



# **Final Report of the Steering Committee on the Development of HSE Transgender Identity Services**

February 2020

## EXECUTIVE SUMMARY

A Steering Committee was formed in May of 2019 to address specific issues in relation to the development of Transgender Identity Services. The specific remit of the Committee was to work on the development of seamless interfaces between the agencies delivering Gender Services and to develop a job description for a Consultant Psychiatrist in Child and Adolescent Psychiatry who would be dedicated to the development of the service for those aged under 18.

This occurred on a background of increasing recognition of the need to develop gender identity services, along with the fact that funding had been made available to develop services in recent years, resulting in the appointment of Consultant Endocrinologists to both the Adult and Children's Services, as well as a Consultant Psychiatrist to the Adult Service. There was also funding for additional team members.

The Committee had a wide range of stakeholders from the agencies involved in delivering care as well as service user representatives and was chaired by the National Clinical Advisor and Group Lead for Mental Health Services. The Committee had its first meeting in July 2019 and met a total of three times. Two work streams arose from the first meeting of the Committee and there were a number of other meetings relevant to the workings of the Committee during its lifetime.

The Committee issued documentation on two occasions, an interim draft report in October 2019 and a final report in February 2020. The Committee made a number of recommendations and concluded with two outcomes.

## BACKGROUND

In line with international trends, the demand for transgender services in Ireland has increased exponentially over the last number of years. Prevalence studies suggest an increase in those experiencing gender dysphoria, with the World Health Organisation (WHO) reporting a prevalence of 1:60,000 in 1997 and the Diagnostic and Statistics Manual version 5 (DSM5) reporting a prevalence of 1:20,000 in 2013.

Services for transgender care in Ireland have evolved organically over the last number of years, with adult services based in St. Columcille's Hospital (SCH), Loughlinstown (part of Ireland East Hospital Group - IEHG) and children's services are located in Our Lady's Hospital for Sick Children (OLHSC), part of Children's Health Ireland (CHI), in Crumlin. Endocrinology and Psychological support services are delivered on both sites.

A Model of Care (MoC) was developed between 2012 and 2017 to support the development of HSE Gender Identity Development (GID) services under the auspices of Dr. Philip Crowley, National Director of the HSE Quality Improvement Division. The development of the MoC was associated with the allocation of additional resources to enhance existing services; see **Appendix 1** for further information on the development and evolution of the MoC.

In Crumlin, the Psychological services are provided by the Tavistock Clinic (a London-based Clinic with expertise in this area), which is funded by the Treatment Abroad Scheme (TAS). In SCH, the Psychological services are led by a Liaison Psychiatry Team, which falls under the governance of St. John of God Community Services, Mental Health Division at the Cluain Mhuire Service (SJOG-MHS). This is funded via a service level agreement (SLA) with CHO 6.

Given the number of agencies involved in the delivery of care to this group, it was decided at senior level within the HSE that the formation of a Steering Committee to develop and enhance governance arrangements across these agencies would be a welcome development. The Chief Clinical Officer, Dr. Colm Henry, asked Dr. Siobhán Ní Bhriain, National Clinical Advisor and Group Lead for Mental Health, to lead out on the formation of the Committee.

## COMPOSITION OF THE STEERING COMMITTEE

A variety of stakeholders involved in the delivery of care to the Transgender Community were contacted to participate in the Committee, including the advocacy group Transgender Equality Network Ireland (TENI). On foot of this, the Chair wrote to the clinical and corporate leads in each of the Irish agencies delivering care, inviting them to participate in the governance committee or to nominate a suitable representative. Other invited members include two representatives from TENI and a representative from the ThisIsMe advocacy group, as nominated by Minister Simon Harris. The National Director of the Quality Improvement Division, Dr. Philip Crowley, who played an early and critical role in the development of Transgender Services was also invited to participate; see **Appendices 2 and 3** for the Terms of Reference (TOR) and initial and final membership of the Steering Committee.

## ACTIONS OF THE STEERING COMMITTEE

The Steering Committee met on three occasions – Thursday July 4<sup>th</sup> 2019, Thursday October 17<sup>th</sup> 2019 and Thursday January 23<sup>rd</sup> 2020. Separate meetings were held in the intervening times by the various workstreams and by the Chair with some committee members as required. The inaugural meeting focused

on scoping out the remit of the Steering Committee, developing a Terms of Reference that reflected that scope, and developing two distinct work streams with the following remits:

1. Develop the draft job description for the Child and Adolescent Consultant Psychiatry post, to be located in CHO 7 but with a defined role in CHI in Crumlin.
2. Work on developing seamless interfaces between the agencies involved in care delivery.

The second Committee meeting resulted in a discussion of the above and it emerged that in the interim, SCH had formed its own Governance Committee following the appointment of a new clinical lead in Endocrinology, Dr. Karl Neff who was appointed to the role of Clinical Lead of the National Gender Service (NGS) in May 2019. Dr. Neff invited Dr. Ní Bhriain to meet with him to explore the commonalities between the two groups and this meeting took place on Monday December 9<sup>th</sup> 2019.

Thus, the following actions were agreed at the second Committee meeting:

1. Dr. Ní Bhriain and Dr. Neff to meet and review how the services are working to develop a seamless transition between Child and Adult Endocrinology services.
2. Following this, Dr. Ní Bhriain will meet with the advocacy representatives to seek their views on the above meeting.

At the meeting between Dr. Neff and Dr. Ní Bhriain in December 2019, Dr. Neff advised of the considerable progress being made in the establishment of a governance committee in SCH and advised that the membership is composed of representatives from the Adult Endocrine and Mental Health Services and from the Children's Endocrine Service; see **Appendix 4** for the Terms of Reference and Membership of the National Gender Service Clinical Governance Group. This Committee reports to the Executive Management Teams for SCH and SJOG-MHS.

## OUTCOMES

The Steering Committee has achieved the following outcomes:

- Development of job description for CAMHS post, the purpose of which is to facilitate the move from the current system of psychological support for those under 18 years old to ensure services are provided and delivered by the Irish Health Services.
- Supported a governance committee across IEHG / CHI which had been developed that will continue to ensure ongoing review of the NGS as it develops, including review of the Terms of Reference for the National Gender Service Clinical Governance Committee to ensure consistency with the aims of this Steering Committee.

## CONCLUSION

The work of the Steering Committee concluded in January 2020, having achieved its intended outcomes as outlined above.

The Chair particularly noted the development of a strong sense of collegiality amongst all committee members and commended the committee members on their work, the level of engagement displayed by

all, the commitment of all to develop a well-governed service for this patient group and the manner in which committee members conducted themselves.

### RECOMMENDATIONS:

A summary of the recommendations emerging from the Steering Committee, and their progress towards completion, are as follows:

Recommendation	Status	Responsibility
1. Move from the current system of psychological support provided by Tavistock Clinic for those under 18 years old to ensure services are provided and delivered by the Irish Health Service.	IN PROGRESS	New CAMHS Consultant / CHO 7 / CHI
2. Develop a full multidisciplinary team (as defined in the Model of Care) within Mental Health Services to support the delivery of the NGS, led by the new CAMHS Consultant Psychiatrist.	IN PROGRESS	NCAGL-MH/CHO 7
3. Develop TOR of a Clinical Governance Committee for the National Gender Service (to include representation from adult and paediatric services, as well as Service Users) that will operate across all services delivering Transgender care to ensure clear clinical and corporate governance structures are in place.	IN PROGRESS- awaiting appointment of Service User.	Dr. Karl Neff
4. Develop a Service User Forum for the NGS, with advice from the HSE Head of Mental Health Engagement & Recovery in relation to service user involvement and representation (expected completion date of Q4 2020).	IN PROGRESS	National Gender Service Clinical Governance Committee
5. Consider revisiting the current Model of Care, as developed by Dr. Philip Crowley (National Director of HSE Quality Improvement Division) under the auspices of new guidelines published by the Department of Health on Model of Care and noting additional resources now available to deliver more comprehensive programme of care.	FOR CONSIDERATION	HSE EMT
6. Continue to roll out Gender Identity Skills Training (GIST) nationally to all relevant staff members across the continuum of care, through primary care, secondary care and tertiary care, including Jigsaw and CIPC staff providing services at a local level.	ONGOING	HSE Social Inclusion / National MHS
7. Consider the establishment of academic partnerships to provide longitudinal evaluation of the service as it develops, and appropriate KPIs for ongoing monitoring of the service, to best ensure service provision develops along with need.	IN PROGRESS	National Gender Service Clinical Governance Committee

## APPENDIX 1 – TRANSGENDER SERVICE DEVELOPMENT BACKGROUND & SIGN-OFF (SEPT 2019)

1. The HSE Quality Improvement Division led the process of developing a model of care (service development model) in response to a request from clinicians, health and social care practitioners, individuals, families and advocates for a systematic response to these concerns. This took place between 2012 and 2017.
  2. A draft document was developed and circulated for comment and feedback in November 2014.
  3. The following groups were consulted and made submissions:
    - Irish College of General Practitioners
    - Our Lady’s Children’s Hospital, Crumlin
    - The College of Psychiatrists of Ireland
    - The Faculty of Child and Adolescent Psychiatry, CPI
    - Irish Endocrine Society
    - Association of Occupational Therapists, Ireland
    - HSE CAMHS
    - HSE Primary Care Psychology
    - The Psychological Society of Ireland
    - Irish Association of Speech and Language Therapists
    - Irish Association of Social Work
    - HSE Health and Well being
    - Irish Institute of Mental Health Nursing
    - Heads of Psychology Services Ireland
    - HSE Social Inclusion Office
    - HSE Treatment Abroad Service
    - TENI
    - Transparenci
    - GLEN
    - BeLonG To
  4. Follow up consultation meetings were held on the following dates and chaired by Dr. Philip Crowley and included representation from all of the above groups:
    - January 2016 – Adults
    - January 2016 – Children
    - January 2016 – Professor Dónal O’Shea
    - January 2016 – Dr. Aileen Murtagh and Dr. Anne Kehoe
  5. Further amendments and submissions were made following the meetings.
  6. The document was completed in November 2016.
  7. An additional proposal for a National Gender Identity service was separately developed for the HSE Mental Health Division during 2016 and was co-authored on behalf of the division by Dr. Paul Moran – Consultant Adult Psychiatrist and Professor Dónal O’Shea – Consultant Endocrinologist, in consultation with Consultant Psychiatrists, Consultant Paediatric Endocrinologists and other medical and mental health colleagues. Dr. Margo Wrigley – Clinical Advisor Group Lead, requested that this proposal was appended to the Service Development Model as Appendix One.
  8. Key differences between this additional proposal and the MOC / service development model were as follows:
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- The appended proposal focuses only on the tertiary, highly specialised element of care in a person's transition. The QID proposal clearly identifies the need for the specialised tertiary service and also identifies the need for clinical and therapeutic input at both primary and secondary care levels in line with international best practice.
  - The appended proposal focuses mainly on the specialist psychiatric input required for transition. It proposes that an adult in transition must be seen by a psychiatrist in all cases in the Gender Identity Clinic.
  - The QID proposal, in line with guidance from Dr. Dónal O'Shea, Consultant Endocrinologist at the time and in line with international best practice, identifies that a person must have an expert psychiatric/psychological assessment prior to starting any medical intervention. It also clarifies the importance of identifying any co-morbid psychiatric/psychological conditions. The QID proposal identifies that specialist psychiatric input through the Gender Identity Clinic may be required for complex cases, as was the current practice at the time of publication.
  - The QID proposal recognises the role of psychiatry at both a secondary and tertiary level. The appended proposal concentrates the role at the tertiary level only. The QID proposal recognises that for this model to work resources, training and protected time for clinicians will have to be put in place to develop the capacity of clinicians within secondary services. However it also acknowledges that this practice is already in place in some Community Mental Health Teams at the time of publication.
  - The QID proposal outlines the pathway of care from primary care to tertiary care and identifies the necessary supports and interventions required on this pathway. The appended proposal focuses primarily on the tertiary element of care without reference to how a person will get to this service (e.g. who makes the referral, how referrals can be made and where).
  - The QID proposal was developed through extensive input from all of the professional bodies and organisations involved in the care of a transgender child, adolescent or adult. Advocacy organisations were partners in the development of the proposal from the outset. They were involved in the planning, consultation, feedback and redesign of the proposal. They were valued partners and equal partners in the process. The appended proposal was developed with input from Psychiatrists and Endocrinologists.
9. A business proposal to change particular aspects of the current provision of service to children and adolescents was developed by Dr. Aileen Murtagh – Consultant Child and Adolescent Psychiatrist and Dr. Anne Kehoe – Clinical Child Psychologist. This proposal specifically addressed the matter of transitioning the service from the Tavistock and Portman NHS Trust to a service delivered directly through the HSE by clinicians based and working in Ireland. This included an initial support phase from the Tavistock and Portman NHS Trust to enable appropriate handover and transfer of expertise to clinicians based and working in Ireland. This was included in Appendix Two.
  10. Following sign-off from Dr. Philip Crowley in 2016, the document was then circulated to the relevant National Directors, National Clinical Advisor & Group Leads and relevant Heads of Service – Acute (Mr. Liam Woods, Dr. Colm Henry, Ms. Emma Benton), Primary Care (Mr. John Hennessy and Ms. Catherine Donoghue) and Mental Health (Dr. Philip Dodd) in late 2016 and early 2017. A number of follow up meetings were held throughout 2017 to commence a process of resourcing and prioritising actions for the 2018 Service Plan.
  11. A number of meetings were held in early 2018 to agree priority posts across the acute and mental health services in an attempt to support and build existing service levels. A number of service-led working groups were established to develop a service-led response to the management of programmes and actions in relation to the provision of care to Transgender children, adolescents and adults, e.g. in SCH, Loughlinstown and in OLCCHC respectively. Subsequent work on mental health was managed through Dr. Philip Dodd and subsequently Dr. Siobhán Ní Bhriain.

**APPENDIX 2 – TERMS OF REFERENCE & INITIAL MEMBERSHIP****Steering Committee on the Development of HSE Transgender Identity Service****Terms of Reference****Mission Statement**

The aim of this Steering Committee is to develop a seamless and integrated service for those who present with gender identity issues with clear pathways of care such that the needs of the patient and their families are placed at the centre of service delivery.

**Context**

Following the development of the Model of Care for the Development of a Transgender Identity Service, in 2019 the Chief Clinical Officer (CCO) Dr Colm Henry, Dr Siobhán Ní Bhriain (SNB) and Dr Philip Crowley (PC) agreed that the National Clinical Advisor & Group Lead (NCAGL) for Mental Health (SNB) would establish and chair a Steering Committee to develop a seamless and integrated service for those who present with gender identity issues with clear pathways of care.

**Outcomes:**

1. Patient-centred service, such that patients and their families do not have to navigate the system.
2. Care based on best available evidence.
3. Seamless transitions between the multiple interfaces delivering this service.
4. Develop job description for CAMHS consultant and submit to CAAC, with agreement of ECD, CHO 7.

**Invited Membership:**

- Mr Stephen O’Hare, Chief Executive Officer of TENI, on behalf of patients/families (resigned on 30/09/19);
- Ms Sara Philips, Chair of TENI, on behalf of patients / families;
- Dr Philip Dodd, HSE Clinical Lead – National Office of Suicide Prevention (NOSP), on behalf of NOSP;
- Dr Brendan McCormack, HSE Executive Clinical Director – CHO 7, on behalf of CAMHS;
- Mr Kevin Brady, HSE Head of Mental Health Services – CHO 7, on behalf of Heads of Mental Health;
- Ms Sharon Hayden, Director of Operational Services – Children’s Health Ireland (CHI), on behalf of CHI;
- Dr Paul Oslizlok, Clinical Director – Children’s Health Ireland, on behalf of Child Endocrine Services;
- Mr Noah Halpin, ThisIsMe Campaign Lead, on behalf of Minister for Health Simon Harris TD;
- Mr Shane Hill, Regional Director – St John of God Community Services, on behalf of Adult MHS;
- Dr Colette Bonner, Deputy Chief Medical Officer – Department of Health (DOH), on behalf of DOH;
- Dr Larkin Feeney, Clinical Director – St John of God Community Services, Cluain Mhuire Service (or representative – Dr. Paul Moran or Dr. Ian Schneider);
- Dr Risteard Ó Laoide, Lead Clinical Director – Ireland East Hospital Group (or representative – Professor Dónal O’Shea);
- Ms Mary Day, CEO – IEHG, on behalf of Ireland East Hospital Group;
- Dr Colm Cooney\*, Executive Clinical Director or nominee – CHO 6, on behalf of Adult Mental Health Services;
- Ms Antoinette Barry\*, HSE Head of Mental Health Service – CHO 6.

**Chair**

- Dr Siobhán Ní Bhriain, NCAGL – Mental Health, or nominee designated by the Chair.



### Frequency and Timeframe

- First meeting to be held on: Thursday 4<sup>th</sup> July 2019 @ 2pm, Brunel Building, Heuston South Quarter, Dublin 8.
- Monthly for 3 months with an initial 2 hour meeting, followed by 2 x one hour meetings and a final two hour meeting to conclude.
- Suggested schedule (*italics indicate date yet to be confirmed with the Steering Group*):
  - Thursday 4<sup>th</sup> July 2019 (Room 6.01, Brunel Building, HSQ, D8);
  - Thursday 29<sup>th</sup> August 2019 (Room 6.01, Brunel Building, HSQ, D8) – 1 hour duration;
  - Thursday 17<sup>th</sup> October 2019 (Room 6.02, Brunel Building, HSQ, D8) – 1 hour duration;
  - *Wednesday 11<sup>th</sup> December 2019 (Room 6.02, Brunel Building, HSQ, D8) – 2 hours duration.*

### Quorum

- Chair / Nominee of Chair plus 50% of membership.

### Reporting / Accountability

- Reports through the Chair to the Office of the CCO and to the National Directors of Acute Hospitals and Community Operations. Final report to the Minister of Health / Chief Medical Officer via CCO / National Directors.
- The reporting structure is designed to reflect the fact that this service operates across the acute hospital / community interface, as well as across the child / adult spectrums of care.

\* *Stood down from the Steering Committee as service is delivered by SJOG on behalf of CHO 6, and SJOG service already represented by Mr. Shane Hill and invited clinical representatives.*

## APPENDIX 3 – FINAL MEMBERSHIP

### Steering Committee on the Development of HSE Transgender Identity Service

#### Final Membership:

- Ms Vanessa Lacey, Health & Education Manager of TENI, on behalf of patients/families;
- Ms Sara Philips, Chair of TENI, on behalf of patients / families;
- Dr Philip Dodd, HSE Clinical Lead – National Office of Suicide Prevention (NOSP), on behalf of NOSP;
- Dr Brendan McCormack, HSE Executive Clinical Director – CHO 7, on behalf of CAMHS;
- Mr Kevin Brady, HSE Head of Mental Health Services – CHO 7, on behalf of Heads of Mental Health;
- Ms Linda O’Leary, General Manager – St Columcille’s Hospital, on behalf of CEO Ireland East Hospital Group;
- Mr Paul Gallagher, Chief Director of Nursing & Midwifery, on behalf of CEO Ireland East Hospital Group;
- Dr Karl Neff, Consultant Endocrinologist – National Gender Service (delegated by Dr Risteard Ó Laoide);
- Ms Sharon Hayden, Director of Operational Services – Children’s Health Ireland (CHI), on behalf of CHI;
- Dr Paul Oslizlok, Clinical Director – Children’s Health Ireland, on behalf of Child Endocrine Services;
- Mr Noah Halpin, ThisIsMe Campaign Lead, on behalf of Minister for Health Simon Harris TD;
- Mr Shane Hill, Regional Director – St John of God Community Services, on behalf of Adult MHS;
- Dr Philip Crowley, National Director – Quality Improvement, on behalf of Quality Improvement Division;
- Dr Colette Bonner, Deputy Chief Medical Officer – Department of Health (DOH), on behalf of DOH;
- Professor Dónal O’Shea, Consultant Endocrinologist\* – SCH (delegated by Dr Risteard Ó Laoide);
- Dr Paul Moran, Consultant Psychiatrist\*\* – St John of God Community Services;
- Dr Karl Neff, Consultant Endocrinologist, SCH;
- Ms Emma Benton, HSE General Manager – Office of the NCAGL Acutes, on behalf of Dr Vida Hamilton;
- Ms Patricia Whelehan Kenny, HSE General Manager – MHS, on behalf of HSE Mental Health Services;

#### Chair

- Dr Siobhán Ní Bhriain, NCAGL – Mental Health, or nominee designated by the Chair.

\* *Declined to participate.*

\*\* *Did not respond to invitation to participate.*

## APPENDIX 4 – NATIONAL GENDER SERVICE (NGS) CLINICAL GOVERNANCE COMMITTEE SCH

### National Gender Service Clinical Governance Committee

#### Terms of Reference

##### Terms of Reference

1. National Gender Service Governance Group to meet 4 times per year and report to service management at SCH and SJOG-CMS via established governance reporting structure.
2. To review implementation of the National Gender Service (NGS) Model of Care currently in operation as agreed by National Gender Service Steering Group September 6<sup>th</sup> 2018
3. To develop a fit for purpose paediatric service in collaboration with colleagues at CHI Crumlin with a goal of ensuring safe care of those moving from the paediatric to adult service.
4. To develop clinical interface with other service providers (referrals to and from National Gender Service) and to ensure governance of clinical interface with other service providers
5. To identify clinical risks within the NGS.
6. To review complaints and compliments addressed to the NGS.
7. To govern research and audit involving the NGS.
8. To develop and monitor media and communication policy with the NGS.
9. To review resources required for the continued development of the NGS in collaboration with management at SCH & SJOG-CMS.

##### Invited Members – January 2020

- Dr Karl Neff, Clinical Lead/Consultant Endocrinologist, NGS (CHAIR)
- Professor Dónal O’Shea, Clinical Director SCH/Consultant Endocrinologist, NGS
- Dr Ronan Canavan, Consultant Endocrinologist, NGS
- Dr Wan Mahmood, Locum Consultant Endocrinologist, NGS
- Ms Rachel Moore, Senior Speech and Language Therapist, NGS
- Ms Kate McCaffrey, Senior Social Worker, NGS
- Ms Jacinta McManus, Grade IV NGS Administrator, SCH
- Dr Paul Moran, Consultant Psychiatrist, SJOG
- Dr Ian Schneider, Consultant Psychiatrist, SJOG
- Dr Suzanne Shaw, Senior Psychologist, NGS
- Ms Mairead Brady, Senior Liaison Nurse, NGS
- Ms Anne Wade, Lead NGS Administrator, SJOG
- Dr Larkin Feeney, Clinical Director, SJOG Mental Health Services
- Dr Eirin Carolan, Consultant Paediatric Endocrinologist, CHI Crumlin
- Dr Susan O’Connell, Consultant Paediatric Endocrinologist, CHI Crumlin
- Ms Kitty Quinn, Endocrine CNS, CHI Crumlin
- Dr Paul Oslizlok, Clinical Director, CHI Crumlin