



## ICS Standardisation Committee meeting minutes

**Saturday 24th June,**

**Venue: Sheraton Skyline Hotel, London**

**Room: Hong Kong Room**

**Time: 09:00-17:00**

**Attendees:** Bernard Haylen (Chair), Salma Kayani, Sohier Elneil, Alexis Schizas, Rizwan Hamid, Luis Abranches-Monteiro, Elizabeth Shelly, Stergios Doumouchtsis

**Also in attendance:** Jenny Ellis (ICS office),

**Apologies:** Jane Meijlink, Alex Digesu

BH welcomed everyone to the meeting. It has been a busy 9 months for the committee, the highlights of which have been outlined in a short video that was filmed at the ICS office yesterday. The video will be shown at the end of the meeting. The terminology documents are the crown jewels of the ICS and the Board are very happy with the work of the committee.

BH confirmed that Jane will be retiring from the committee this year with Jacky Cahill as her replacement, starting in Florence. BS highlighted that there is an issue with consistency with the terms- some use different terms for their report. BH aware of this issue and is proposing that the Committee create a consistency consultant position.

### **1. Working group updates (See attached overview);**

#### **a) SSCWG20 and SSCWG17**

The committee started by reviewing the 2 new working group applications starting with SSWG20. These were discussed and the final selections made for each group.

#### **b) All current WG review**

The committee reviewed all WG updates. The below working groups have finished and been published in NAU:

- An International Urogynecological Association (IUGA) / International Continence Society (ICS) Joint Report on the Terminology for Female Pelvic Organ Prolapse (POP). Dual NAU/IUJ Publication. 2016 Feb; 35(2):137-68. doi: 10.1002/nau.22922
- A standard for terminology in Chronic Pelvic Pain syndromes: A report from the chronic pelvic pain working group of the international continence society, 2016. August 2016, DOI: 10.1002/nau.23072
- International Continence Society Good Urodynamic Practices and Terms 2016: Urodynamics, Uroflowmetry, Cystometry and Pressure-Flow Study, December 2016 2016. DOI 10.1002/nau.23124
- International Urogynecological Association (IUGA)/ International Continence Society (ICS) Joint Report on the Terminology for Female Anorectal Dysfunction, 2016. Dual NAU/IUJ Publication. Published January 2017, Volume 36, Issue 1, DOI: 10.1002/nau.23055
- An International Urogynecological Association (IUGA)/ International Continence Society (ICS) Joint Report on Conservative and Nonpharmacological management of female pelvic floor dysfunction, 2016. Dual NAU/IUJ Publication 5 December 2016, DOI 10.1002/nau.23107.

After careful consideration the below working group was published independently of the SSC but still under the ICS banner:

- Terminology for Detrusor Underactivity (SSCWG10)

The current projects and which stage they are at are:

- **IUGA – ICS Sexual Health (SSCWG6)** - Currently available on the ICS website for peer review; <https://www.ics.org/news/673> Deadline for comments 7th July.
- **Terminology of Lower Urinary Tract Function – Review (SSCWG7)** - MD confirmed waiting for the Nocturia WG report, he has collaborated with Jerzy for the Neuro-urology working group updates. Currently on second draft of the document. June 2017 Update – No draft document received at this stage.

RH expressed concern that SSCWG7 was now superseded by SSCWG17. BH suggested that we could invite Marcus to attend the SSC meeting in Florence to discuss.

**Action:** Office to invite MD to come to Florence SSC meeting to discuss his 2 working groups.

- **The Standardisation of Terminology of Adult Neurogenic Lower Urinary Tract Dysfunction. Report of the Working Group of the International Continence Society (SSCWG5)** - The SSC have reviewed the draft document and provided their feedback. BH confirmed need to cross check with the ICS-ICCS Nocturia and Nocturnal enuresis (SSCWG9) document. JE provided the updated document. Working group are reviewing both the updates and Nocturia document. Any minor changes will be signed off by BH. If large scale changes are made then it will need to go for SSC review again. Once signed off this document will go for Board review and then publication. June 2017 Update – Revisions after SSC review – Chair yet to see final version. Possible referral to Board in near future for publication.
- **ICS-IUGA joint terminology document on reporting urodynamics in women (SSCWG12)** - Final draft document has been reviewed by Bernie, suggestions for changes have been provided. The working group are currently updating the draft document with all proposed changes. Scope of document extended to Comprehensive Female Pelvic Floor assessment under new Chair, Steven Swift. IUGA terminology Chair Joe Lee, fully involved. June 2017 Update – Changes to improve quality and relevance resisted by previous Chair who resigned. It may be Joe Lee who steers this project forward.

**Action:** BH to email JL regarding SSCWG12 progress.

- **Standardisation of Terminology for Incontinence Products; working group of the International Continence Society (ICS) (SSCWG11)** - Working group Chairs have the questionnaire data and findings and circulated this to the WG members. Chairs have suggested a peer review in Florence at the nursing group meeting and at the Incontinence: The Engineering Challenge conference in London in November. The Chairs have requested feedback on this proposal. June 2017 Update – Alan Cottenden and Mandy Fader provided report following the completion of questionnaire (appendix item on agenda.)

Committee members didn't have time to review the report before the meeting as the document is 32 pages long. JE advised that she would upload to the committee forum for review post meeting. All members to review and comment.

**Action:** JE to upload SSCWG11 report to the committee forum for review and discussion.

**Action:** JE to email Alan and inform him that the committee will review the report and provide their feedback after the meeting.

SK asked whether the office could email her a copy in word- she finds this easier to add comments.

**Action:** Office to provide SK with a word version of the SSCWH11 report.

- **Basic Science (SSCWG8)** - MD confirmed waiting for the Nocturia WG report, he has collaborated with Jerzy for the Neuro-urology working group updates. Currently on second draft of the document. June 2017 Update – No document yet received.  
This was discussed with SSCWG7.
- **ICS-ICCS Nocturia and Nocturnal enuresis (SSCWG9)** - We have a final draft from the WG chair. Currently cross checking this against the Adult Neurogenic Lower Urinary Tract Dysfunction (SSCWG5) document. June 2017 update – Should be ready to send for publication in next 3-4 months.

BH suggested some changes to the definitions which he asked the committee to review. SK felt that these changes would be suitable for the Middle East where people normally sleep during the day and are up at night. The group discussed these changes and it was suggested that further discussion would be required post meeting.

**Action:** JE to upload the proposed changes to the definitions to the SSC forum for committee review.

- **Pelvic Floor Function and Dysfunction (SSCWG16)** - New working group, set up post Tokyo Meeting. The working group has 3 chairs (1st Helena Frawley, 2nd Beth Shelly, and 3rd Melanie Morin.) The Chairs have met (via skype) on 4 occasions to discuss direction and progress. Minutes taken & distributed by HF. All electronic correspondence kept by HF, available for audit.  
Initial aims & scope re-drafted to separate into 2 projects.  
Project 1 underway; project 2 on hold (temporarily named WG 16 B)  
Project 1 title re-named to narrow focus on assessment definition and description: "Report of the terminology for pelvic floor muscle function and dysfunction assessment"

BS asked the committee whether they thought vaginismus was a diagnosis, sign or condition? BS needs the committee to help decide.

**Action:** BS to email JE questions for the SSC to review and discuss regarding key terms for SSCWG16.

The committee discussed the concern regarding changing diagnoses as this affects insurance and therefore patients. AS felt that we shouldn't be concerned about affecting codes, our focus should be on terms only. BS do not agree with this and feels it is important to consider how changing our terms will affect patients. One way it affects patients is through diagnosis coding.

*Postscript note: JM suggested that the SSC should form a working group to look at coding issues, including ICD, to see what the impact/consequences are, what role these play, what terminology/definitions take precedence in coding systems (whose terminology is being used etc), and what the ultimate impact can be on the patient. Standardisation committees and their working groups cannot continue to work in a vacuum and should be accountable for the impact on the patient.*

SD agrees with this suggestion.

*Postscript note: JM suggested that the Committee ask WG chairs and members at the end of a wg project to write a review on their experiences, what went right, what went wrong, why they may have stagnated etc?*

**New working groups**

- **ICS-IUGA Joint Report on the Terminology for Female Pelvic Floor Fistulae (SSCWG18)** - Working group selected, Suzy Elneil confirmed as Chair, Lauri Romanzi as co-chair. Group are working on project plan and communications with members.

**Members:** Suzy Elneil, Laura Romanzi, Bernie Haylen, Joe Lee

**June 2017 Update:** Welcoming letter to 18 members sent out by Chair. Suzy to outline timetable.

SEN confirmed that the committee are planning on having the final version ready by December.

- **ICS Report on the Terminology for Male Anorectal Dysfunction (SSCWG14)** - Working group members selected, Alexis Schizas Chair of the group. Invitation send out for nurses/PTs to join the group. Chair working on project plan and communications. June 2017 Update: Alex to report on progress forming Committee.

**Members:** Alexis Schizas

AS confirmed they need more members- all suggestions welcome.

*Postscript note: BS suggested Julia Herbert UK PT as she does a lot of work with bowel dysfunction and is a respected teacher in the field.*

**Action:** All SSC members to email AS suggestions for additional working group members on SSCWG14.

SEN suggested some contact in Africa, she advised she would contact them on behalf of AS.

- **ICS-IUGA Joint Report on the Terminology for Female Laparoscopic Pelvic Anatomy (SSCWG19)** - Salma working on draft scoping document. June 2017 Update – Salma to report on completion of scoping document? Advertising in July

The committee discussed why laparoscopic surgery? SK felt that there were key landmarks that surgeons need to be aware of, the document will focus on images that people can use. RH felt that this wasn't a terminology document, SK disagreed, when you read an anatomy document it is not clear- this document will provide clarity. Group discussed this and felt that the title should be changed to laparoscopically visible pelvic anatomy.

**Action:** Office to change WG title to laparoscopically visible pelvic anatomy.

Planned advertising date- late August/beginning September.

- **ICS Report on the Terminology for Conservative Management of Male Lower Urinary Tract and Pelvic Floor Dysfunction (SSCWG21)** - The physiotherapy committee have been approached to draft the scoping document, no updates, the office to chase Doreen.

**Action:** Office to contact Doreen regarding the draft scoping document for SSCWG21.

- **ICS Report on the Terminology for Sexual Health in Men with Lower Urinary Tract and Pelvic Floor Dysfunction (SSCWG22)** - We need a suggestion for an urologist to draft this scoping document. Group discussed possible titles for the document. BH requested that RH & LAM review and confirm a final title.

**Action:** RH & LAM to review the currently titled ICS Report on the Terminology for Sexual Health in Men with Lower Urinary Tract and Pelvic Floor Dysfunction (SSCWG22). Advise whether any changes are required to this title.

**Future projects**

SEN is interested in creating a supportive paper for Female Pelvic Floor Dysfunction (Haylen, 2010 document) a user friendly version of this document. BS agreed that the 2010 needs to be revised, suggested this is revised in 2019.

**Action: Female Pelvic Floor Dysfunction (Haylen, 2010 document) to be revised in 2019**

Group discussed order of future projects and confirmed:

- Male 1<sup>st</sup>
- Messelink (2005) 2<sup>nd</sup>
- Female PF dysfunction 3<sup>rd</sup>

All agreed.

## 2. Approval of Tokyo meeting minutes

All agreed to approve the Tokyo minutes- 1<sup>st</sup> RH, 2<sup>nd</sup> AS.

## 3. Wiki updates

BS provided an update on the wiki website. The key topic this year is scrotal pain! We had a spike in traffic to the website, BS was unsure why this was- SEN confirmed this was due to EAU. Presenters used wiki in their references so delegates followed these links at the meeting. BS thanked SEN for this information, we weren't aware of this.

BS asked the SSC to suggest hot topics for the pages, we also need more authors. The committee were then shown wiki and ICS twitter and discussed current view and access to pages.

BH asked committee members to review wiki and make suggestions for improvements.

**Action: All SSC members to review the wiki website and email suggestions to Beth.**

Group suggested changing #ICSWiki to @ICSwiki as this will generate more traffic. JE happy to trial this and see if it makes a difference.

**Action: Office to change #ICSWiki to @ICSwiki**

*Postscript note: After discussing this further, post meeting, it was agreed that this wouldn't be possible without setting up a separate Twitter account for wiki. Which for marketing purposes would not be preferable.*

Group discussed BS's term of office, she doesn't have long left on the committee- we need to add a Chair elect to this project. After reviewing the options it was agreed that Jacky will be invited to become the Chair elect on wiki.

**Action: Jacky Cahill to be invited to become the Chair elect on wiki once confirmed office to add Jacky to wiki microsities.**

BS also keen for SSC members to encourage people to attend the wiki meeting in Florence- please can everyone invite people to attend.

**Action: SSC to invite friends/colleagues to attend the wiki session in Florence.**

## 4. AUGS

BH advised that AUGS have approached ICS with some suggestions for new working group document suggestions. BH will email the information regarding proposed groups.

**Action: BH to email draft scoping documents to SSC for proposed AUGS-ICS-IUGA documents.**

## 5. Florence workshop discussion

The current plan for the workshop is:

- Agenda: Overview of Standardization Steering Committee, WGs, projects
  - 4 minutes (plus 3 minutes questions) – Bernie video
  - Fistula project (Suzy) – 4 mins (plus 3 minutes questions)
  - Pelvic Floor Function and Dysfunction (SSCWG16)- 4 mins (plus 3 minutes questions)
  - Male Lower Urinary Tract and Pelvic floor Dysfunction (SSCWG15)- 4 minutes (plus 3 minutes questions)

**Action:** Office to email HF and request that she prepare some information for a 4 minutes summary of the document.

## 6. Status of the glossary

BS asked how we can help current working group Chairs/members find terms? Is the glossary useful? BH suggested a review of the glossary would be useful and suggested that this would be a job for the consistency consultant. All agreed that this would be a good idea.

**Action:** Consistency consultant to review glossary and suggest updates.

JE suggested that the Chairs of the working group should check the glossary for changes to terms. Group discussed how effective this would be for terms that are changing but not final. It was therefore suggested by JE that we create a working group chair microsite and forum. Chairs can then ask each other questions on this forum and highlight any changes that other chairs may need to be aware of. Group thought this would be a possibility. The committee asked whether it would be possible to add a glossary search to the homepage to increase awareness- JE advised that she would need to discuss with the IT team.

**Action:** JE to speak to Dom about changing the homepage to increase awareness of the glossary.

BS suggested that we clean up the SSC homepage to make viewing the information clearer- we could move the documents information to a separate page and this information could be shown in chart/graph format. JE said that would be no problem. BH advised that he would review the documents and order/group (like wiki) and email to JE.

**Action:** BH to group current SSC documents and email the information to JE to create a graphical version of this information.

## 7. Projects before Florence

Nothing planned except Salma's document. BH highlighted the SUI scoping document has been received- BH will email this around to the SSC.

**Action:** BH to email SUI scoping document to SSC.

13<sup>th</sup> June fundamentals of urodynamic practice- follow up with Marcus, CC Bernie.

## 8. NAU

The committee are concerned about the delay in SSC documents being published. JE advised that the office was aware there was a backlog that NAU rectified by producing additional journals. Group discussed the parameter on how the journal order which documents go in which edition. JE suggested that BH contact Roger to discuss further in Florence.

**Action:** BH to meet with Roger Dmochowski in Florence

## 9. What can be done about members/delegates submitting abstracts for the annual meeting not using ICS terminology and definitions?

The group discussed possible options and all felt that the easiest way to ensure that people adhere to ICS terms is to include a tick box on the abstract application process. This would state that their abstract may be rejected if the ICS terms had not been used in the application. We can also include links to the terminology reports and glossary.

**Action:** Office to raise abstract tick box with IT team.

The committee watched the SSC updates video that BH filmed yesterday in the office.

BH thanked the office for their support, particularly Tracy for coordinating this meeting and Jenny for her support throughout the year.

**Ends**