Agenda and Notes

Sex and Gender Working Group

July 22, 2025

Via Teleconference

July 22, 2025

	Item	Purpose	Allocated Time	Presenter
1	***Welcome and Acknowledgement***		2 minutes	Karen
2	***Ground rules for respectful dialogue***		1 minutes	Karen
3	***Purpose of Infoway Sex and Gender WG***		2 minutes	Karen
4	**Intersex Panel Discussion**		33 minutes	Caroline Sanders & Martin Gramc
5	***Schedule Review & Adjournment***		18 minutes	Karen

Agenda and Notes

1. ***Welcome and Land Acknowledgement and Ground Rules***

Completed. See slide deck for details.

2. ***Ground rules for respectful dialogue***

Completed. See slide deck for details.

3. ***Purpose of Infoway Sex and Gender Working Group***

Completed. See slide deck for details.

4. ***Intersex Panel Discussion***

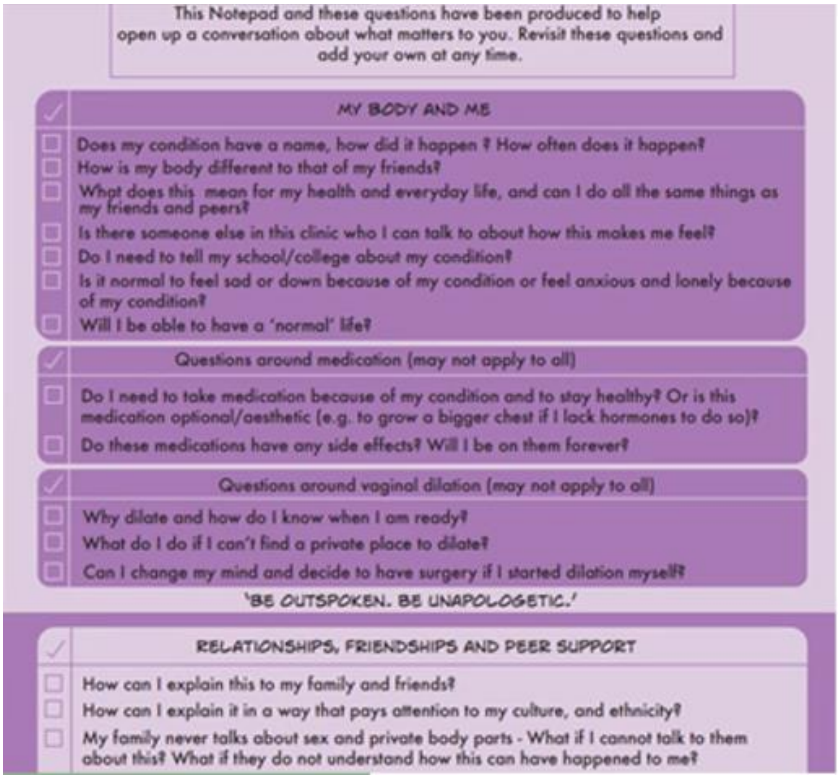
- Approaches to Care for Intersex Children in Europe – Martin Gramc
    - Agenda
    - Aims
    - Methodology
    - Focus Groups
        - Qualitative design
        - Semi-structured interview guide
        - Reflexive thematic analysis
        - Focus groups lasted 45-75 minutes
        - Results:
            - Biomedical assessment
            - Active engagement
        - Challenges:
            - Lack of trained healthcare specialists
            - Lack of psychosocial support providers
    - Survey
        - October 2022- January 2023
        - 301 responses
        - Focused on psychosocial support
        - Challenges
            - Lack of training among healthcare providers (68.9%)
            - Parental distress (69.9%)

- Conclusions
  - Most provider teams focused on assessment
  - Inadequate psychosocial support (especially in adult care)
  - Inadequate transition of care
  - Uncertainty in provision of care
  - Lack of shared decision making and patient-centered care
  - Prevalence of multidisciplinary approach, and lack of interdisciplinary approach
  - Implications:
    - More time and resources are needed
    - More training and health care providers for adult care
    - Valid measurement criteria to assess psychosocial care are needed

- Why 'good' healthcare matters – Caroline Sanders
  - Why 'good' healthcare matters
    - Holistic, accessible engaging care across the life course
    - Connection, communication, capacity building for all
    - Knowledge and research (bioecological – providers, individuals, and society)
    - Equity gaps in approaches to care (knowledge, diagnostic process, newborn screening, technology pharma)
    - Informed-decisions, involvement, shared-decision making and taking, informed consent, decisional regret, access to health records
    - Advocacy, peer support systems, disability tax credit (high needs CAH)
    - Transition & transfer services, life expectations, fertility, growing old 'well'
  - Life Course thinking
    - Need for urgent investment in psychological support, building resilience, information and communication/skill development for children, young people, adults, older adults and their families
    - Information disclosure, duty to share information (parent & provider, access to medical records)
    - Aging upwards and the change in information needs, access – new research and technologies, finding and building trust with providers

- Impact on daily life, the taken for granted (medication, complex care needs, chronic health conditions, emergency care)
- Research gapes, longer lives, physical health, longevity

- Notepad
  - Close the gap
  - Target
  - Goal
  - Easy to use



This Notepad and these questions have been produced to help open up a conversation about what matters to you. Revisit these questions and add your own at any time.

MY BODY AND ME

- Does my condition have a name, how did it happen ? How often does it happen?
- How is my body different to that of my friends?
- What does this mean for my health and everyday life, and can I do all the same things as my friends and peers?
- Is there someone else in this clinic who I can talk to about how this makes me feel?
- Do I need to tell my school/college about my condition?
- Is it normal to feel sad or down because of my condition or feel anxious and lonely because of my condition?
- Will I be able to have a 'normal' life?

Questions around medication (may not apply to all)

- Do I need to take medication because of my condition and to stay healthy? Or is this medication optional/aesthetic (e.g. to grow a bigger chest if I lack hormones to do so)?
- Do these medications have any side effects? Will I be on them forever?

Questions around vaginal dilation (may not apply to all)

- Why dilate and how do I know when I am ready?
- What do I do if I can't find a private place to dilate?
- Can I change my mind and decide to have surgery if I started dilation myself?

'BE OUTSPOKEN. BE UNAPOLOGETIC.'

RELATIONSHIPS, FRIENDSHIPS AND PEER SUPPORT

- How can I explain this to my family and friends?
- How can I explain it in a way that pays attention to my culture, and ethnicity?
- My family never talks about sex and private body parts - What if I cannot talk to them about this? What if they do not understand how this can have happened to me?

- Moving Forward
  1. Access, understanding and applying health literacy is a determinant of health and critical aspect of consent and equity at all ages
  2. Wellness, wellbeing as a lifelong eco-social and health goal
  3. Long term endocrine care and mental health care/peer networks
  4. Reproductive possibilities
  5. Living with atypical biology – mental wellbeing, paying attention to lived experiences, building networks (peers) and provider (MDTs)

6. Co-design, co-production and dissemination – working with people (parents, children, youth, adults, and older adults)

5. Schedule Review & Adjournment

Done.

Question: When it comes to intersex people, would traditional Transgender labels (transwoman/transman) still be appropriate to use/adopt