The Royal Wolverhampton NHS Trust

Transition in Healthcare Report – Health Scrutiny Panel December 2023		
Title of Report:	Transition in Healthcare – update report.	Enc No: To be completed by Board Administrator
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Presenter/Exec Lead:	Debra Hickman – Chief Nursing Officer	

Action Required of the Board/Committee/Group (Please remove action as appropriate)			
Decision	**Approval**	**Discussion**	**Other**
Yes☐No☒	Yes☐No☒	Yes☒No☐	Yes☐No☐
Recommendations: • The Health Scrutiny Panel is asked to receive the report for information and assurance.			

Implications of the Paper:			
Risk Register Risk	Yes ☐ No ☒ Risk Description: On Risk Register: Yes☐No☒ Risk Score (if applicable):		
Changes to BAF Risk(s) & TRR Risk(s) agree	None		
Resource Implications:	None		
Report Data Caveats	N/A		
Compliance and/or Lead Requirements	CQC	Yes☒No☐	Details: Contribution to the Trust's compliance with CQC fundamental standards.
	NHSE	Yes☒No☐	Details: Contribution to the Trust's compliance with NHS Oversight Framework requirements.
	Health & Safety	Yes☐No☒	Details: N/A
	Legal	Yes☐No☒	Details: N/A
	NHS Constitution	Yes☐No☒	Details: N/A
	Other	Yes☐No☒	Details: N/A
CQC Domains	**Safe:** patients, staff and the public are protected from abuse and avoidable harm. **Effective:** care, treatment and support achieve good outcomes, helping people maintain quality of life and is based on the best available evidence. **Caring:** staff involve and treat everyone with compassion, kindness, dignity and respect. **Responsive:** services are organised so that they meet people's needs. **Well-led:** the leadership, management and governance of the organisation make sure it's providing high-quality care that's based around individual needs, that it encourages learning and innovation, and that it promotes an open and fair culture.		

Equality and Diversity Impact	In being awarded the Race Code mark, the Trust agreed to increase its awareness and action in relation to the impact of Board & Board Committee business on people with reserved characteristics. Therefore, the Committee must consider whether anything reviewed might result in disadvantaging anyone with one or more of those characteristics and ensure the discussion and outcome is recorded in the minutes and action taken to mitigate or address as appropriate. **Please provide an example/demonstration:** No adverse impact is anticipated as a result of the points articulated in this report.		
Report Journey/Destination or matters that may have been referred to other Board Committees	Working/Exec Group	Yes☐No☒	Date:
	Board Committee	Yes☐No☒	Date:
	Board of Directors	Yes☐No☒	Date:
	Other	Yes☐No☒	Date:

Summary of Key Issues using Assure, Advise and Alert

Assure

- Following a 12-month pilot, the role of Transition Clinical Nurse Specialist has been made permanent.
- A Transition Steering Group has been established, which oversees the transition strategy.
- Involvement with children and young people (CYP) and their families has been strengthened. For example, pathways are now being developed with services, young people and their families.
- A Health Passport in Wolverhampton has been successfully rolled out for CYP with long term health conditions.
- The Ready Steady Go transition programme has been implemented, designed by the TIER network. This will ensure that all young people going through the transition programme will have a transition plan.
- Transition clinics in the acute setting that involve both, the paediatric and adult teams, that will be receiving the young person have been established.
- At Penn Hall Special School, transition coffee mornings have been established, to enable health, allied health professionals, learning disability and education services meet with young people and families starting the transition programme.
- Strong links have been established with other transition coordinators around the Midlands, and in collaboration with Partners in Paediatrics, a Healthcare Transition Regional Network has been formed.
- In collaboration with the Living Well Team, the Trust has set up a transition group at Compton Care for young people with life limiting health conditions.
- The Trust has expanded the paediatric services by employing a paediatric Attention Deficit Hyperactivity Disorder (ADHD) Clinical Nurse Specialist and an Autism Spectrum Disorder (ASD) Clinical Nurse Specialist.

Advise

- The role of 'Transition Champions' in services across children and adults is being developed.
- Key areas that require strengthening include, raising awareness of the Transition policy and ensure it is embedded; the governance surrounding the Transition service and relevant data collection, including patient feedback.
- An action plan, to implement the recommendations from the National Confidential Enquiry into Patient Outcome and Death (NCEPOD) report, 'The Inbetweeners' is being developed.
- The Trust is awaiting the National Framework for Transition from NHS England (NHSE), which will set out minimum standards for hospitals in relation to Transition. Alongside the National Framework, the Core Capabilities document, which will set out training requirements and competencies specific to transition are awaited.
- Collaborative working between the transition coordinators from health across the Black Country is in place to ensure there is equity in the transition offer for young people across the region.

• A Youth Forum, to help with the design of the transition service and obtain feedback from young people on different projects, is being planned.
Alert • There is currently a gap within the community services for young people who have medical equipment at home, but do not meet the threshold for adult Continuing Healthcare. • The Ready Steady Go national transition programme is not suitable for all young people that require transfer to adult services. As a result, the Trust is currently looking at designing a transition programme for these young people with complex needs.

Links to Trust Strategic Aims & Objectives (Delete those not applicable)	
Excel in the delivery of Care	• Embed a culture of learning and continuous improvement • Prioritise the treatment of cancer patients • Safe and responsive urgent and emergency care • Deliver the priorities within the National Elective Care Strategy • We will deliver financial sustainability by focusing investment on the areas that will have the biggest impact on our community and populations
Support our Colleagues	• Be in the top quartile for vacancy levels • Improve in the percentage of staff who feel positive action has been taken on their health and wellbeing • Improve overall staff engagement • Deliver improvement against the Workforce Equality Standards
Improve the Healthcare of our Communities	• Develop a health inequalities strategy • Reduction in the carbon footprint of clinical services by 1 April 2025 • Deliver improvements at PLACE in the health of our communities
Effective Collaboration	• Improve population health outcomes through provider collaborative • Improve clinical service sustainability • Implement technological solutions that improve patient experience • Progress joint working across Wolverhampton and Walsall • Facilitate research that improves the quality of care

The Royal Wolverhampton NHS Trust

Transition in Healthcare Report for the Health Scrutiny Panel.

EXECUTIVE SUMMARY

This report provides an overview of The Royal Wolverhampton NHS Trust's Transition service. Key achievements are presented, followed by the priority areas and next steps, to continuously improve service provision for the benefit of young people requiring this support.

BACKGROUND INFORMATION

1.0 Transition – definition and its importance

Transition is defined in the Department of Health's 2006 publication 'Transition: getting it right for young people' as "a purposeful, planned process that addresses the medical, psychosocial and educational/vocational needs of adolescents and young adults with chronic physical and medical conditions as they move from child centred to adult-oriented health care systems".

The transition process should be commenced between the ages of 11 and 14, with the young person and their family at the centre of the planning. The aim of the transition programme is to empower the young person and their family to manage their own health condition in adulthood and prepare them for the move to adult services. The formal transfer of care should be planned both by the paediatric team and the receiving adult team and subsequent developmentally appropriate support should be in place to welcome and establish them into the adult service.

In 2014, the Care Quality Commission (CQC) produced a report 'From the Pond into the Sea' that looked at children's transition to adult services. As part of the review, they spoke to 180 young people, or parents of young people, between the ages of 14 and 25 with complex health needs. It was found that the transition process was variable, and that previous good practice guidance had not always been implemented. Young people and families were often confused and at times distressed by the lack of information, support, and services available to meet their complex health needs. They suggested that planning must start early, and funding responsibilities should be clear. Adult and children's services should work together, and information must be shared routinely so that young people and their parents do not waste precious time repeating information about their health. Young people must not fall in the gap between children's and adult services.

The transition process can be a vulnerable time for young people and their families, during this period they stop receiving health services they may have had since a young age and move to equivalent adult services which may be structured and funded differently. Poor transition from children's services to adult services can lead young people to disengage with health services and consequently, their health can deteriorate. There is evidence that mortality and morbidity rates increase during and directly after transfer to adult services. It is a period of risk for poor clinical outcomes and increased healthcare costs associated with emergency department visits, hospitalisations and intensive care admissions. It also has a negative effect on social participation and educational achievement.

Transitioning through healthcare services also often occurs during pivotal periods of education e.g., exams and moving to college or university. The transfer of care, if possible, should be at a stable point in the young person's life to minimise impact.

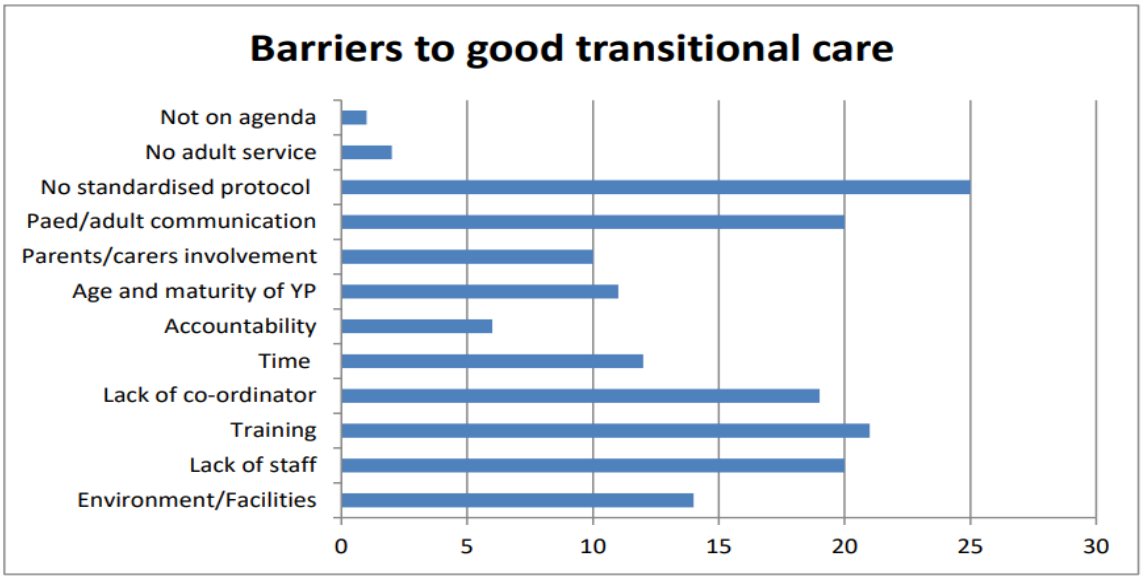
NICE (2016) recommend that managers in children's and adult services work together to ensure a smooth and gradual transition but research suggested that staff feel ill equipped and lacked confidence in providing this support. Healthcare professionals speak of the frustrations of working with disjointed systems and unclear pathways, and the time it takes to arrange care for young people with complex needs that needs to continue into adulthood.

2.0 Key Achievements at The Royal Wolverhampton NHS Trust

We have an established Transition Steering Group where we meet quarterly to review the Transition strategy and received updates from key stakeholders such as the Regional Transition Lead from NHS England. The Steering Group has developed a Transition policy which has been rolled out to services and it will be audited next year to ensure staff are aware of it and follow guidance in the policy.

The Royal Wolverhampton NHS Trust (RWT) Transition Collaborative working group was also developed to ascertain the views of staff and users on how we can improve the way we organise care for young people transitioning from paediatric to adult services to incorporate these into the trust transition strategy, ensuring its relevance to the needs of the local population. A graffiti wall was made available in Paediatric Outpatients for young people and parents/carers to write down their thoughts and ideas regarding transition. Parents of 4 young people aged 15-21 with chronic illness cared for at RWT were asked to discuss their experiences and express what they feel would improve their lives for the future. In order to enable young people to learn new skills whilst helping shape future plans, we had some help from local company Radio Active who came along to the Gem Centre and transformed one of the meeting rooms into a studio. We were privileged to have 7 young people aged between 15 and 21 years to come along to share their thoughts and experiences of transitional care at the Trust. Under the presenter's expert guidance, they learnt about production and media communication, culminating in the creation of a podcast. Questionnaires were then developed with the help of young people with chronic illness undergoing transition and Voice for Parents and were given to young people in paediatric and adult care and their parents. This was advertised via twitter and Trust Talk as being on survey monkey and paper versions were made available in clinic.

The graph below shows responses to the question 'barriers to good transitional care'.



The feedback received, along with the NICE standards for transition and the NCEPOD recommendations were used to guide us on what to include in the transition programme in the Trust.

We have had a 12 month pilot of the Transition Clinical Nurse Specialist (CNS) post, this role has recently been made permanent. During the 12 month pilot, the main focus was to scope what services were doing in Wolverhampton to address the transition risk. Transition was added to the risk register, then services were asked to benchmark themselves against the NICE guidelines, this showed areas of good practice and also areas that needed improvement. Services then mapped their current state of transition and where they wanted to be, incorporating the NICE recommendations. Across acute and community, four areas were then chosen to pilot the transition programme, these were the epilepsy service in paediatrics and

adults, rheumatology service in paediatrics and adults, the Children's Community Nursing Service and Penn Hall Special School. The Transition CNS worked with the services to set up transition pathways that met the individual needs of the service.

We have successfully rolled out a Health Passport in Wolverhampton for children and young people with long term health conditions. It has been coproduced with the parent and carer forum and was then piloted by a group of young people. There is also a Hospital Passport in place for young people and adults over the age of 16 who have a learning disability.

We have implemented the Ready Steady Go transition programme in the Trust that has been designed by the Transition & Patient Empowerment Innovation, Education and Research Collaboration (TIER) Network. A key principle throughout Ready Steady Go is 'empowering' the young people to take control of their lives and equipping them with the necessary skills and knowledge to manage their own healthcare confidently and successfully in both paediatric and adult services. This is initiated through the completion of a series of questionnaires which assess knowledge of their condition, their treatments, that they know who is who in their healthcare team, and develop an understanding of the concept of transition. It supports the development of self-advocacy and the extent to which they can speak up for themselves and ask their own questions in clinic and be involved in shared decision–making. It helps the young person develop an understanding of the issues around a healthy lifestyle, sexual health and where relevant pregnancy. It also reviews educational and vocational issues to ensure the young person has a plan to achieve their potential.

It was discovered while trialling the Ready Steady Go transition programme that it was not suitable for all young people. Some young people identified in our special schools did not benefit from this generic style transition programme and their more complex health needs were not addressed. We are currently working with parents and the special school on a bespoke transition programme that will meet the young people's needs.

Transition clinics in the acute setting that involve both the paediatric team and adult team that will be receiving the young person have been established. The young person and their family get to meet their adult team while still having the comfort of the paediatric team they know so well around them. Joint care planning before they move to adult services can happen to build up the adult team's knowledge of the young person and the young person's confidence in the adult team. The paediatric diabetes team has gone one step further and have moved their transition clinic to the adult diabetes centre so that young people can also get used to the new environment while still having their paediatric team with them, this is something we would like to replicate in other services.

At Penn Hall Special School we have set up transition coffee mornings where health, allied health professionals, learning disability services and education meet with young people and families starting the transition programme. Later in the programme we have transition clinics in school with young people and their families to discuss their move to adult services and address issues such as where their care will transfer to, discussions around medical equipment they may have and ongoing needs such as servicing and the ordering of ancillaries, medication, Continuing Health Care assessments and possibly further education and residential places. Individual MDT meetings can then be arranged with children's services, receiving adult teams, primary care, education, social care, learning disability services, the young people and their families on Microsoft Teams where the formal transfer of care can be planned and support after transfer put in place.

We have made strong links with other transition coordinators around the Midlands and in collaboration with Partners in Paediatrics we have set up a Healthcare Transition Regional Network where we can share ideas with other organisations, discuss barriers we have faced and also share areas of good practice. In collaboration with Walsall, Sandwell and Dudley trusts we approached the Black Country Integrated Care System (ICB) to ask about funding for a Youth Worker pilot. We have secured funding for a 12 month post for each trust in the Black Country to have a dedicated youth worker her help young people in the transition

process with any additional needs they may have such as medication compliance, body image. After a successful recruitment campaign, we are awaiting the start date of the youth worker for Wolverhampton.

We are developing the role of 'Transition Champions' in services across children's and adults. We will have regular meeting where staff who have volunteered to be transition champions from across children's and adult services will meet for updates and to share areas of good practice and any barriers they have faced.

In collaboration with the Living Well Team we have set up a transition group at Compton Care for young people with life limiting health conditions. We found there were issues with young people accessing adult hospices and there was a stigma attached to this. We meet once a month on a Saturday and have arranged a variety of activities such as bowling trips, film afternoons, arts and crafts and Christmas parties. This has helped the young people and their families build up a relationship with the team at Compton Care.

3.0 Key Priorities at the Royal Wolverhampton NHS Trust

A key priority is to raise awareness of the Trust's transition policy and ensure it is embedded into the practice of all professionals working with young people both going through the transition programme and the receiving adult services.

The governance surrounding transition requires strengthening, including the associated reporting arrangements. Transition will be required to report into the Transition Board in the ICB once it has been established. In addition, data collection, including patient feedback, on the service need to be improved.

In 2022, RWT was involved in a review of transition and in June 2023 the National Confidential Enquiry into Patient Outcome and Death (NCEPOD) report was published entitled as 'The Inbetweeners'. This report outlined the barriers and facilitators in the process of the transition of children and young people with complex chronic health conditions into adult health services. The report includes the following recommendations:

- Every young person should have a personalised transition plan.
- Copy all young people in correspondence.
- Joint transition clinics.
- Request input from MDT for young people with ongoing health needs.
- Involve primary care.
- Convene an overarching trust transition team.
- Implement an overarching trust transition policy.
- Ensure transition is in job plans.
- Ensure staff receive training around transition.
- Electronic patient systems can identify young people of transition age.
- Ensure transition is specified in the service outcome measures.

Following these recommendations, an action plan for Wolverhampton has been developed, which is currently going through the Trust's governance process and has been presented at the divisional governance meetings. The progress with the action plan will be monitored by the Transition Steering Group.

We are awaiting the final National Framework for Transition from NHS England which will set out minimum standards for hospital trusts in relation to transition. In the framework there will be principles, models, and resources to help set up a 0-25-year service model. Organisations will be required to demonstrate that they we are meeting the minimum standards to receive payments via 'Transition Currencies'. This will be shown by building pathways that meet best practice and through audits.

Alongside the National Framework, we are awaiting the release of the Core Capabilities Document from NHSE which will sets out training requirements and competencies specific to transition. It will set expectations that all NHS providers provide a training package for all staff working with young people going

through the transition process, including primary care, mental health services and adult services. The Transition Clinical Nurse Specialist will lead the development of these resources.

After the publication of the National Framework for Transition and the Core Capabilities Document, along with the NCEPOD recommendations and the NICE guidelines we will be compiling an overarching improvement plan to ensure all the actions are together.

The Transition Clinical Nurse Specialist has been working with transition coordinators from health across the Black Country to ensure there was equity in the transition offer for young people across the region. We are working on a benchmarking document for services to use that will incorporate the NICE guidelines and the NCEPOD recommendations. This will then be used as a standard reporting tool to inform the ICB.

Core20PLUS5 is a national NHS England approach to support the reduction of health inequalities. The approach, which initially focussed on healthcare inequalities experienced by adults, has now been adapted to apply to children and young people. The Core20 is the most deprived 20% of the national population and the PLUS population groups include ethnic minority communities, inclusion health groups; people with a learning disability and autistic people, people with multi-morbidities and protected characteristic groups. This approach suggests five clinical areas of focus, asthma, diabetes, epilepsy, mental health and oral health. The Transition CNS will expand their scope to more services to help set up pathways, concentrating on asthma, diabetes and epilepsy. The purpose of the pathways is to ensure a robust process for young people with long term health conditions to make the transfer from children's to adult healthcare services in a holistic and safe way.

The Ready Steady Go Transition Programme will be embedded into the relevant services and audits will be completed to ascertain how successful the programme has been. Wolverhampton has been accepted onto a pilot to trial the Ready Steady Go documents digitally. This will be through the creation of QR codes and weblinks per Trust and subspeciality. The Ready Steady Go programme can also be translated into a range of different languages. We have identified that Ready Steady Go Programme is not suitable for all young people and are therefore developing a bespoke transition programme for young people with complex needs.

It is also our priority to work with specialist centres such as Birmingham Children's Hospital to ensure that the transfer of care from these centres is seamless for the young people and their families. We first need to identify early who these young people will be and work with children's services and the receiving adult services through clinics, MDT meetings and discussions with families.

We have expanded the paediatric services by employing a paediatric ADHD Clinical Nurse Specialist and an ASD Clinical Nurse Specialist. It has been noted that there are few adult services for young people with ASD and ADHD therefore we are developing a transition programme that will prepare the young people and their families to manage their conditions with the help of their GP into adulthood and where to get support if things deteriorate.

There are plans to set up a Youth Forum to help with the design of the transition service and receive feedback from young people on different projects in the Trust. It is important that young people's voices are heard to help ensure services are appropriate and accessible for them. After the successful group at Compton Care, we would also like to develop more peer support groups for young people within specialities.

We will continue to review gaps in services between children's and adult healthcare services. A gap has been identified in community services around young people with medical equipment at home, who do not meet the criteria for Continuing Health Care. We are working with adult services, the ICB and primary care to try and address these gaps.

We have seen a need for information sessions regarding mental capacity and decision making both for staff involved in the transition programmes and parents of young people. We are going to include mental

capacity awareness into the transition programme for parents as this has been a cause of anxiety to parents who are unsure what happens when their young person reaches adulthood, and they no longer have parental capacity. This will be completed in collaboration with the learning disability team and will take place in transition clinics and coffee mornings.

Another area of focus will be to identify young people who are eligible for learning disability annual health checks and ensure they are offered an appointment from their General Practitioner (GP). Everyone over the age of 14 who is on their GP's learning disability register should have an annual health check as people with a learning disability have often poorer physical and mental health. We have incorporated this question into the transition programme and are able to check if a young person is on their GP's learning disability register. Should this not be the case, we are able to contact their GP to arrange this.

RECOMMENDATIONS

- The Health Scrutiny Panel are recommended to note report.

Any Cross-References to Reading Room Information/Enclosures:

N/A