Exploring the Delivery of Adolescent and Young Adult Care Across the United Kingdom:

A BANNAR Quality Improvement Project

Flora McErlane, Victoria Harbottle, Amit Parekh, Mukaro Sheunesu and Coziana Ciurtin

Contents

Figures

Background

Adolescence and young adult life are developmentally distinct periods, characterised by rapid brain development, and focussed around achieving a successful transition from the dependence of childhood to independent adult life. (1) In response to growing awareness of the distinct physical and cognitive changes associated with adolescence and young adulthood, the World Health Organization (WHO) has defined adolescence as a unique stage of human development and a critical period for laying the foundations of lifelong health. (2)

"Adolescents experience rapid physical, cognitive and psychosocial growth. This affects how they feel, think, make decisions, and interact with the world around them…
…To grow and develop in good health, adolescents need information, including age-appropriate comprehensive sexuality education; opportunities to develop life skills; health services that are acceptable, equitable, appropriate and effective; and safe and supportive environments. They also need opportunities to meaningfully participate in the design and delivery of interventions to improve and maintain their health. Expanding such opportunities is key to responding to adolescents' specific needs and rights." (2)

Failure to achieve a successful transition from childhood to independent adulthood can impact on behaviour patterns as well as physical and mental health throughout life. (3) The success of adolescent developmental outcomes can be impacted by both physical health and social disadvantage. (4) The Marmot review emphasised the strong and persistent link between social inequalities and disparities in health outcomes, underscoring the importance of tackling the wider determinants of overall wellbeing to improve health outcomes and reduce health inequalities.

Holistic and developmentally appropriate healthcare (DAH), which incorporates education and support and is delivered in safe and accessible environments, acknowledges the evolving developmental needs of adolescents and young adults (AYA). It provides a framework for adolescent-responsive healthcare and mitigates the negative impact of key social determinants of health, empowering young people with the knowledge, skills and attitudes they need to live healthily and independently long into adult life.

The 2014 Care Quality Commission (CQC) report, From the Pond into the Sea, was the first national report to describe the particular challenges facing AYA navigating current healthcare systems. (5) In response, a series of quality care and policy frameworks have advocated for developmentally appropriate improvements to health services accessed by young people.

The 2016 Transitional Care NICE Guideline [NG43] recommends involving young people and their carers in the improvement of AYA services to deliver person-centred DAH during the transition from child to adult health or social care services. (6) Subsequent “You’re Welcome” standards include self-assessment quality criteria intended to empower commissioners and service providers to review the quality of AYA care. In 2023, the National Confidential Enquiry into Clinical Outcomes and Deaths (NCEPOD) published The Inbetweeners, a review of the transition of children and young people from paediatric to adult health services. (7) The review concluded that the process of transition and transfer can be fragmented, both within and across specialties, commenting that DAH should be a shared responsibility across all sectors, acknowledging the additional resourcing required.

Thinking particularly of rheumatology, the quality of paediatric care has been reviewed in detail over the past few years, with two data-driven national reviews published during 2025.

1. The NCEPOD Joint Care report explored the standard of JIA care across England and Wales from point of diagnosis to early adult life (24 years). (8) The report noted that the importance of DAH is clearly recognized by rheumatology teams, with 76/103 (73.8%) hospitals implementing a dedicated transition process, most following the NICE guidance for transition. However, despite this, approximately 30% of case notes contained no evidence of developmentally appropriate adaptations to healthcare, with the frequency of support and signposting decreasing as towards young adult life.
2. The paediatric rheumatology GIRFT report, although focussed on the paediatric population, explored DAH and the transfer of paediatric patients

into adult services across England. [Report expected November 2025] Paediatric teams, supported by their young adult colleagues, highlighted significant between-centre variation in access to DAH following the transfer to adult services.

Despite multiple suggested improvements to AYA healthcare delivery, equitable and sustainable implementation within current healthcare systems remains challenging. Nevertheless, to date, no national quality reviews have focussed on the vulnerable and transitional adolescent years, with existing rheumatology data derived or extrapolated from paediatric reviews. There is a clear need to better understand the quality of AYA care across the nation.

Aim

The aim of this project was to build on the existing evidence to inform the development of a four-nation improvement project exploring the current state of AYA rheumatology service provision. The ambition is to use the service delivery data to connect, support and ultimately improve AYA rheumatology services across the UK.

Methods

Funded and supported by **Arthritis UK**, we designed a staged multimethod study. Phase 1 aimed to identify adult rheumatology services providing care to 16 to 24 year olds across the UK. Phase 2 collected more detailed survey information exploring the delivery of DAH across the four nations.

Phase 1: Mapping Young Adult Services

Contact details for young adult service providers were identified via several routes: the BANNAR membership was invited to provide local adult team(s) contact details, paediatric rheumatology hub centres were invited to provide details for teams receiving young adult transfers and relevant patient organisations approached for contact details of any young adult teams they were working with. Young adult care providers across the four nations were logged and mapped on an interactive document, linking teams to their local paediatric rheumatology hub, where possible.

Phase 2: Survey of AYA care providers

The BANNAR leadership group used existing survey and/or questionnaire tools to develop and pre-test a bespoke survey for all young adult care providers exploring services offered and local funding models.

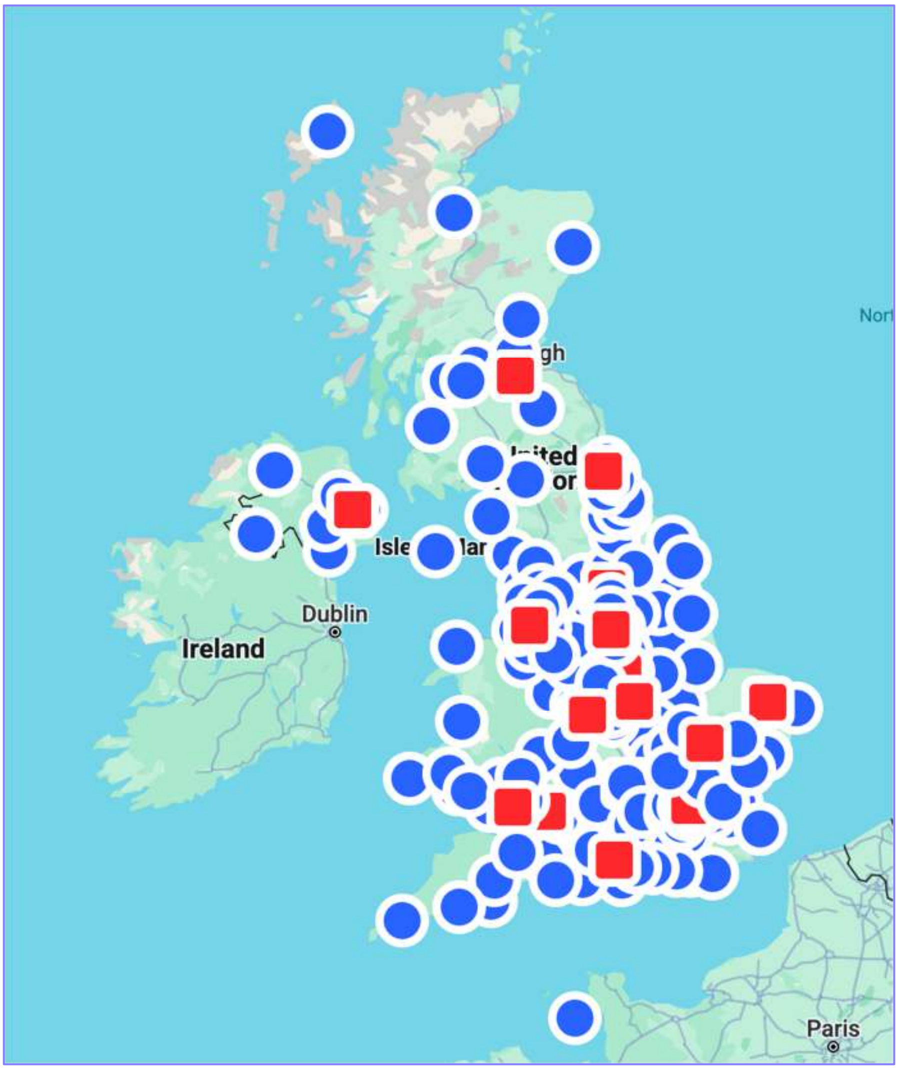
The survey was disseminated across the young adult teams identified during the mapping project with a maximum of three follow up requests for completion.

Results

Phase 1: Mapping Young Adult Services

Phase 1 of the study identified a total of 220 adult rheumatology centres providing AYA care (16- to 24-year-olds) across the four nations. [Figure 1]

Figure 1: Heat map illustrating rheumatology centres caring for 16- to 24-year-olds



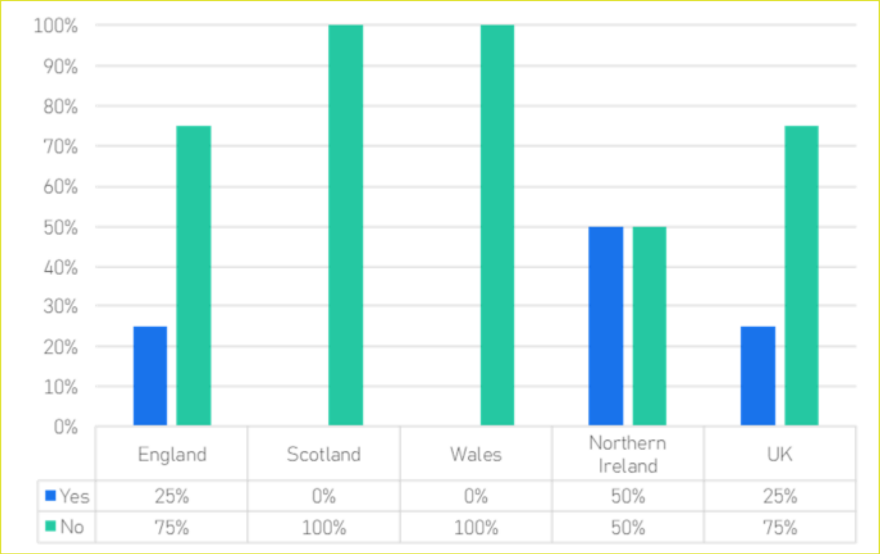
Blue circles: adult rheumatology centres caring for 16- to 24-year-olds

Red squares: paediatric rheumatology hub centres referring into services

Phase 2: Survey of AYA care providers

During Phase 2, we collected 28 survey responses from adult services across the four nations: 20 responses from England, 4 from Northern Ireland, 3 from Wales and 1 from Scotland.

Figure 2: survey responses from across the four nations

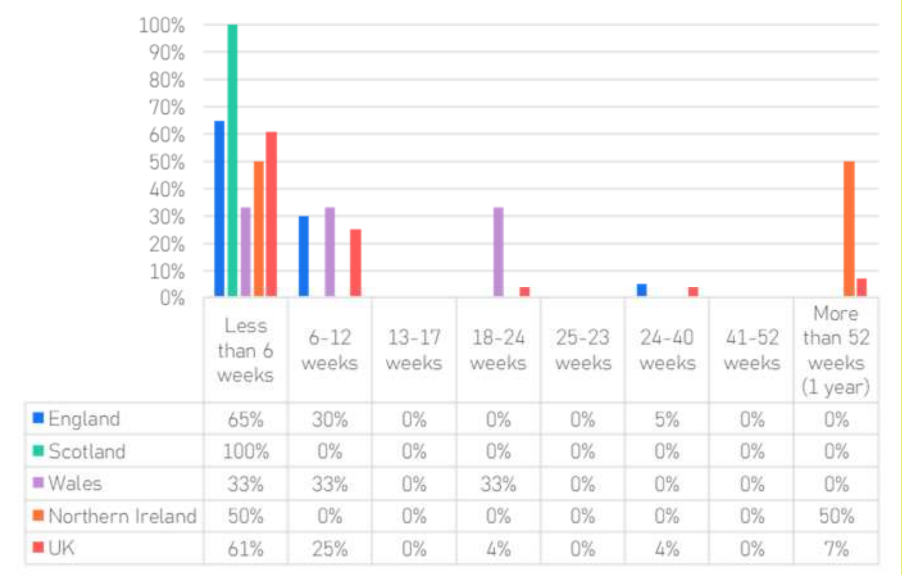


	England	Scotland	Wales	Northern Ireland	UK
🟦 Yes	25%	0%	0%	50%	25%
🟩 No	75%	100%	100%	50%	75%

21/28 (75%) respondents were uncertain about the number of 16- to 24-year-olds under their care, with just 11% routinely collecting data on young adults as a distinct group.

79% of respondents stated that they accept new patients from the age of 16 years with 61% appointments offered within 6 weeks of referral. Just 7% of new referrals wait >52 weeks in England, rising to 50% in Northern Ireland.

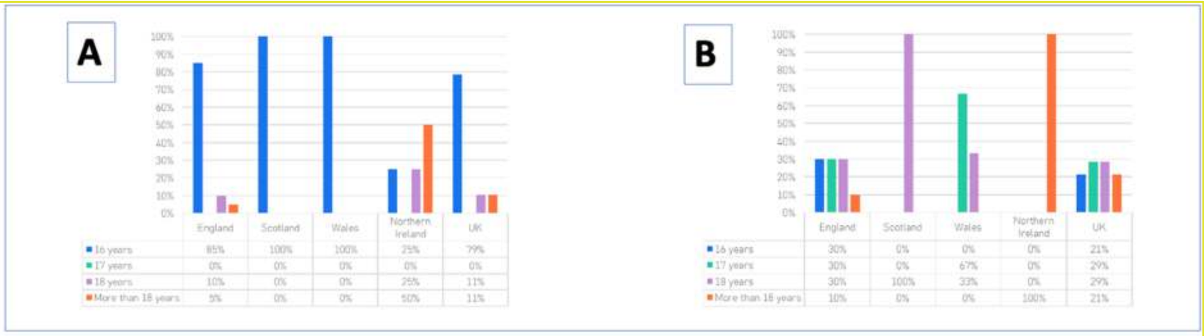
Figure 3: Graph to show wait times for new patient appointments for AYA aged 16 to 24 years



	Less than 6 weeks	6-12 weeks	13-17 weeks	18-24 weeks	25-23 weeks	24-40 weeks	41-52 weeks	More than 52 weeks (1 year)
🟦 England	65%	30%	0%	0%	0%	5%	0%	0%
🟩 Scotland	100%	0%	0%	0%	0%	0%	0%	0%
🟪 Wales	33%	33%	0%	33%	0%	0%	0%	0%
🟧 Northern Ireland	50%	0%	0%	0%	0%	0%	0%	50%
🟥 UK	61%	25%	0%	4%	0%	4%	0%	7%

79% of services accept transfers from paediatric care between 16 and 18 years of age, generally arranged when the paediatric team considers the disease well controlled, and the young person developmentally ready. Northern Ireland is an important outlier with young people remaining under paediatric care until over 18 years. Overall, 61% of UK services provide a new patient appointment for AYA aged 16 to 24 within 6 weeks of referral.

Figure 4: Graphs to show minimum age for new adult referrals (A) and average age at transfer from paediatric to adult services (B)



	England	Scotland	Wales	Northern Ireland	UK
🟦 16 years	85%	100%	100%	25%	79%
🟩 17 years	0%	0%	0%	0%	0%
🟪 18 years	10%	0%	0%	25%	11%
🟧 More than 18 years	5%	0%	0%	50%	11%

	England	Scotland	Wales	Northern Ireland	UK
🟦 16 years	30%	0%	0%	0%	21%
🟩 17 years	30%	0%	67%	0%	29%
🟪 18 years	30%	100%	33%	0%	29%
🟧 More than 18 years	10%	0%	0%	100%	21%

82% of respondents reported adapting their usual approach to healthcare to improve accessibility for the AYA population (DAH). Adaptations included wider conversations with AYA to address needs beyond medical conditions (82%), adaptations to care designed to support AYA with learning disabilities (43%) and adaptations to care designed to support AYA with neurodiversity (43%). With regards to young people moving from paediatric to adult services, 68% respondents reported involvement in transition planning. Most respondents offered virtual care but just one 1 service (in England) offered out of hours appointments.

With regards to delivery of care, 54% of respondents reported reviewing AYA in designated young adult clinics but just 14% hosted their clinics in a discrete young adult space.

Figure 5: Graph to show proportion of 16- to 24-year-olds reviewed in designated young adult clinics

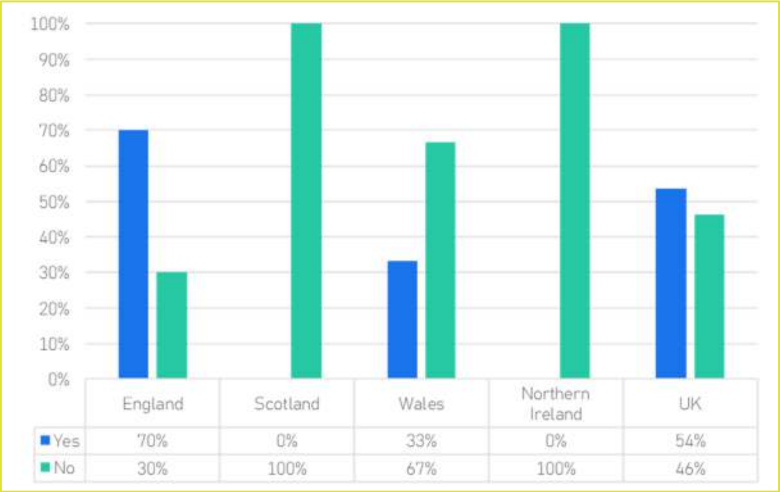


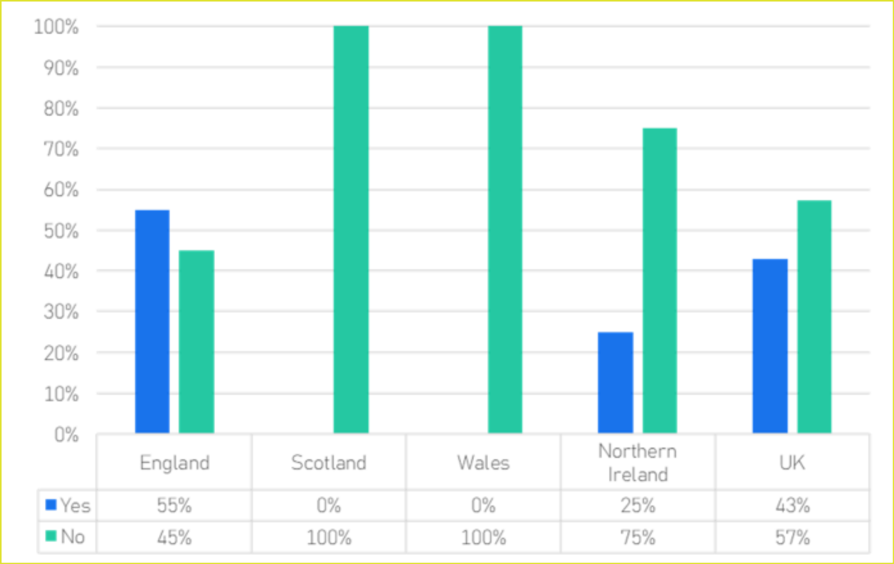
Table 1 illustrates access to multidisciplinary care, with limited access to the wider team reported by a high proportion of survey respondents.

Table 1: Access to an experienced multidisciplinary team

MDT member	No access	Yes – without job planned time	Yes – with job planned time
Designated young adult consultant	52%	22%	30%
Designated young adult nurse	59%	7%	37%
Adult rheumatology nurse	15%	56%	33%
Physiotherapist	11%	70%	22%
Occupational therapist	26%	59%	19%
Psychology	85%	11%	7%
Youth work	70%	7%	26%

Thinking about non-attendance and possible adaptations to usual organisational policies, just 50% of respondents reported a local system for identifying and supporting AYA unable to attend appointments. 57% of respondents were not aware of the ‘Was Not Brought / Did Not Attend’ approach outlined in NICE guideline QS 140.

Figure 6: Graph to show proportion of services able to adapt trust wide DNA policies for 16- to 24-year-olds



	England	Scotland	Wales	Northern Ireland	UK
■ Yes	55%	0%	0%	25%	43%
■ No	45%	100%	100%	75%	57%

Thinking about youth engagement, the responding teams stated that opportunities for peer support and/or youth involvement were not common. Whilst 39% of respondents offer AYA opportunities to meet/learn from peers, 64% do not involve AYA in QI and/or research projects and 79% do not involve AYA in the design, delivery, and evaluation of services.

Regarding health professional training and education, 57% respondents reported no access to internal or external training in DAH.

Funding statement

We are grateful to Versus Arthritis for resourcing and supporting the work presented in this report.

Discussion

This report describes the first UK-wide review of AYA rheumatology care. The service mapping data are important, highlighting that 16- to 24-year-olds with rheumatological conditions are cared for by a wide range of secondary and tertiary rheumatology centres across all four nations. This finding is supported by the recent paediatric rheumatology GIRFT review, which reported young people across England moving to a wide variety of centres following the transfer to adult care (personal communication). The more detailed survey data suggest that, although respondents are enthusiastic about delivery of developmentally appropriate care, equitable and sustainable implementation within current healthcare systems is challenging across the four nations.

Our survey data suggest that, although new referrals are generally accepted by adult services from the age of 16, transfer of care from paediatric to adult services is often later, between 16 and 18 years. Northern Ireland is an important outlier with young people remaining under paediatric care until >18 years, perhaps reflecting the significant pressure on adult rheumatology services in Northern Ireland. Paediatric rheumatology services in Northern Ireland are similarly overstretched, making challenging for the clinical team to manage adult patients within the constraints of their paediatric-focused settings.. The delayed transfer of care into adult services is important, suggesting that paediatric teams do not consider 16-year-olds developmentally ready for adult services. It may therefore be reasonable to question whether new patients aged 16 are developmentally ready for adult orientated care, given that they are typically referred directly into adult services.

Respondents reported a broad enthusiasm for DAH with 82% describing local adaptations designed to improve the accessibility and/or experience of care for the AYA age group. However, respondents reported facing challenging systematic barriers precluding the consistent establishment of developmentally appropriate care pathways. Concerningly, 75% of respondents were unsure how many 16- to 24-year-olds were under their care with just 11% routinely collecting data on young adults as a distinct group. Data-driven improvements to the quality and safety of AYA care will not be possible until clinical teams are supported to collect and analyse local age-specific datasets.

Funded (protected) time for AYA care is a significant concern with just 30% of respondents reporting any funded time dedicated to AYA care. The funding issue is a concern across the wider MDT with many respondents reporting limited AYA access to the wider team. Timely access to the wider MDT, including nursing care, therapy support, youth work involvement and psychology where needed, has been clearly shown to improve outcomes and experiences for AYA. (9) Peer support is equally key to improving outcomes, with good evidence to support its positive impact on psychological wellbeing, resilience, and self-management among young people with chronic illnesses. (10) Limited opportunities for peer support and/or youth involvement is, therefore, a further opportunity lost.

It is worth commenting that multidisciplinary care and peer support are difficult to deliver without access to suitable hospital environment. Clinical space, particularly in outpatient areas, is difficult to access, with few hospitals having designated AYA clinical areas for non-oncology patients. Our survey highlighted this challenge with just 14% of respondents reporting access to designated clinical spaces for AYA care. Busy adult or paediatric clinical areas, lacking age-appropriate shared areas, can impede delivery of holistic AYA health education.

Supporting attendance is a further concern with just 50% of respondents reporting local systems for identifying AYA unable to attend appointments. Loosing young people from care at this critical stage in their lives is a huge concern and, for many young people, likely to result in a future re-presentation with evolving and potentially more difficult to treat disease. Furthermore, limited or absent access to effective health education during adolescence is a lost opportunity, precluding informed decision making and reducing opportunities to build the cognitive and behavioural foundations necessary to sustain physical and emotional health long into adult life.

Despite multiple efforts to contact healthcare teams, we had a low number of survey responses (n=28), an important limitation of the study. Many responses were from clinicians well-known to the AYA rheumatology community, suggesting a high likelihood of positive response bias. The poor response rate may indicate that it is difficult for busy adult teams to prioritise AYA care, which likely represents a relatively small proportion of their overall activity.

The survey data illustrate that AYA healthcare is delivered across a wide range of adult rheumatology services with providers across the four nations reporting a clear desire to deliver accessible and effective healthcare and health education for young people. Unfortunately, providers also report a range of system-wide barriers precluding delivery of developmentally appropriate care. Our findings are similar to previous studies; a study reporting data collected between 2013 and 2015 (reported in 2019) presented a picture of enthusiastic healthcare professionals ,with limited organisation-wide support precluding delivery of accessible DAH outside of informal networks of trust. (11) Despite multiple suggested improvements to AYA healthcare delivery, it is frustrating but important to note that so little has changed.

This survey highlights a complex and multi-faceted problem, difficult to define and with no single solution, rendering traditional guideline-based approaches to improvement ineffective. Local data-driven approaches have the potential to improve care, but change cannot be implemented without the support of operational and management teams. It is no surprise that clinical teams feel disheartened, struggling to engage with a problem that appears insoluble.

The recent publication of the NHS 10 Year Plan, designed to tackle inequalities in access to and outcomes of healthcare, offers a further opportunity for improvement. (12) The plan advocates three radical shifts: (i) from hospital to community, (ii) from analogue to digital and (iii) from sickness to prevention, intended to allow all service users the means to engage with the NHS on their own terms. (13) Implementation of youth-friendly adaptions to NHS services, including integrated working and a holistic approach to improving mental health, and health equity, aligns strongly with the 10 Year Plan priorities. Forward-thinking organisations have a unique opportunity to use national resources such as the NICE transition guideline, the 2019 NCEPOD review of adolescent care and the NIHR Transition Programme, to devise a practical roadmap informing organisation-wide strategies and training to inform sequential and youth-led improvements to the delivery of accessible and effective AYA healthcare.

To summarise, the data presented in this paper suggest that the different healthcare needs of AYA are not well understood by trust leadership teams across the four nations and, despite multiple suggested approaches to inform the delivery of DAH, there is insufficient support for healthcare professionals to allocate time, identify appropriate clinical spaces and access the professional education necessary to inform provision of developmentally appropriate AYA care. The absence of any clear improvement over the past ten years likely reflecting the ‘wicked’ nature of healthcare challenges faced by AYA with long-term conditions, is a wake-up call for our community, highlighting an urgent need for improved advocacy efforts. Cognisant of the potentially life-long impact of inaccessible and developmentally inappropriate AYA healthcare, the BANNAR network is enthusiastic, energetic and keen to work with young people, healthcare professionals and relevant patient organisations, towards a coherent and articulate four-nation strategy to drive meaningful improvement.

Recommendations

The survey data summarised in this paper present the rheumatology community with a challenge; how to work with colleagues to improve DAH in a vast organization operating without shared understanding and unified policy guiding and informing AYA care. The recommendations presented below are intended as a framework, suggesting short, medium and long-term approaches to improvement across a range of key stakeholder groups.

Clinical teams delivering AYA care

- Create opportunities to listen to your AYA patients: short surveys completed in the waiting area can provide powerful data for change.
- Create opportunities to work with colleagues providing AYA care in other specialties: a shared approach to improvement would be more powerful locally.
- Use the JIA NCEPOD report (Joint Care) and the paediatric rheumatology GIRFT report to highlight the challenge to your directorate, trust and commissioning leadership teams.
- Create opportunities to train the new generation of rheumatology care providers: embed DAH principles into training curriculae and continuing education programmes.

Hospital trusts and health boards

- Prioritise AYA care in strategic planning and workforce development

Local Health Authorities

- Support the implementation of DAH through commissioning and service design

Health services researchers

- Evaluate models of care, identify gaps, and generate evidence for policy.

Patient organisations and professional bodies

- Data-driven and targeted advocacy will be central to future improvement: the recent publication of the 10 Year Plan for England and the data included in the

NCEPOD and paediatric rheumatology GIRFT reports presents an opportunity to highlight the potential impact of DAH, supporting AYA to move from sickness to living healthy adult lives.

- Acknowledging our important and impactful support from Arthritis UK, BANNAR is keen to continue working with influential national bodies: our professional network, unparalleled amongst other specialties, presents a unique opportunity to share best practices, pilot innovations, and build consensus across regions.

References

1. Viner RM, Ozer EM, Denny S, Marmot M, Resnick M, Fatusi A, et al. Adolescence and the social determinants of health. Lancet. 2012;379(9826):1641-52.

2. Organisation WH. Health topics: adolescent health [cited 2024 March]. Available from: https://www.who.int/health-topics/adolescent-health#tab=tab_1.

3. Organisation WH. World Development Report 2007, Development and the Next Generation. 2007.

4. A Hagell RS, R Viner, D Hargreaves, L Varnes, M Heys. The social determinants of young people's health. The Health Foundation; 2018.

5. (CQC) CQC. From the Pond into the Sea. 2014.

6. Excellence NIfC. Transition from children's to adults' services for young people using health or social care services NG43. 2016.

7. NCEPOD. The Inbetweeners: a review of the barriers and facilitators in the process of the transition of children and young people with complex chronic health conditions moving into adult health services 2023 [Available from: https://www.ncepod.org.uk/2023transition/The%20Inbetweeners_full%20report.pdf.

8. NCEPOD. Joint Care? A review of the quality of care provided to children and young adults with juvenile idiopathic arthritis 2025 [Available from: https://www.ncepod.org.uk/2025jia.html.

9. Nooteboom LA, Mulder EA, Vermeiren R, Eilander J, van den Driesschen SI, Kuiper CHZ. Practical Recommendations for Youth Care Professionals to Improve Evaluation and Reflection During Multidisciplinary Team Discussions: An Action Research Project. Int J Integr Care. 2022;22(1):26.

10. Tong A, Wong G, Hodson E, Walker RG, Tjaden L, Craig JC. Adolescent views on transition in diabetes and nephrology. Eur J Pediatr. 2013;172(3):293-304.

11. Rapley T, Farre A, Parr JR, Wood VJ, Reape D, Dovey-Pearce G, et al. Can we normalise developmentally appropriate health care for young people in UK hospital settings? An ethnographic study. BMJ Open. 2019;9(9):e029107.

12. Government U. Fit for the Future: 10 Year Health Plan for England 2025 [Available from: https://assets.publishing.service.gov.uk/media/6888a0b1a11f859994409147/fit-for-the-future-10-year-health-plan-for-england.pdf.

13. (NCEPOD) NCEiPOaD. The Inbetweeners: Transition from Child into Adult Healthcare. 2023 June 2023.