

## Northern Ireland Lifespan Gender Service

### CHILDREN AND YOUNG PEOPLE'S COMPONENT OF THE LIFESPAN SERVICE – COMPLIANCE WITH CASS REVIEW RECOMMENDATIONS

Visit 4-6 NOV 2025

This visit was commissioned by Minister Nesbitt to assess whether planned changes to services for children and young people with gender incongruence / gender dysphoria in Northern Ireland are compliant with recommendations of the Cass Review in England.

In order to address a growing waiting list for gender services, Minister Nesbitt recently approved funding to bring together two existing services - the CAMHS Knowing Our Identity (KOI) Team for under 18s and the Adult Gender Service - into one all-age model of care alongside an appropriately resourced endocrine service. This would operate under a single management structure within Belfast Health & Social Care Trust.

This is a challenging and contested area of medicine and aligning the Northern Ireland services with those in England would be beneficial, giving the Regional Northern Ireland team a network for peer learning, and giving children and young people using the NI services the opportunity to take part in wider research programmes, such as the recently approved PATHWAYS programme in England.

#### The aims of the visit were as follows:

- To assess the staffing and model of care of the Regional Lifespan Gender Identity Service against the recommendations of the Cass Review regarding children and young people, to determine compliance with the Cass Review recommendations and the evolving model of care in England.
- To ensure the standardisation of clinical pathways, where relevant in line with NHS England.
- To ensure that core data collection in the Lifespan Gender Identity Service for the children and young people element is consistent with the data being collected in the English services.
- To ensure that the holistic assessment framework being used in the English services can be applied in the Lifespan Gender Identity Service, and through joint work with core Child and Adolescent Mental Health Service (CAMHS) colleagues.
- To assess whether the documentation underpinning endocrinology referrals is suitable to enable review by the National Provider Network's Multi-Disciplinary Team (MDT) process prior to commencing on a medical pathway.

The latter 3 steps are essential pre-requisites to being able to include Northern Ireland in the planned PATHWAYS research programme, including the puberty blocker trial, and any longer-term follow-up studies.

- To determine if there are any gaps in the service delivery plans which might impede any of the above objectives, and if necessary, make recommendations to address these.

- To provide training to the Regional Gender Identity service staff in line with training provided to the NHS English teams to ensure ability to deliver consistent assessments and formulate holistic management plans in line with the other centres.

**The visiting team comprised:**

- Dr Hilary Cass - Chair, Independent Review of Gender Identity Services for Children and Young People (England)
- Dr Camilla Kingdon – Chair, National Provider Network, Children and Young People’s Gender Services (England)
- Dr Julie Alderson – Clinical Director, Children and Young People's Gender Service, University Hospitals Bristol and Weston
- Prof Judith Ellis – Independent Chair of two multiprofessional reviews of English Children and Young Peoples gender services

## **BACKGROUND INFORMATION**

### **1) Under-18 gender identity services:**

The current Knowing Our Identity (KOI) service for under 18s was established in 2014, within the Belfast Health and Social Care Trust. This was commissioned as part of Step 4 provision in a stepped model of care with CAMHS.

The original funding allocation provided for the following staffing:

0.2 WTE Child and Adolescent Psychiatrist

0.2 WTE Paediatric Endocrinologist

0.5 WTE Psychologist Band 8a

0.5 WTE Clinical Nurse Specialist (CNS) Band 8a

In order to meet increasing demands on the service, from June 2016 the Belfast Trust funded additional hours (0.3 WTE) for both regional posts, creating two 0.8 WTE (30 hours) posts, and from Jan 2020 the CNS was increased to full time. However, by 2022 this additional funding by Belfast Trust was no longer sustainable given the impact on CAMHS resources. Belfast Trust had to reduce the clinical psychology hours to their original quota of 0.5 WTE (18.5 hours) as the post became vacant in June 2021. Recruitment to these posts has subsequently been problematic; the Trust could not recruit into part time posts so made the two 0.5 posts into 1 WTE 8a nurse post. The postholder is currently on maternity leave. The Trust commission psychology assessments if required.

We were told that KOI offered access to hormone interventions for young people where appropriate, following careful psychological assessment and consideration from 2014 to 2020. Unfortunately, due to limited adult gender provision with growing waiting lists, new referrals after March 2020 ceased to have access to the endocrine path.

#### **We were provided with the current pathway summary as follows:**

Step 1: Referral is received from Health and Social Care Trust (HSCT) CAMHS Team.

Step 2: KOI Team meet with HSCT CAMHS Team to discuss case.

Step 3: If agreed that the young person meets the threshold, they attend KOI services for assessment.

Step 4: If agreed at the end of assessment, they attend KOI for psychological treatment - exploration around gender identity – and will also remain with the HSCT CAMHS team during this period. If the young person has no other comorbidities, the CAMHS team will just review them every 3-6 months.

Step 5: As there is no current endocrine pathway, treatment may cease – they may be open to KOI until transfer to the Brackenburn (adult) clinic. Their time in KOI will count towards their waiting time for adult services.

In March 2025, KOI had 15 open cases with a further 51 on the waiting list for assessment. At that time, KOI estimated that around 45 young people with gender related distress may be held in core CAMHS - not known to KOI.

## 2) Gender identity services review

Starting from September 2019, a review of gender identity services was commenced. In common with services across the rest of the UK and internationally, there were long waiting list pressures on the adult services at Brackenburn Clinic and staffing challenges.

In November 2022, the Permanent Secretary, DoH, considered a submission from officials about the review report and implementation plan for the new Gender Identity Service. Subsequently, given the scale of the costs involved, the Permanent Secretary asked officials to consider whether there were substantially more affordable options.

In March 2023, given ongoing challenging budget constraints, officials submitted a more affordable proposal for a new Regional Lifespan Gender Service, bringing together Children’s and Adult Gender Services under a single management structure. This was felt to be a way to put the combined service on a more stable footing. By December 2023, this was generally accepted as a feasible way forward. A business case was developed through 2024 and approved by the Minister in April 2025.

### Proposed changes in staff establishment

The existing gender staff establishment is as follows:

CAMHS KOI and Endocrine	0.2 WTE Consultant 0.2 WTE Endocrine 1 WTE 8a (Split between 2x 0.5 posts, 1 for a Nurse and the other for a Psychologist)
Adult Gender Service	1.0 WTE Consultants 1.6 WTE Band 7 Practitioners 1.0 WTE B4 Med Secretary (B4 is registered as a member of staff within gender but job role expands beyond that. Therefore, 1 WTE B4 is not a true reflection of actual delivery as staff member assists other services).
Adult Endocrine	0.2 WTE Adult (Endocrinologist currently providing a limited service. This is at a net loss to the endocrine service – business case will be developed to substantively resource this 0.2wte.)

The proposed additional staffing for the Lifespan Gender Service is as follows:

Post	Band	WTE
Psychologist	8C	1.0
Service Manager	8B	1.0
Practitioner	8A	1.0
Psychologist	8A	1.0

Practitioner	B7	0.4
Admin Support	B4	1.0

The proposed staffing for the endocrine service is as follows:

Post	Band	WTE
Consultant Endocrinologist	Consultant	1.0
Medical Secretary	4	0.5
Nurse	7	2.0
Pharmacy Technician	5	0.6

The stated rationale within the business case for the Lifespan Gender Service staff structure is as follows

*“It is intended that the staffing structure would provide clear routes for staff to progress.*

*The Service Manager would set strategic direction, developing governance and policy underpinnings for the newly established service, responding to constituency and media queries and managing the team accountable to them. This would include implementing learning from the Cass Review, clinical supervision, and engagement with primary care to develop GP shared care-prescribing hubs. He / she would also co-ordinate the final approach to the research element of the Cass recommendations, outlining the resource required, develop procedures to facilitate data collection and lead any future discussions on potential additional funding for this part of the role.*

*The creation of two senior Psychologist posts aims to create two leaders within the team to support the Service Manager and provide clinical direction. It meets a need identified within the Cass Review, which highlighted how psychological therapies had been overshadowed by the focus on puberty blockers and medical interventions.*

*The Cass Review called for multidisciplinary teams to be developed within regional centres, hence the addition of 1.4 WTE Practitioners split between Band 8a and Band 7, whilst also advocating further research to evaluate effectiveness, which would form part of the professional training element within the job roles.”*

## **MEETINGS WITH STAFF**

Over the 3 days, the visiting team met with members of the Regional Gender Identity Team (staff from adult and KOI services), the Minister and officials, the commissioning team, the core CAMHS teams, the clinical director and senior consultants from the Children's Hospital, and service users / family members. In addition, a teaching session was provided for staff across the services.

The following is an outline of the key themes discussed across the various meetings.

### **1) Service reconfiguration and alignment with England**

Northern Ireland's gender identity service is at an early stage of remodelling based on the plans for a new Lifespan Service. Within these plans is an aspiration to align with the multidisciplinary team approach recommended in the Cass Review and to collaborate with the UK-wide National Provider Network for consistency and shared learning.

Even though the service redesign process is at an early stage, NI has some distinct advantages over the English regional centres:

- There is already an established network between the 5 core CAMHS teams and the KOI service, with KOI currently being an integral part of the staged CAMHS service.
- In England, prior to the Cass Review, patients could be referred from primary care and even from non-NHS services. By contrast, in NI patients have to be referred and under active follow-up by core CAMHS services. This approach prevents unresolved mental health and developmental issues from being overlooked before gender identity assessment.
- The new proposed model of an integrated lifespan service has potential to move faster than the English regional services to provide seamless transfer of care. This is because although follow through services for 17-25 year olds were recommended in the Cass Review, this recommendation has not yet been implemented in England.

The advantages of a collaborative approach with services across the UK were discussed; specifically, this brings the potential to work to the same clinical standards and protocols despite regional staffing differences, and to share clinical improvement insights. The network also facilitates shared clinical discussions and training. One of the challenges for the Tavistock Clinic was being a single national service without the scope for peer review; it is important that no service finds itself in that position in the future.

There was some concern from KOI staff that this might mean service users would not be able to have an individualised package of care based on their specific needs. The visiting team emphasised that this was not the case. The key focus in the new services is on developing a care plan that is predicated on each young person's biopsychosocial assessment and formulation; hence each will need different and personalised approaches. The point at which there is a need for greater consistency is if there is a decision for the young person to proceed on a medical pathway.

There was also concern that the lifespan approach may pull the previous KOI approach away from its roots in CAMHS. The visiting team was clear that this close working relationship with CAMHS is an important benefit of the NI service.

## 2) Referral Patterns, Caseloads, and Service Demand

The KOI Service currently manages a small caseload with approximately 60-80 children and young people referred annually, contrasting with higher volumes seen in England and Wales, and Scotland. We were informed that KOI has a focus on comprehensive assessment and MDT collaboration before treatment and ongoing monitoring.

Adult services state that they are handling approximately 150 active patients and around 25 new adult patients monthly. The adult service has a waiting list of about 1,200 patients, indicating significant demand in that cohort.

The closure of the endocrine pathway for youth in the Regional Service has complicated follow-up and referral options. Hence although children and young people's referrals are stable, they may increase as pathways to endocrine intervention re-open.

The current wait for NHS endocrine access may have contributed to the increase in private prescribing and self-directed hormone use.

If an adult patient has accessed treatment from an unregulated provider, adult services provide safety monitoring without dose adjustments or prescribing for over 18s; they do accept private assessments from specialised London providers to reduce wait times.

## 3) Workforce Planning and Clinical Roles in the Lifespan Service

Workforce recruitment and configuration are critical constraints shaping service development. The need to ensure that clinicians retain broad paediatric or adult mental health expertise alongside gender specialty expertise was discussed. The English children's and young people's services follow a model where clinicians working in gender services also hold roles in other children's services to avoid burnout and loss of clinical perspective.

Recent investment will aim to strengthen the service, but vulnerabilities may remain. Recruitment has been difficult due to the controversy and vilification clinicians face, impacting workforce stability.

Most participants agreed that, in practice flexibility is needed about precise age of transfer. Collaborative transition clinics are preferable to expecting clinicians to cover both paediatric and adult caseloads. This would allow professionals to capitalise on their age-related specific skills.

## 4) Clinical Approach and Consistency of Care

### England

The visiting team described the key elements of their approach.

Secondary care referral from CAMHS or paediatric services has now replaced the option for referrals from primary care or even non-medical routes.

Ensuring a safe, standardized clinical pathway from assessment to treatment is a priority, with detailed attention to psychosocial assessment, informed consent, safeguarding, and monitoring, ensuring that the voice of each child/young person is heard.

The holistic assessment framework (HAF) is fundamental, capturing individual physical, psychosocial, mental health, neurodiversity, and educational needs, enabling tailored interventions before any medical pathway is considered. Accurate and consistent completion of HAFs, allowing biopsychosocial formulation, is necessary for the creation of individualised care plans. These prioritise pressing clinical priorities including patient safety concerns.

The national MDT reviews these assessments including patient engagement and the psychoeducation upon which informed consent rests. The national MDT provides assurance of the eligibility for medical pathways, ensuring uniform decision-making. The informed consent processes require uniform psychoeducation delivered within therapeutic relationships, enabling young people and families to understand impacts and risks of medical treatments. This counters the risks of self-directed research leading to uninformed decisions.

This consistent approach includes consideration of options for fertility preservation and essential and appropriately timed investigations, such as auxology, blood tests, DEXA scans etc., to inform safe and effective ongoing treatment plans. Safeguarding is also a significant focus, as past national services missed critical child protection issues due to a lack of professional curiosity, limited shared access to local records, and inconsistent thresholds.

### Northern Ireland

Northern Ireland's model benefits from integrated CAMHS involvement, which is underpinned by a single electronic health record that services community and secondary care (EPIC).

Referral routes for children and young people come exclusively through CAMHS, which acts as a needs assessment and triage point, helping manage volumes and ensuring early mental health treatment when needed. As noted above, this contrasts with historical arrangements in England, where direct GP referrals created an undifferentiated caseload of young people with complex presentations.

The service in NI is an integrated health and social care model. Social work input is considered essential, with some hubs led by social workers and others by senior nurses. There are regional reflective spaces where safeguarding concerns are regularly discussed across teams. The regional safeguarding team (Gateway) handles formal investigations, while these multidisciplinary reflective groups support ongoing case discussions.

Shared care agreements with GPs (for adult patients) are under consideration but remain challenging due to varying GP knowledge and resource constraints.

## **5) Early Childhood and Pre-Pubertal Pathway Considerations**

Addressing the needs of pre-pubertal children expressing gender incongruence is an emerging priority, and there was broad discussion about this.

In England there is currently a quality improvement project to capture data on early referrals and family experiences, aiming to inform development of a pre-pubertal pathway. The study will explore

parental support needs, and school engagement. Early intervention in primary care, with secondary care support, was proposed as a model to avoid unnecessary labelling or service overload. Social transitions in early childhood have profound developmental impacts, with some children maintaining fluid identities and others eventually following medical pathways.

There was recognition that there is a very small subgroup of children whose gender incongruence persists long-term and who may require ongoing support and possible medical interventions. However, support for parents to keep options open and manage distress is critical to avoid premature or inappropriate social transitions.

Safeguarding concerns include cases where parental motivations may drive social transitions inappropriately, necessitating careful assessment and family support.

## **6) Endocrinology input**

Allocated paediatric endocrinology time for the NI service is 0.2 WTE consultant sessions. At present, endocrinology clinics are reduced to 2 per month because of the closure of the endocrine pathway since 2020. Not all patients referred to endocrinology will progress to a hormone pathway following clinical assessment.

Young people should be transferred to the adult service at the age of 17½ but this has been challenging in recent years due to lengthy waiting lists. By March 2025, young people could transition to the adult gender service for psychological support at 17½, but no new referrals were being accepted to adult endocrinology service. This was flagged as a patient safety risk as it means the paediatric endocrinologist has had to continue managing patients as they move into adulthood.

There was clarity that adult endocrinologists would not be able to provide services for paediatric patients within the new service model.

Discussions with the clinical director and paediatric colleagues at the Children's Hospital touched on the possible expansion of paediatric endocrinology capacity. This is potentially challenging given that paediatric endocrinology waiting list pressures within the hospital are long. There are endocrinology 'Grid' trainees within the Northern Ireland training scheme, but no-one currently close to consultant level. Despite these potential obstacles, the discussion was positive and the potential to build the case for investment in a holistic adolescent service with Gender Services as part of that, was seen as a possible way forwards. In addition, the idea that there might be funding for endocrinology in Gender Services with the explicit intention of making this part (not all) of a consultant's job plan, was seen as a welcome way of growing paediatric endocrine capacity more generally.

## **7) Integration and Transition Between Child and Adult Services**

Maintaining effective interfaces between child and adult gender services is vital to avoid gaps in care during transition, particularly for vulnerable groups aged 16–25, and it is envisioned that the Lifespan Service will be a step forward in addressing this issue.

Flexible models tailored to individual maturity and clinical needs could improve service responsiveness. Cross-service collaboration is important for neurodiverse or learning-disabled young people who require extended transition support. Participants reiterated the need for "fuzzy edges"

or transition clinics to support young people moving from paediatric to adult services, whilst recognizing distinct clinical, legal and governance differences between those over and under 18.

Staff joint working and part-time roles in both child and adult services are being considered to preserve clinical expertise and continuity. However, there was concern about recruiting clinicians who can effectively cover the entire lifespan, with consensus that distinct paediatric and adult roles aligned through close collaboration are preferable. In addition, as previously discussed, maintaining CAMHS clinical perspectives, particularly on child and adolescent development within KOI is a priority, as is the need to avoid over-specialisation on one clinical pathway only and loss of developmental context.

## **8) Perspectives from Core CAMHS staff**

A major frustration for CAMHS staff is that there are children and young people on their caseload who are awaiting the KOI service but cannot access it for the reasons outlined above. Hence CAMHS staff are needing to see them on a quarterly basis when there is no clear therapeutic goal. They therefore have to spend a lot of time managing expectations.

They described a very heterogeneous caseload, which is similar to that recognised in other services; for example, many have a history of trauma, bullying and systemic challenges. Also, many are known to ASD services. Historically they had seen the more 'classically recognised' children with a very long trajectory from preschool years, but now the more usual age of presentation is 12-13, and they are more commonly female to male identities, and often same sex attracted. There were instances of children presenting from the same school and class.

There was discussion about a 'waiting well' service so that young people can access advice while waiting, and this is something that the English services are also exploring and piloting.

Various outcomes were observed, with some young people persisting in their gender identities and others resolving their gender questioning in different ways.

## **9) Meeting with service users**

The visiting team met two adult service users and a parent of a service user. Themes raised included the need for more training for GPs, the longstanding concerns about some of the assessment processes which were felt to be mental health based and intrusive, and the lack of support for those with non-binary identities. However, there was support for a lifespan service that bridges the gap between under-18s and adult services, and an individualised approach to care.

## **COMPLIANCE WITH RECOMMENDATIONS OF CASS REVIEW**

In discussing the aims of the visit with the management and commissioning team, it was acknowledged that the visiting team could only advise on the measures necessary to achieve compliance, but the task of ensuring achievement of this compliance would rest with the local managers and clinical leaders within the service. Some adjustments would also potentially be needed to take account of the forthcoming NHSE service specification for use in England from April 2026 to ensure consistency with NHS English services in as far as is possible.

There are two levels of compliance with the Cass Review recommendations that the Regional Lifespan Service aims to put in place:

- The first addresses the issue of aligning clinical practice so that standards of care in Northern Ireland are consistent with those in England. This would allow shared clinical improvement initiatives, shared learning and a peer network to support consistency of the care model and avoid the professional isolation which was so challenging for the GIDS service at Tavistock and Portman.
- The second level of compliance is more rigorous and demanding, and is based on Northern Ireland's commitment (and the support by the Minister of Health) to be a research site within the Kings College London puberty blocker trial and the wider PATHWAYS research programme. Achieving this would require significant staff training, changes in clinical processes, and establishment of the necessary research infrastructure, as well as a paediatric endocrinologist to be a principal investigator for the trial and another staff member to be a principal investigator for the non medical intervention arm (HORIZON). The entry point for the trial is via the National MDT, so an MoU would need to be established with the National Provider Network. Patients going to the National MDT for consideration for inclusion would need to have been taken through identical assessment, baseline core data collection, first line psychological support, essential psychoeducation and detailed informed consent.

## 1) Cass Review recommendations which are responsibility of NI services

This group of recommendations are ones that the NI service could adopt (locally adapted) within the newly remodelled service.

### *Cass Review recommendations*

***Recommendation 1:** Given the complexity of this population, these services must operate to the same standards as other services seeing children and young people with complex presentations and/or additional risk factors. There should be a nominated medical practitioner (paediatrician/child psychiatrist) who takes overall clinical responsibility for patient safety within the service.*

***Recommendation 13:** To increase the available workforce and maintain a broader clinical lens, joint contracts should be utilised to support staff to work across the network and across different services.*

### **NI Visit Recommendation 1: Shared clinical posts with other under 18's services**

The visiting team recognised the significant advantages of a lifespan service, with safer transfer to adult care and economy of scale of posts such as the service manager, pharmacy technician and secretarial support. However, **for patient-facing clinical posts, the recommendation was that it would be preferable to have split posts with other under 18's services.**

There are several reasons for this:

- there are differences in developmental focus, clinical governance, and training between paediatric and adult services, and clinical staff need expertise in child and adolescent development, and in family based approaches to care; therefore, unless an individual had extensive training and experience in both adult and child & adolescent physical and mental health, working across the lifespan would be suboptimal
- the Cass Review recommended that within under 18's services clinical staff should not work exclusively in gender services because of the loss of broader perspectives on child and adolescent development and clinical presentations
- by staff having roles in other services, they would bring wider expertise (for example in ASD, trauma etc) into the gender service
- conversely, staff would also take gender expertise back into their home teams (e.g. if they worked a shared post between the gender service and core CAMHS)
- there have already been recruitment problems for full time posts, and joint posts would be a way to prevent burnout and support career progression

### **NI Visit Recommendation 2: Closer integration with paediatric services**

Although the service has developed as Stage 4 CAMHS, **there would also be advantages in taking the opportunity to exchange some sessions with the Children's Hospital team**; for example, early discussions about a general paediatric resident doctor undertaking some sessions would be one way of providing some supervised support for the paediatric endocrinology work. As it is, the current paediatric endocrinology provision could be vulnerable without support. As the service matures, staffing the KOI MDT with sessions from allied health professionals (e.g. in occupational therapy or speech and language therapy) would be a valuable consideration. **One possibility would be to develop a co-located service, with AHPs and paediatrics forming part of the KOI MDT and providing clinics as required.** This would help address recruitment problems at practitioner level and further align the NI service with NPN services.

### **NI Visit Recommendation 3: Service leadership**

There is already CAMHS consultant input to the service, as per Recommendation 1 of the Cass Report, but a single consultant working 0.2 WTE leaves the individual without peer support, making the service vulnerable. It is hoped that additional sessions will be available through the development programme

The Role of the Service Manager for the Lifespan Gender Service incorporates many of the strategic and transformation leadership duties of the Clinical Director (CD) within the CYPGS (in England) service model. The English CYPGS CD is a senior clinician with leadership experience within each regional service. The Lifespan Gender Service Manager will draw upon the clinical expertise of senior psychologists, senior nurses, endocrinology consultants (adult and paediatric) and consultant psychiatrists (adult and child & adolescent).

We would recommend that **the children and young people's component of the lifespan service additionally needs a nominated senior Clinical Leader** to ensure service cohesion, and to take responsibility for the quality of the CYP elements of the service. The clinical leadership should be provided via a substantive post, enabling clinical involvement in service provision, and availability to clinicians and managers for strategic and operational aspects of service delivery. In the English CYPGS

there is a Clinical Lead in addition to the Clinical Director in each regional centre; the Clinical Lead is one of the few near full time posts (0.8-1.0 WTE).

**Cass Review recommendations**

**Recommendation 2:** *Clinicians should apply the assessment framework developed by the Review's Clinical Expert Group, to ensure children/young people referred to NHS gender services receive a holistic assessment of their needs to inform an individualised care plan. This should include screening for neurodevelopmental conditions, including autism spectrum disorder, and a mental health assessment.*

**Recommendation 18:** *The national infrastructure should be put in place to manage data collection and audit and this should be used to drive continuous quality improvement and research in an active learning environment.*

**NI Visit Recommendation 4: Full training on Holistic Assessment Framework and Core Data Set, and research support**

A first training session based on the background of gender care for children and adolescents and the Holistic Assessment Framework was delivered during the visit. This training was based on the CYPGS national induction training but did not include the full HAF training. Further training to cover all KOI and CAMHS staff would be required to ensure the consistency with England described above for entry to the PATHWAYS programme.

Ultimately, there would also need to be training on the core dataset that will be used across the collaborating services. The programme requires funded research assistant support for collaborating research centres, to collect essential data for the research programme.

It is noted that service users have expressed opposition to the assessment framework and the pathway from CAMHS to KOI as this is seen as pathologising. It will be for the local team to engage with stakeholders if this is still a significant barrier for service users.

**Cass Review recommendations**

**Recommendation 3:** *Standard evidence based psychological and psychopharmacological treatment approaches should be used to support the management of the associated distress and co-occurring conditions. This should include support for parents/carers and siblings as appropriate.*

**NI Visit Recommendation 5: Psychoeducation programme as part of consent process**

The existing arrangements with core CAMHS mean that NI patients are at an advantage over English patients in already having shared care arrangements and appropriate therapy embedded in the model.

However, the specific elements of **the psychoeducation programme utilised in England will need to be shared and embedded** as part of the process of evidencing engagement and informed consent to a medical pathway.

***Cass Review recommendations***

**Recommendation 8:** *The option to provide masculinising/feminising hormones from age 16 is available, but the Review would recommend extreme caution. There should be a clear clinical rationale for providing hormones at this stage rather than waiting until an individual reaches 18.*

**NI Visit Recommendation 6: MOU with National Provider Network and decision making for masculinising / feminising hormones**

The aim of the National Provider Network is to avoid a significant variation in care approaches and ensure that thresholds for starting masculinising / feminising hormones are similar across centres. Although the PATHWAYS trial is focused on puberty blockers, there would need to be consistency of approach to transition to hormones, as this is one of the important outcomes. Further discussion will be needed between NI and English services about the consistency of approach to decision making at this important juncture. An MOU to join the National Provider Network is currently used.

***Cass Review recommendations***

**Recommendation 11:** *NHS England and service providers should work to develop the regional multi-site service networks as soon as possible. This could be based on a lead provider model, where NHS England delegates commissioning responsibility to the regional services to subcontract locally to providers in their region.*

Northern Ireland has the advantage over England of already having a network between KOI and the 5 regional CAMHS services, so no further changes recommended

***Cass Review recommendations***

**Recommendation 23:** *NHS England should establish follow through services for 17-25-year-olds at each of the Regional Centres, either by extending the range of the regional children and young people's service or through linked services, to ensure continuity of care and support at a potentially vulnerable stage in their journey. This will also allow clinical, and research follow up data to be collected.*

As above, the Lifespan model puts Northern Ireland ahead in having scope for a much smoother 17-25 year transitional care pathway from children's to adult services.

## 2) Recommendations involving collaboration with National Provider Network in England

This group of recommendations are related to collaboration with the English services, and will involve ongoing discussions over the coming months.

### *Cass Review recommendations*

**Recommendation 9:** *Every case considered for medical treatment should be discussed at a national Multi Disciplinary Team (MDT) hosted by the National Provider Collaborative.*

**Recommendation 16:** *The National Provider Collaborative should coordinate development of evidence-based information and resources for young people, parents and carers. Consideration should be given as to whether this should be a centrally hosted NHS online resource.*

**Recommendation 17:** *A core national data set should be defined for both specialist and designated local specialist services*

**Recommendation 19:** *NHS England and the National Institute for Health and Care Research (NIHR) should ensure that the academic and administrative infrastructure to support a programme of clinically-based research is embedded into the regional centres.*

**Recommendation 20:** *A unified research strategy should be established across the Regional Centres, co-ordinated through the National Provider Collaborative and the Research Oversight Group, so that all data collected are utilised to best effect and for sufficient numbers of individuals to be meaningful.*

For NI to participate in the National Provider Network and the PATHWAYS study, the crucial steps will be to ensure that assessment processes and data collection are aligned, as set out in the previous section.

There will also need to be training on all relevant aspects of the research protocol, including preparatory work in the lead up to a young person being considered eligible for puberty blockers.

Local funding for research support would need some additional investment, some of which should be available via funded collaboration as a centre within the PATHWAYS programme.

Other activities of the network, such as shared training, audit, and quality improvement programmes would be helpful in providing peer support and development, and this option seemed to be welcomed by the team. Sharing the development of online resources for service users and families may also be useful.

## 3) Recommendations for future consideration

This group of recommendations are not core essential elements, and could be considered at a later stage if appropriate to local circumstances.

### *Cass Review recommendations*

**Recommendation 4:** *When families/carers are making decisions about social transition of pre-pubertal children, services should ensure that they can be seen as early as possible by a clinical professional with relevant experience.*

**Recommendation 22:** *Within each regional network, a separate pathway should be established for pre-pubertal children and their families. Providers should ensure that pre-pubertal children and their parents/carers are prioritised for early discussion with a professional with relevant experience.*

**Recommendation 25:** *NHS England should ensure there is provision for people considering detransition, recognising that they may not wish to reengage with the services whose care they were previously under.*

**Recommendation 26:** *The Department of Health and Social Care and NHS England should consider the implications of private healthcare on any future requests to the NHS for treatment, monitoring and/or involvement in research. This needs to be clearly communicated to patients and private providers.*

**Recommendation 27:** *The Department of Health and Social Care should work with the General Pharmaceutical Council to define the dispensing responsibilities of pharmacists of private prescriptions and consider other statutory solutions that would prevent inappropriate overseas prescribing.*

**Recommendation 28:** *The NHS and the Department of Health and Social Care needs to review the process and circumstances of changing NHS numbers and find solutions to address the clinical and research implications.*

## SUMMARY OF FINDINGS AND RECOMMENDATIONS

The visiting team received a warm welcome from everyone across the clinical and management teams in Northern Ireland, as well as from the Minister and officials. It was a pleasure to meet such a committed and enthusiastic group of staff.

The development funding approved by Minister Nesbitt presents a crucial opportunity to reopen the endocrine service at the same time as developing a new lifespan model of care and building the foundations for a collaborative relationship with the English under-18's services.

The networked model between CAMHS and KOI which exists already is a key asset of the NI approach, as is the chance to have a seamless interface across the age range.

The specific recommendations from the visiting team are noted throughout the section on compliance. ***It will be for the clinical and management team to consider which of the recommendations are feasible within the available resources and change management capacity.***

- Recommendations 1-3 relate to workforce, integration with paediatric services and clinical leadership within the under-18's service, and are suggestions to make the NI service consistent with the English services, regardless of whether or not there is a decision to join the UK National Provider Network and research programme.
- Recommendations 4-6 would be required in order to join the UK National Provider Network and participate in the research programme

### **1) Workforce, integration with paediatric services and leadership**

The financial and practical advantages of management, administrative and pharmacy posts which cross the age range were clear. However, for clinical posts it was recommended that there should be 'horizontal' integration with other CAMHS and paediatric services rather than 'vertical' integration between under 18's services and adult services.

The balance of investment and clinical sessions between the under and over 18's component of the service is a matter for the local management team to decide, based on planned activity, which has already been carefully modelled. However, the very limited consultant time in both the KOI service and the paediatric endocrinology service are key vulnerabilities that should be addressed through the development plans, including closer integration with paediatric services. In addition, it was recommended that the under-18's service would need a substantive clinical lead post which is a minimum of 0.6-0.8 WTE.

Rather than 'hard edges' to clinical responsibilities, it was recognised that for some less mature young people, or those with additional needs, an extended relationship with a trusted clinician may be preferable for a period across the 18-25 period, and the option for transition (transfer) clinics would be facilitated by the new service arrangements.

The recruitment and training of new staff will be the immediate priority, and it will take some time for the new arrangements and model of care to bed in.

## 2) Fuller alignment with National Provider Network and engagement in PATHWAYS research programme

In order to become a PATHWAYS research centre, engagement with Kings College London is urgent and should be led by the paediatrics manager in liaison with the Lifespan Service manager and the paediatric endocrinologist (all in post currently). This would need to happen in parallel with aligning all aspects of service delivery with the model of care being used in England, which is fully laid out in the 2026 service specification.

The additional training and development needed to progress alignment with the National Provider Network, as well as securing a small amount of top up funding for research support will inevitably take additional time. This is a significant piece of transformational work and would need a workplan developed by the KOI manager; this will include ensuring alignment of assessment frameworks, development of comparable approaches to safeguarding and consent, and a standardised psychoeducation programme as described above. By way of comparison, it has taken between 1-2 years for each of the English services to reach a state of readiness to join the network. Therefore, there will be a need for some expectation management if young people are hoping to join the PATHWAYS trial in the very near future.

Having a looser relationship that involves the sharing of some training and quality improvement initiatives would require less preparation and resource.

This visit represents a first step in a future collaborative relationship, and it will obviously be a matter for the management and clinical team to consider what is feasible and desirable in terms of pacing of the various suggestions that were made.



**Dr Hilary Cass on behalf of the visiting team**