

Relocation of RNHRD's Specialist Paediatric CFS/ME and Paediatric Rheumatology Services

Introduction

The following report details the outcomes of Patient and Public Engagement activities on the proposal to relocate the Specialist Paediatric CFS/ME and Paediatric Rheumatology services from the Mineral Water Hospital site.

Background to the engagement

The Royal National Hospital for Rheumatic Diseases (RNHRD) was acquired by the Royal United Hospitals Bath (RUH) on the 1 February 2015 in order to resolve its long standing financial challenges and to preserve the valued services currently provided at the Mineral Hospital Site (also known as The Min). Throughout the acquisition process, which has spanned a number of years the RUH has clearly stated its intention to relocate services from the RNHRD's Mineral Hospital site to the RUH site or, where clinically appropriate and to maximise patient benefit, to suitable community settings. The relocation of services from the Mineral Hospital site will allow a number of promised benefits to be realised for the patients and communities served:

- **Integration:** Improved integration of services and skills will support further expansion of shared care models, particularly for patients with multiple, and complex long term conditions. In time, this is expected to lead to further development of new service models in areas such as therapies and self-management in line with the national direction of travel. Access to specialist expertise and diagnostics will also be extended.
- **Sustainability:** Through integration of service models and closer working with community partners, services will be sustainable for the future, both financially and operationally. All clinical services are expected to continue in line with commissioner requirements.

The ability to fully integrate and align services on a single site was a core component of the original business case for acquisition and sustainability of services. It will improve efficiency and effectiveness, maintaining patient experience and quality of service delivery as well as increasing value for money from the public purse.

- **Profile and people:** The profile and brand of the RNHRD is both nationally and internationally recognised. This will continue to be maintained and further developed as part of the RUH to ensure that high quality, innovative service models are supported and in turn, promote further research investment in the local area that will ensure the strong track record of and ability to recruit high calibre staff can continue.
- **Service development:** The plans for the future development of services have been produced jointly with clinical teams. These plans take into account both local concerns such as ensuring the development and delivery of a long-term strategy for valued local amenities e.g. hydrotherapy, as well as the wider direction of travel from commissioners, focusing on:

- Delivering innovative and outcomes oriented care for patients across our community.
 - Reducing reliance on bed-based models of care where appropriate and safe.
 - Increasing self-care through empowering our patients and supporting them with community based delivery.
 - Delivering quality and operational performance standards across all services, aligned with national best practice.
 - Through delivery of all of the above, containing the costs of service provision now and in the future to enable services to better keep up with increased demand.
- **Research and Development:** The combined (RNHRD & RUH) organisation has the second largest R&D portfolio amongst medium-sized hospitals in the NHS. Bringing together the expertise and diverse research areas through the acquisition has resulted initially at a simple level in the pure addition of the studies of both hospitals whilst maintaining recognition of both RUH and RNHRD brands. The joining and co-location is however expected to also provide significant growth in research as bid writing, research culture and fund management are further strengthened alongside access to a larger population for clinical trials.
 - **Environment:** It is recognised that whilst the Mineral Hospital building is highly regarded by the patients it serves; in the longer term it is not a suitable or cost effective base for high quality service provision.

About the Specialist Paediatric CFS/ME service

The Specialist Paediatric CFS/ME service at the Mineral Water Hospital currently provides the following:

- Initial assessment and outpatient treatment programme tailored to individual needs.
- Treatment is offered via 3-12 follow up appointments, these are a mixture of CBT, therapies and active management.
- Support for families
- Support for schools/education.
- Access to research and evidence based treatment
- Transitional clinic with the adult fatigue service

In addition, the following clinics are provided in the community:

1. Salisbury
2. Cadbury Heath (South Gloucester)
3. Wroughton
4. Wells
5. Dursley
6. Castle Cary
7. Yeovil
8. Swindon
9. Macclesfield
10. Warminster
11. Southville (Bristol)
12. Eastgate (Bristol)

13. Cheltenham
14. Cirencester
15. Bridgwater
16. Taunton

There are 2-3 clinics a week for all patients, which need to be delivered in an acute setting and be accessible to all patients.

About the Paediatric Rheumatology service

The Paediatric Rheumatology service at the Mineral Water Hospital currently provides a dedicated outpatient paediatric and adolescent rheumatology service. The service aims to maintain the function and independence of any child or adolescent with rheumatic disease and musculoskeletal problems by reducing disease activity, helping to prevent any disability, and supporting them to achieve their full potential socially, educationally and psychologically. It provides:

- Two outpatient based clinics per month from RNHRD site with Consultant, Registrar and Nurse present.
- All patients will be reviewed by the Consultant.
- Access is via GP or consultant referral

The service offers:

- Initial assessment and outpatient treatment programme for children and adolescents tailored to individual needs.
- Expertise in case management and outreach consultations to support local teams, the family and schools.
- Management of common and specialised musculoskeletal and soft tissue conditions.
- Management of acute and long-term musculoskeletal and rheumatological conditions.
- Prevention and management of osteoporosis in children.
- MDT – Consultant/Nurse Specialist/ Physiotherapy Support.
- Support for families.
- Access to Research and evidence based treatment.

Relocating the Specialist Paediatric CFS/ME and Paediatric Rheumatology services to the RUH site would ensure continuity of care for patients and their families, enable the services to be co-located with wider paediatric services in a designated paediatric department, and provide an improved environment and dedicated facilities for younger patients.

As part of a larger acute hospital, it also further strengthens governance and safe guarding processes and increases the clinical team's access to peer support and clinical guidance. There will be no impact to patients accessing the Specialist Paediatric CFS/ME community or satellite clinics, all of these clinics will continue in their usual location, only the location of the RNHRD based service and the administrative base will change. There will be no change in the level of service provision for Specialist Paediatric CFS/ME and Paediatric Rheumatology patients, they will have access to the same clinical teams and benefit from wider clinical support.

Methodology

A programme of Public and Patient Engagement was carried out to determine people's views about the proposal to move the service, delivered by the same staff as currently, to new premises at the Children's Unit at the RUH site. Broad engagement activity regarding the proposals to relocate RNHRD service out of the Mineral Water Hospital Building commenced in September 2015, and outlined the Specialist Paediatric CFS/ME and Paediatric Rheumatology services as the first to potentially relocate to the RUH site. A dedicated email (ruh-tr.haveyoursay@nhs.net) to seek feedback at any point in the process has been established and published on the RUH website and in all communications materials.

Methods used to obtain feedback

A number of communication and engagement activities have been undertaken in order to obtain feedback from a wide range of people including; service users, relatives and carers, staff and other healthcare professionals and support groups.

The aim of the activity was to raise patient and the public awareness of proposal to relocate the service, outline the rationale for change and highlight how people could influence the proposal and encourage feedback.

A period of focussed communications and engagement activities on the proposal to relocate the Specialist CFS/ME service was launched in October 2015 and people had the opportunity to feedback until 6th January 2016.

Key activities undertaken to obtain feedback during this period are outlined below:

Activity	Purpose
Dedicated email address for feedback established ruh-tr.haveyoursay@nhs.net	Provide a dedicated channel for stakeholder feedback.
Information about the proposals to relocate services from the Mineral Hospital site is available on the homepage of B&NES CCG website.	Wider circulation of information regarding proposals and signposting for further details and opportunities to feedback directly to the CCG or the RUH.
B&NES CCG Annual General Meeting 17 September 2015.	RUH Chief Operating Officer presented proposals to relocate RNHRD clinical services from their current location along with potential timings for relocations and inviting feedback on proposals. The slides and the minutes from this meeting are available on B&NES CCG website: http://www.bathandnortheastsomersetccg.nhs.uk
B&NES GP Forum 24 September 2015.	B&NES CCG Clinical Chair update on proposals
RUH Annual General Meeting 30 September 2015.	RUH Chief Executive outlined proposals for RNHRD service relocations and invited feedback on proposals.

	<p>Presentation from Clinical lead for the Paediatric CFS/ME service outlined proposal and rationale for service relocation.</p> <p>Information stands relating to service relocations and the RUH estates redevelopment programme were available and manned during the event.</p> <p>Opportunities to discuss proposals and ask questions or provide feedback anonymously through a feedback box.</p> <p>The slides and the minutes from this meeting are available on the RUH Website www.ruh.nhs.uk</p>
Letter from RUH Commercial Director (dated 6 October 2015, circulated to the Health & Wellbeing Select Committee via Policy Development and Scrutiny Project Officer).	Provide an update on proposals, timings and activity information for the proposal to relocate this service relocation, and provide the opportunity to suggest any questions the committee would like asked during PPE.
October 2015, service specific information about the proposals to relocate the paediatric rheumatology and CFS services available on the RUH and RNHRD websites.	Inform current and future patients of proposals and signpost opportunities to feedback and influence.
October 2015, information about the Paediatric service relocations was made available in the outpatient area at both the Min and RUH children's unit.	Raise awareness amongst current patients, relatives and carers.
October 2015, Information about proposals on BaNES and Wiltshire Clinical Commissioning Group websites	Raise awareness amongst current patients, relatives and carers. Signpost to how people can provide feedback
November 2015, Wiltshire Clinical Executive meeting	Briefing on proposal to clinical Chair and Clinical Executives from the three main GP localities.
15 th November 2015, media release issued.	Raise awareness of the proposals, channels for feedback and to advertise the engagement event. Features online and in print in Bath Chronicle
Wc 16 th November 2015, online service specific questionnaire available on RUH and RNHRD websites.	Capture feedback on proposals.
23 rd November 2015. Letters and	To encourage feedback to identify what is

<p>questionnaires sent to 350 past and current Paediatric CFS patients to outline:</p> <ul style="list-style-type: none"> • the proposal to relocate the service • the rationale for change • supporting background information • inform them about the engagement event • provide channels to feedback, email address, survey link (a hard copy of the survey was also enclosed). 	<p>important to maintain or improve in relocating the service, and also reassure patients that they will still have access to the service and be cared for by the same clinical teams.</p>
<p>November 2015, information on the NHE England Youth Forum</p>	<p>To invite feedback and advertise engagement events</p>
<p>November 2015 issue of the RUH staff Newsletter @RUHBath, (available to all staff and publically available across the Trust) featured the proposals to relocate the service and the rationale for the proposed move.</p>	<p>To outline information about Paediatric CFS/ME service relocation, how to feedback and signpost to where further information could be found.</p>
<p>25th November 2015, report and update on activities at the Health & Wellbeing Select Committee meeting held in public</p>	<p>Update on activities.</p>
<p>November 2015, Association of Young People with ME published information on the homepage of their website.</p>	<p>Raise awareness and promote the engagement event</p>
<p>December 2015. Winter edition of Insight, the RUH Community Magazine issued to approx. 8,000 stakeholders at the end of November</p>	<p>Outlined information about proposal, rationale for change, signpost to further information and invite feedback.</p>
<p>December 2015, inclusion in Healthwatch Wiltshire and Healthwatch B&NES newsletters</p>	<p>Outlined information about proposal, rationale for change, signpost to further information and invite feedback.</p>
<p>2nd December 2015, an engagement event was held in the dedicated children's area on the RUH site.</p> <p>The event was facilitated by the Head of Stakeholder Engagement</p>	<p>To capture feedback from patients, carers, staff and other interested stakeholders on the proposal to relocate the service and enable them to see the proposed future location for the service.</p>

Specialised Commissioning - NHS England South.	
<p>w/c 2nd December 2015. Letters and questionnaires sent to 120 past and current Paediatric CFS patients to outline:</p> <ul style="list-style-type: none"> • the proposal to relocate the service • the rationale for change • supporting background information • inform them about the engagement event • provide channels to feedback, email address, survey link (a hard copy of the survey was also enclosed). 	<p>To encourage feedback to identify what is important to maintain or improve in relocating the service, and also reassure patients that they will still have access to the service and be cared for by the same clinical teams.</p>
<p>14th December 2015, an engagement event was held in the dedicated children's area on the RUH site.</p>	<p>To capture feedback from patients, carers, staff and other interested stakeholders on the proposal to relocate the service and enable them to see the proposed future location for the service.</p>

What did we ask people during patient and public engagement activities?

Patient and Public Engagement activities undertaken outlined; what was changing and why, how patients and public could influence proposals and the channels for feedback. It highlighted the fact that the Paediatric CFS/ME service had to relocate out of the Mineral Water Hospital building (as part of a careful and phased programme of service relocations) and that one proposal was to move it to the dedicated Paediatric Department on the RUH site. It was also outlined that the proposed relocation only affected the Paediatric CFS/ME service provided from the Mineral Water Hospital Site and that the satellite clinics (outlined earlier in this document) would continue in their current locations.

During patient and public engagement feedback was invited on how people would like to see the service provided now and in the future, specifically:

- To identify the potential benefits of moving location
- To highlight any concerns they may have.
- Outline what they think is good about the service so far?
- Indicate what could be improved about the service they have received?

In addition, feedback on travel and parking, the physical environment and the range of services available, and what they felt the most important things for us to consider in relation to the care of people with this condition was sought.

How did we let people know about the public and patient engagement activities?

In addition to the activities outlined in the table above, other ways in which patient and public engagement activities were outlined through this period included; social media channels such

as Twitter and Facebook. Local Health Economy communications Working Group colleagues and other partner organisations including BaNES and Wiltshire Clinical Commissioning Groups and voluntary sector organisations such as the Association of Young People with ME also cascade information out to their patient populations and signposted to further details and channels for feedback. Information was also circulated to other relevant supporting charities including Action for ME, Arthritis Research UK, NRAS and local support groups. Information relating to the proposals and how to influence them was also published on the Careforum and BaNES Healthwatch websites.

Steps taken to ensure equalities duties were met

A number of steps were taken to ensure that engagement and consultation activities were accessible to all. The RUH is working with the Local Health Economy (LHE) Forum, whose membership includes Executives from B&NES, Wiltshire and Somerset Clinical Commissioning Groups (CCGs), NHS England, RUH Governor and patient representation, to agree the process for communication and engagement activities to support the potential relocation of clinical services from the Mineral Water Hospital site over the next three years.

To support this activity, the RUH has established an LHE Communications Working Group (which is comprised of RUH and NHS England and CCG communications and engagement leads and a patient representative) to ensure all service related PPE is conducted in line with the Government's Consultation Principles for Public Bodies (Oct 2013).

The RUH Equality and Diversity lead scrutinised the questionnaire, and all patients families were contacted and given the opportunity to feedback and attend the engagement event. The lead clinician for the service has been involved in planning the Public and Patient Engagement strategy and developing supporting communications and engagement materials.

Impact Assessment and Equality Impact Assessments have been completed for both service areas. There will be no change in the level of service provision for Paediatric CFS/ME and Rheumatology patients they will have access to the same clinical teams and benefit from wider clinical support. There are no impacts on patient choice for either service by the proposal to relocate the services to the RUH site and there is support from senior clinicians whose services will be affected.

Results (You said):

The engagement event for the Specialist Paediatric CFS/ME service held on 2nd December 2015 was attended by a range of individuals; seven families, parents of children with CFS/ME, the CEO of Association of Young People with ME, a CFS/ME researcher, the Specialist CFS/ME Paediatric service lead and the RUH Divisional Manager for Women and Children.

The engagement event for the Paediatric Rheumatology Service held on the 14th December 2015 was attended by three people, an NHS Lay Patient Rep, a Specialist Commissioner and a representative from Wiltshire Parent Carer Council.

17 completed surveys were received for the Specialist Paediatric CFS/ME service. Six of these had been completed by relatives or carers of a young person with CFS/ME. Ten young people with CFS/ME and one retired GP. Eleven people provided the first part of their postcode which breaks down as follows:

First part of postcode	Number of people
BA	5
BS	2
SN	1
GU	1
GL	1
SO	1

Respondents were predominantly accessing services at the RNHRD, other locations included Swindon, Bristol, Cirencester, Cheltenham and Gloucester and Skype consultation.

Eleven people completed the equality and diversity questions at the end of the survey, details below:

Age	Disability	Type	Religion	Language	Ethnic Group
1 - Under 12	4	1 – physical	Christianity- 6	English- 10	White British - 8
9 - 13-17		2 Long term illness	Hinduism -1		Indian- 1
		1 – sensory	No religion -2		White Irish- 1
			Not stated -1		Not stated -1

2 completed surveys were received for the Paediatric Rheumatology service. One had been completed by a patient and the other respondent was a carer of a young person with a rheumatic condition. Both respondents provided the first part of their postcode which breaks down as follows:

First part of postcode	Number of people
BA3	1
TN11	1

No respondent completed the equality and diversity questions at the end of the survey.

Feedback received through Patient and Public Engagement activities

Feedback received for the Specialist Paediatric CFS/ME Service:

During Patient and Public Engagement activities overall respondent's feedback positively on the service they were currently receiving, and there have been positive comments in relation to the proposed new location in the dedicated children's unit on the RUH site.

- *"I think they will get a better service here because there are more facilities at RUH and more services we can access – we don't know yet if she just has one thing or several things wrong with her so we don't know what services we might need. "*

- *“I can’t wait to move to RUH because they have patients my own age here. The Min is full of old people.”*
- *“...RUH is more accessible, which is what we need...”*

The majority of respondents felt that the level of expertise of the people treating the patient was the most important thing to consider in relation to the care of young people with CFS/ME.

- *“We have received excellent care and advice from the specialist team so far and we hope that the service will continue to provide the same into the future.”*
- *“They have been really supportive and have helped me use methods to try and cope with CFS/ME.”*

Parking at the Mineral Hospital site was mentioned by several patients and carers as an issue, particularly when considering that often patients are unable to walk long distances

- *“RNHRD is an awful location – parking isn’t on site and ill children with CFS/ME have to walk too far from the car to the hospital. The difficulty in parking and then getting my child to hospital has been too much for her in the past.”*
- *“Awful, there is nowhere near enough to the hospital to park, especially when walking is a problem.”*
- *“In the middle of Bath and there is no parking so involves a considerable walk”*
- *“Moving the service here is better for me as I work at RUH. I know the staff, they know us, and they’re all so friendly at both hospitals so it is good that the kids will have continuity of care. There’s also a good bus service to RUH so the parking doesn’t affect us.”*

Respondents also identified improved communication between healthcare professionals and a child friendly environment as additional factors to consider.

- *“Better ways of communicating with other healthcare professionals to improve continuity of care. Improved communication with schools – education provision is poorly managed.”*
- *“I think it would be really important for my children to visit an environment that is not too clinical but child friendly, inviting and peaceful.”*

A minority of respondents felt that there were some aspects of care that they would prefer not to have delivered in a hospital setting.

- *“I would prefer to avoid a hospital setting wherever possible. Remote access from home is desirable.”*
- *“The catch up appointments do not need to be in a hospital setting.”*

Most respondents agreed that they would be prepared to travel more than ten miles for the very best care, with around a third saying they would travel 50 miles or more.

- *“Travelling is tiring, but if it makes be better it’s worth it up to a certain distance.”*
- *“I want to get better so I will travel a long way.”*

Suggestions for how the service could be improved in the future included better education in the wider community, opportunities to take part in research and continued emphasis on continuity of care.

- *“Please provide literature for schools, there is no understanding of this illness in the education sector. We want to be part of the research into the cause and potential cure for this illness. How can the CFS/Me service provide input for medical trials?”*
- *“I think that seeing the same group of professionals is good, but having a group of multi agencies linking together is an advantage.”*
- *“It takes time for a child to trust the professional they are talking to and so seeing the same person each visit is hugely important. It is an invaluable service.”*
- *“...I would like to talk to someone like a psychologist about how I feel and I would like to be able to meet other siblings to share our experiences and have a break and some activities that are just about us for a change.”*
- *“We would like family therapy to help relieve our stress and we need time in private as mums and dads to be able to say things and ask questions, but not in front of our children.”*
- *“It would be good if every service had meeting groups for young people the same age to talk to each other about what it is like to have CF and we can tell each other how we’re feeling and support each other. Tonight is good because we are able to meet each other and there’s time to have fun.”*

Only one respondent specifically said that they would prefer the service to remain at the RNHRD.

- *“Attending RNHRD is the best place for this service as it’s more relaxed than a main hospital setting.... Keep it the same as now.”*

Feedback received for the Paediatric Rheumatology Service:

The respondents indicated they are happy with high standard of care currently received (includes treatment at RNHRD)

Comments on what is good about the service so far:

- *“Excellent service for the last seven years and for other family members for longer”*
- *“Prompt appointments. Prompt return of phone calls when questions arise. Generally efficient and good service.”*

Respondents were prepared to travel any distance for the very best care:

- *“Relocating ‘Min’ is v. much a good idea, seems v. dated and needs to be in a new environment.”*

An area of suggested improvement was:

- *“treatment for adolescents, sometimes the treatment was insensitive and ill-informed about the difficulties teenagers have with treatment”*

Comments on important things to consider in relation to care for young people with rheumatic and musculoskeletal conditions:

- *“Essential for young people to be treated separately from old- psychologically very hard for them to be experiencing the same illness as them.”*
- *“Sensitive consultants”*
- *“Psychological support”*

Next Steps (we did):

The Paediatric Specialist CFS/ME service is currently in the process of a number of activities which will address some of the comments above:

- The service is in the final stages of employing a part time Child Psychiatrist and two further Psychologists. This will increase capacity and increase the opportunity for patients to see the same clinician when it is clinically appropriate, and will increase multi-professional links.
- In December 2015 the service published research which looked at the needs of siblings, and aims, within the next 12 months, to produce information for siblings which will include signposting to places they can get help.
- A website will be launched over the next couple of months to support access to research trials, and the service works hard to ensure that patients and their families have access to research opportunities. The service has a patient advisory group which enables service user input into the design of research trials.
- A research trial with a family therapy model is due to commence in November 2016.
- Further signposting the Association of Young People with ME (AYME) will continue so young people with this condition can meet others.