no facility to land directly at Great Ormond Street or in the Evelina in London! Your child needs to go on a life saving heart and lung machine immediately. You'll be forced to take the risk of your child dying in transfer.
- **Public funded (£14m) Oxford Children's Hospital (CHOX) threatened**
A comprehensive range of tertiary or specialist services, plenty of accommodation for parents CHOX offers a fully integrated service at the John Radcliffe campus with immediate access to other services such as A+E/ Maternity and Neonatal Intensive Care. The loss of children's heart surgery which is a key resource may threaten the whole future viability of CHOX
- **Safe & Sustainable to spend £60 million+ of NHS money** - When for £4million existing hospitals (centres) could recruit an extra paediatric heart surgeon(s) plus 2/3 other extra members of the team to meet the new Safe & Sustainable standards for 24/7 care – thus eliminating the need to spend £60million
- **Specialist children's surgical services (CHOX) under threat of closure** Many other services rely on the availability of the paediatric cardiac team to safely operate on children with cranio-facial /neuro-surgery/respiratory/orthopaedic/maxillo-facial problems.

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- **Future of the Paediatric Intensive Care Unit threatened** as it may not be viable without paediatric cardiac services which make up a third of its cases
- **High Risk Maternity & Neonatal Intensive Care (NICU) to lose out**
Oxford has one of the biggest Maternity Units in the UK with over 8,000 births each year. 900 pregnancies a year have detailed fetal cardiac assessment and some benefit from fetal interventional cardiology in the womb to correct heart problems before birth. All this would cease if Safe & Sustainable's plans are adopted. NICU would suffer as a user of paediatric cardiology and is reliant on the availability of a cardiac opinion being available 24 hours a day
- **Adolescence cardiac surgical services will be weakened** as they are an integral part of the service allowing continuity of care and shared expertise relevant to all ages and will be seriously weakened if paediatric cardiac surgery is removed from a centre which has the potential to deal with the continuum from the unborn to adult life.

Young Hearts believes that Safe & Sustainable

1. Have no clinical evidence to base their proposal or back up their figures
2. Do not have the support of the GP commissioners
3. Are not promoting patient choice
4. Have not engaged the public, patients, local authorities fairly. Are utterly biased in its delivery
5. Do not pay attention to clinical opinion
6. Lack real public engagement
7. Have no scientific evidence to say that bigger centres are better?
8. Are unable to say how many more lives will be saved by doing this?
9. Are wasting millions of pounds of NHS money

Young Hearts aims/asks

1. That the Safe & Sustainable proposal is not passed in Parliament to proceed
2. That the government ensures the proposal is fairly put in the hands of patients, communities, clinicians and surgeons
3. That Safe & Sustainable creates a service centred on the needs and wishes of patients
4. That all clinicians, doctors, nurses and surgeons have an input
5. That existing centres are improved and meet quality standards
6. That children are provided with a life saving local service which we are entitled to
7. Patients and clinicians are in control
8. There is a 'less centralised, less bureaucratic stronger children's heart services and surgery within the NHS'

PLEASE ACT NOW!

Save your local Oxford hospital

A child's life depends on it

Safe & Sustainable's proposal aims to close 4 or 5 of 11 Children's heart surgery units. Oxford does not appear in any options despite a new joint service with Oxford and Southampton working together to meet all the standards for 24/7 care set out by the review. The Oxford ORH Trust is collaborating with Southampton to form an integrated service for the South of England. Young Hearts supports the new partnership which has already delivered an excellent service for our members at Southampton. We are demanding that Safe & Sustainable support this option as a better and more cost effective solution.

What you can do to HELP

- ♥ Sign our petition www.younghearts.co.uk
- ♥ Contact your MP www.parliament.uk Write to or email your Local MP Telephone 020 7219 4272
www.younghearts.co.uk has a letter you can download
- ♥ Contact Your GP Write to or Email your GP
- ♥ Write to Professor Ted Baker. Medical Director, ORH Trust
John Radcliffe Hospital, Headley Way, Headington, Oxford OX3 9DU
- ♥ Follow Mums on Facebook
Maria Crocker: Save Oxford Children's Heart Surgery Unit
Julie Langston: Save The John Radcliffe Kids Cardiac unit in Oxford
- ♥ Register now to attend The Safe & Sustainable Public Consultation
www.eventsforce.net/safeandsustainable
- ♥ Attend The Public Consultation at Oxford and Southampton

This is your chance to fight for the future of your child's heart service and ask about the real danger to your children – We urge you to attend the Public Consultation

Oxford

Wednesday May 4th 2011 - 6pm – 8pm

Kassam Stadium, Oxford (Oxford Football Ground)

You need to register to attend this event.

Southampton

Tuesday 24 May 2011, 6pm-8pm, Guild Hall, Southampton

(A free bus ride to Southampton and back will be provided for YH members but please reserve your place by contacting Maria Crocker on 0845 4673052)

YH & MP Nicola Blackwood meet Simon Burns, Health Minister

Nicola Blackwood, Conservative MP Oxford West, is very concerned about moving paediatric heart surgery from the JR and arranged for YH members Jude Kelly, Caroline Langridge and Kim Homewood along with Dr Nick Archer (Paediatric Cardiologist, JR Oxford) and Vincent Kehoe (parent) to meet with Simon Burns, Health Minister in Westminster. Our meeting on 14.2.11 went very well and Mr Burns gave a commitment to ensuring new joint Oxford/Southampton proposals would be considered as part of the consultation process.

NHS urges people to have their say on future of children's congenital heart services

The NHS has launched a major four month public consultation on the way children's congenital heart services should be provided in the future. The NHS is urging everyone with an interest in children's congenital heart services to take part. Please view the website (or request a hardcopy from Safe & Sustainable). If you wish to read it on line then do so on:

www.specialisedservices.nhs.uk/news

Young Hearts Press Statement in response to Safe & Sustainable – Children's Congenital Cardiac Services in England 16.2.11

1. Young Hearts rejects the flawed analysis of the Safe and Sustainable review which suggests that surgical services for children with congenital heart disease should no longer be provided at the John Radcliffe Hospital in Oxford. For the following reasons.
2. Young Hearts believes that the S&S review should be making recommendations based on the fact that paediatric congenital heart patients need many services over a long period of time and that integrated tertiary care from antenatal diagnosis to old age is better placed within one hospital or campus. Furthermore those children that do not have congenital heart defects but have acquired heart problems e.g.: infections that attack the heart; trauma from chest injuries (road accidents) etc may also need many services over a long period of time.
3. At the start of the review process, we participated in a stakeholder's consultation meeting to agree the key components for future services. There was broad support for the fact that congenital heart patients need many services over a long period of time and that care should be given in an integrated way within one hospital or campus where the whole range of services can be provided.
4. The John Radcliffe Hospital is a prime example of a large specialist hospital where patients can be treated for all aspects of their care from conception onwards. In the early pre-birth stage parents are offered fetal cardiology services to correct birth defects in the womb. This includes ante-natal screening, monitoring and treatment of the fetus in the womb for some conditions. Mothers are then delivered in the Silver Star high risk maternity unit in the JR's Women's Centre. This unit also

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provides maternity care to adult congenital heart patients jointly with the Oxford Heart Centre as these women may be at higher risk when giving birth.

5. Once born a child may be offered support in the JR's Neonatal Intensive Care Unit which serves a large regional catchment.
6. Children needing in-patient treatment for congenital heart surgery are treated in two designated wards at the Oxford Children's Hospital at the JR which are beautifully equipped following the successful charitable fundraising campaign which raised £14million towards the £30 million costs of the new children's hospital. In addition parents are offered on-site accommodation in the Ronald Macdonald unit.
7. Children with congenital heart conditions often need treatment for other conditions (kidney, liver, brain, gastro-intestinal, genetic etc) so have access to on-site related children's specialties within the dedicated Oxford Children's Hospital
8. An excellent range of outpatient facilities are also provided in the Oxford Children's Hospital with ready access to the full range of diagnostic modalities. These include the Oxford Homograph Bank (Heart Valve Bank.)
9. The JR also has a dedicated new paediatric Emergency Department and 24 hour helicopter landing facilities for acutely ill patients
10. The Oxford Radcliffe Hospital NHS Trust jointly with the University of Oxford hosts one of the 5 Biomedical Research Units in England. Oxford is highly regarded for its research and has also pioneered many new surgical techniques including Professor Westaby's ground breaking use of an artificial heart pump to save the life of Sophy Barton, by providing a temporary bridge whilst her heart recovered and repaired itself. This was a world first and an important area for further research.
11. When children reach adolescence they move on to be cared for in the Adult Congenital Heart Service which is housed in the new state of the art Oxford Heart Centre which opened in 2010 with designated children's cardiac catheter lab
12. All of the above are reasons why we believe that Oxford is the ideal site to provide the 21st century state of the art children's heart services on a single integrated site with excellent access for many parts of the country.
13. By contrast few of the options suggested by the S&S Review include services on integrated hospital sites where all the relevant services are co-located. For example, neither Birmingham Children's Hospital, Alder Hey Children's Hospital or Great Ormond Street Children's Hospital provide on-site maternity or adult congenital heart services as by their very nature they are limited to only providing children's services.
14. The S&S Review team also based its assessment of the capacity of Oxford to meet new higher standards on a visit to the JR in June 2010 criticising the Trust's former governance, leadership and management. This analysis is deeply flawed as the ORHT has a new top flight Chief Executive and a new Medical Director both of whom recently held these positions with distinction at the highly rated Guys St Thomas Foundation NHS Trust. Under their leadership the Trust has made significant changes including the creation of an innovative new clinical management structure put in place in

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November 2010. The S&S Review team has ignored these positive new developments and based their assessment on the past and not current position.

15. We acknowledge the argument put forward by the S&S Review that it is desirable in future for units to have access to a larger group of surgeons to offer 24/7 services. That is why we are supporting new proposals being put forward by the Oxford Radcliffe Hospitals NHS Trust jointly with Southampton University Hospitals NHS Trust for a South of England Congenital Heart Service providing services jointly in both Oxford and Southampton to the same jointly agreed policies offering high standards of care to a population of 7 million people.
16. We are disappointed that the S&S Review team were unwilling to postpone their launch on 16 February to include proper consideration of this new option but we were re-assured at our meeting with Simon Burns, Minister for Health on 14 February 2011 that full and proper consideration will have to be given to this new option as part of the response to the consultation process.
17. Young Hearts continues to support the provision of local accessible services for parents. We are concerned that the options put out for consultation will mean parents having to travel further to access services which are no better than the services we have experienced in Oxford and now Southampton. Costs of the proposed new services are likely to increase significantly as few of our parents will choose to go to Birmingham as most would prefer to travel to London.
18. From the commissioning perspective services from London is considerably more expensive so more money will need to be allocated to funding children's heart services from what are already tight budgets if the London services are expanded
19. Parents would also have to fund higher travel and accommodation costs including the cost of family support for other family members left at home as there is simply not enough parental accommodation to meet increased demand at other sites. Young Hearts has made charitable grants of many thousands in the last quarter alone to help parents meet these excess costs whilst the surgical unit at Oxford is temporarily closed.
20. The question in our member's minds is, in any of the proposed configurations, what will be the benefits and what the risks are. We are very concerned at the risk of children dying in transit to one of these larger more distant locations. We know from our own experience that many children successfully treated in the recent past as an emergency case at the JR would not have survived without urgent local treatment. We urge Simon Burns, Minister of Health to press his medical advisers to state quite clearly how many children's lives will be saved or their outcomes improved as a result of the implementation of these proposals and at what cost in terms of lives lost of children in transit.
21. Finally, we wish to point out that closure of a congenital cardiac surgical service anywhere is disruptive and has many disadvantages and adverse consequences. In a teaching centre such as Oxford with a wide range of services, closure of a congenital cardiac surgical service would have a profound knock-on effect, which would destabilise many cardiac interventions, fetal, neonatal and paediatric specialties, as well as cardiac surgery and adolescent / adult cardiology.

Press statement – ORH 16.2.11

Oxford joins Southampton in children's heart surgery network

Date: 16 February 2011

Oxford Radcliffe Hospitals NHS Trust has formed a strategic partnership with the children's heart surgery centre in Southampton, which has been rated as providing the country's highest quality service outside London.

The Children's Hospital, Oxford

The partnership with Southampton University Hospitals Trust has increased the number of operations being carried out and puts Southampton within easy reach of the new requirements being introduced for centres that perform children's heart surgery in England.

The national Safe and Sustainable review of children's heart surgery services recommends that children's heart surgery should only be provided in a smaller number of larger centres to achieve the best outcomes for children.

Since the John Radcliffe Hospital in Oxford suspended children's heart surgery in February last year, the majority of children needing heart operations and other invasive cardiology procedures have been going to Southampton for treatment.

This arrangement has worked well for Oxford's patients and has increased the number of patients being treated in the Southampton centre, which needs to be performing at least 400 operations every year to meet the requirements to be one of new larger centres.

An independent report by Professor Sir Ian Kennedy ranked Southampton as the highest quality centre outside London and described its service as exemplary in three key areas. Despite this, the review has decided to ask the public later this month to consider whether Southampton should remain open in the future.

In a four month period of public consultation, four options will be presented and the public, patients and staff will be asked which centres they think should remain open. One of the options includes Southampton. Oxford is not included in any option because the Safe and Sustainable review team felt that, as one of the smallest centres in the country, it had the least chance of achieving the new standards being set.

Southampton and Oxford are working together in a clinical network to create a comprehensive and high quality service for children with heart disease in the South of England, whilst ensuring that families in all areas have access to excellent local care.

The Safe and Sustainable review has focused on cardiac surgery, but surgery is only one part of a life-long journey of care for patients who come under the cardiac teams. Both hospitals consider it important that patients have access to the other aspects of their care – like outpatients appointments – as close to home as possible.

Mark Hackett, Chief Executive of Southampton University Hospital NHS Trust said:

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"The results we have achieved in Southampton over the last 40 years speak for themselves and we are delighted that the Kennedy report has supported the confidence our patients and families have always had in the high quality of our service.

"However, we remain concerned that the review has not yet guaranteed the future of the country's leading centre outside London, and it is now important that the public supports us during this period of consultation.

"The Southampton-Oxford clinical network demonstrates that our organisations have already understood and acted on the principles of Safe and Sustainable in this area."

Sir Jonathan Michael, Chief Executive of the Oxford Radcliffe hospitals NHS Trust said:

"A partnership between Oxford and Southampton will ensure that children and families in the areas we serve receive the best treatment available. We believe that it is in the best interests of patients that services are preserved as locally as possible and it is important to remember that surgery is only one part of the treatment of children who often have complex needs.

"The networking arrangement that is working so successfully with Southampton is an innovative opportunity to provide excellent care in a way that fulfils the aims of the Safe and Sustainable review while preserving the wishes of many families that they access the majority of the care for their children as close to home as possible."

Notes

- Southampton University Hospitals NHS Trust has four children's heart surgeons (the fourth surgeon is a new appointment and starts with the Trust in July 2011). There are seven paediatric cardiologists in the service which involves more than 400 staff in total. Oxford clinicians have been working in Southampton for several months and the system has worked well for patients.
- During 2010, Southampton performed 404 congenital heart surgery procedures, 338 of them were in children aged 16 or under. In February 2010 when surgery was suspended in Oxford, the majority of operations for its patients were performed in Southampton.
- The Kennedy Report ranked Southampton as the leading centre outside London. It described the service as exemplary in the following areas: management of paediatric intensive care; supporting parents with information and choice; and training and innovation
- The 2003 Paediatric and Congenital Cardiac Services Review stated that "The overwhelming impression of the Southampton service was that it represents a model of what services for children and adults with heart disease should offer."
- Both the Oxford and Southampton hospitals provide a wide range of services. Patients born with heart disease often have complex health needs and the co-location of services like maternity, specialist children's services and paediatric intensive care, as well as the provision of adult cardiac services all on one site – ensures a more joined-up service for patients and a smoother transition to adult care.
- The clinical teams at Oxford and Southampton have been working closely to develop proposals for a network of care across the South of England that provides a more sustainable paediatric cardiac surgical service in line with the aims of Safe and Sustainable, while at the same time maximising the benefits from the co-location of the interdependent services that are so often needed by this group of patients who are born with heart defects.

ORH Trust to deliver Oxford/Southampton proposal

- On 16th February 2011 Sir Neil McKay, of the PCT Panel said he would welcome any other options being put forward for consideration. The ORH Trust will put forward a proposal for Oxford to join Southampton.

The ORH Trust (JR Oxford) plans to merge its paediatric cardiac service with the Southampton service as the Oxford service is too small to survive on its own. Southampton is recognised nationally as a centre of excellence providing safe and high quality care for children with heart problems, but because of its geographical location is considered a small centre. Southampton is at risk of losing surgery and interventional cardiology services. If Southampton and Oxford join together, the number of patients output will rise to more than 400 cases per annum which is the level specified by the S&S guidelines.

Medical Directors and Chief Executives of both Trusts are committed to this project for all the reasons to do with co-location and strengthening existing networks in many specialities.

Professor Ted Baker is working with Southampton on a joint 'Oxford/Southampton' proposal, for a 'South of England Congenital Cardiac Service' and welcomes letters from parents in support of this. Dr Archer, Cardiologist is in full support of having some surgery at Oxford with more complex operations done at Southampton.

View this website to hear about Southampton's comments:

<http://www.suht.nhs.uk/AboutTheTrust/Newsandpublications/Latestnews/2011/Haveyoursaytokeepworld-classchildrenshearturgeryinsouthampton.aspx#>