



Commitment to Collaboration in Continence Care (4Cs)

11.30-12.30 pm, 10 November 2023, Valencia and Online

Meeting report

Executive Summary

The Commitment to Collaboration in Continence Care (4Cs) multistakeholder group met in Valencia on 10 November 2023. The meeting objectives were to: a) review progress made in 2023, and b) agree priorities for 2024, aligned with the 4Cs objectives. Discussion focused on maintaining momentum from the 1st EU Continence Health Summit “An Urge to Act”, which was held on 8 November in Brussels, Belgium.

Participants agreed that policymakers are a key audience for engagement in 2024. Participants also discussed ways to continue to increase awareness and education of urologists, faculties of medicine, allied healthcare professionals and the general public.

Summary of proposed activities and next steps:

- **Immediate next step:** *Eamonn will speak to the EAU Policy Office to coordinate plans for following up on the Brussels Summit and will report back to the 4Cs members.*
- **Policy engagement at national and European levels:**
 - Agree consistent messaging for policy maker engagement across 4Cs member organisations.
 - Invite policy makers to be present at scientific society meetings, with specific tracks focusing on economic costs of incontinence and quality of life.
- **Increase awareness of the “Urge to Act” initiative:**
 - Publish data on the economic cost of incontinence.
 - Coordinate media engagement, and plan for key dates such as bladder/bowel awareness events, World Continence Week 2024.
 - Email society members and reach out to membership via other channels (e.g. ICS TV channel).
- **Improve education of healthcare professionals:**
 - Involve faculties of medicine, noting that there has already been progress this year through the EAU talent incubator.
 - Dedicate a 4Cs workstream to evaluate and repurpose educational materials that already exist.
 - Discuss running State of the Art lectures at the meetings of all 4Cs members, either on the economic costs of incontinence, or on soft skills and shared decision-making [*NB: Educational activities were not fully agreed in the meeting and require further discussion*].



Attendees

- Pedro Blasco Hernandez, President, SINUG
- Lynne van Poelgeest, President, WFIPP
- Margot Voskamp, Communications Officer, WFIPP [Online participant]
- John Heesakkers, Secretary General, ICS [Online participant]
- Eamonn Rogers, Chairman, EAU Patient Office
- Esther Robijn, EAU Patient Office [Online participant]
- Francisco Cruz Miranda Rodrigues, EAU Chair of the Section of Female & Functional Urology
- Salvador Arlandis Guzmán, Former President, SINUG
- Alicia Martín-Martinez, Vice-President, SINUG
- Jana Rodriquez, Medtronic [Online participant]
- Sally Snow, Medical Writer [Online participant]

Apologies:

- *Philip van Kerrebroeck; Frankie Bates*

Objectives

Pedro Blasco outlined the objectives for the meeting, which are to:

- Review progress made by 4Cs partners over the past year
- Agree tangible actions for 2024

He reviewed the 4Cs objectives agreed in November 2022, which were:

- Objective 1 – EDUCATION: Ensure soft skills are viewed as complementary to technical skills, and given the same level of importance in professional training programs.
- Objective 2 – INFORMATION: Improve access to trusted information for the general public, patients and healthcare/allied professionals.
- Objective 3 – ORGANISATION/POLICY: Embed the principles of patient-centred care throughout public and private healthcare structures.

Discussion topics:

1. Building on the 1st EU Continence Health Summit “Urge to Act”, held on 8 November in Brussels, Belgium

- Pedro extended congratulations to Philip van Kerrebroeck and the EAU Policy Office on arranging the Continence Health Summit.
- Lynne commented that the Continence Health Summit was a great start and a solid foundation on which to build. She emphasised that 4Cs members must ensure the momentum from this initiative is harnessed. She also proposed that the 4Cs initiative should operate within the sphere of the Continence Summit, and that follow-up activities should focus on media engagement (press release) and lobbying policy makers.
- Francisco agreed with Lynne and Pedro that the Summit in Brussels was valuable and that simple steps to maintain momentum can be taken immediately. He raised the fact that



faculties of medicine, a key stakeholder, did not appear to be involved in the Continence Health Summit. He mentioned that in Portugal there is an organisation representing all medical schools who could be involved in a multi-stakeholder national summit to publicise the “Urge to Act” message. He also recommended rapid publication of the cost evaluations so that these data can be leveraged in discussions with stakeholders. He mentioned that Philip has prepared an article for the last issue of Urology Today on incontinence in Europe, and that as Chair of the Section of Female & Functional Urology, he has been asked to sign a text for the 2024 EAU meeting in Paris.

- [Eamonn arrived in the meeting room at this point] Eamonn stated that from the EAU point of view a lot is being done already to maximise publicity of the Continence Health Summit, and that it would be important to engage with Sarah in the EAU Policy Office. However, he agreed that it was important to inform all EAU members about the summit, for example via European Urology Today/Uroweb.
- Esther also proposed that emails could be sent out to national urology societies and EAU members about the summit.
- Eamonn emphasised the importance of engaging policymakers, as urologists are already on board. However, he acknowledged the need to partner with the EAU Policy Office on this issue. Eamonn also highlighted opportunities to engage with national governments and national public health offices. For example, in Ireland, there is a role of Chief Public Health Officer, who is likely to be a key stakeholder moving forward. There is likely to be a similar role in other countries.
- Jana summarised this part of the discussion by stating that awareness is key – among patient advocacy groups, scientific societies, the public and policy makers via social media. She stated that all parties have (social media) channels to disseminate content, and that industry partners such as Medtronic can help with publicity, but that there needs to be consistency in the message. She particularly highlighted opportunities to share updates through the Support In Continence Blog page. She also emphasised the importance of using awareness moments, such as faecal incontinence month, bladder and bowel awareness events.
- Lynne agreed that consistency in message is essential and that the 4Cs partners should have a single document to speak from.
- John agreed that policy makers are key stakeholders, as most urologists will agree with the need to act on incontinence. From an ICS point of view, he proposed a State of the Art lecture on the Continence Health Summit and manifesto, and to address how the progress in Europe can be promoted in the rest of the world. He suggested that the ICS TV channel could be used to raise awareness among professionals. He also mentioned Dianne Newman as a possible interviewer on the UroToday channel to spread the initiative to the USA.

Summary of actions proposed as follow-up to the Continence Health Summit:

- **Increase awareness of the cost of incontinence:** Publication in a urology journal to raise awareness of the costs of incontinence; media engagement/press release; ICS TV channel.
- **Improve education of healthcare professionals,** particularly to include faculties of medicine, noting that there has already been progress this year through the EAU



talent incubator. Also a need to educate GPs and nurses (the EAUN meeting was mentioned).

- **Policy engagement** Political lobbying at national and European levels to spread awareness of the “Urge to Act” initiative.

2. Education/ 4Cs Workshops

- Referring back to the first objective of the 4Cs, agreed in November 2022, Pedro introduced the topic of education on soft skills such as shared decision-making. He asked whether the scientific societies would commit to including a session on patient-centred medicine etc.
- Lynne reminded the group that there is already a lot of material in circulation that can be re-used and that there is no need to start from scratch.
- Pedro proposed a 4Cs educational course with the following topics to be launched in 2024:
 - Soft skills
 - Information for patients
 - Shared decision-making
 - Discussing taboo topics
 - Value-based healthcare
 - Attention to carers
 - Relationships between professionals and patients?
- Pedro proposed that online course content could be developed by EAU, SINUG and ICS for deployment during continence week 2024. This would be something tangible that could come out of the 4Cs.
- Lynne mentioned a recent webinar on shared decision-making from the EAU. Attendance numbers were quite striking and webinars can be produced quickly and easily.
- Alicia mentioned a desire to include regional workshops in the program; that the message is clear but that it is not clear how to do this.
- Pedro also proposed a “State of the Art” lecture on these topics to be held at the meeting of every 4Cs member, to present a coordinated educational program.
- John stated that the ICS is willing to start a Patient Office if they can access the right resources and funding. He also stated that he agrees with a joint educational program but that he thinks the topic of a “State of the Art” lecture should be focused on the data on incontinence.
- Lynne reiterated that it is the duty of the 4Cs members to share the information that was presented in Brussels, and that it should be a coordinated effort to bring people together. She proposed WFIPP would run an international symposium in 2024 to bring patient representatives from all over the world together and that there would be a workshop on 4Cs.

Proposed actions on education:

- ***Designate a 4Cs workstream to evaluate educational materials that are already available.***
- ***Further discuss State of the Art lectures at the meetings of all 4Cs members, either on the economic costs of incontinence (as presented at the Continence Health Summit), or on soft skills and shared decision-making.***



3. Engaging policy makers

- Pedro recommended inviting policy makers to be present at scientific society meetings.
- Salvador agreed with inviting policy makers to meetings but felt that they would need to hold specific sessions on quality of life and social policies, as the scientific sessions would be too high level.
- Eamonn agreed that the message for policy makers needs to be simple: Continence is an essential function, like eating and breathing. Why are we not talking about this?
- Alicia mentioned progress that has been made in Spain at a government level, and that similar action needs to be taken in other countries.
- Eamonn mentioned that he had spoken to an Irish MEP at the Continence Health Summit, about advancing incontinence within her group and she had agreed to do so.
- Eamonn mentioned his experience of engaging with policy makers and the importance of persistence – writing follow-up letters and arranging meetings. He proposes writing a letter to policy makers in early 2024. If the policy makers engage positively, then we need to consider what to do next once we get their feedback.
- Francisco mentioned a conversation with a Portuguese MEP who was interested in further engagement on incontinence issues. He agreed that policy makers should be invited to a forum where incontinence impact is presented in a simple way – the costs are similar to diabetes and oncology.
- Lynne described her experience of engaging with policy makers in Brussels. She feels it is essential to engage the people who were at the Brussels Summit “strike while the iron is hot”, and engage other organisations like the European Public Health Alliance, European Health Coalition, EFPIA. She believes that if the facts and figures around incontinence are published, it will gain traction with these audiences.

4. 4Cs administrative structure

- Finally, Pedro proposed a structure for how the 4Cs should operate in future: each party leads an initiative and seeks funding for that initiative.
- Jana reiterated Medtronic’s commitment to patient-centric activities. Medtronic is happy to fund activities, but they need to understand the milestones, who will be delivering, and a timeline. She stated that there is an upcoming agreement with ICS that could be used, for example, to set up a Patient Office.
- Lynne asked whether it would be a good idea to set up a separate 4Cs website. There was general agreement that it was too soon to do this.
- Eamonn stated that Education and Policy should be the two main areas of focus for 2024. He reflected on the progress that had already been made through the EAU Talent Incubator, Continence Health Summit and educational materials on the EAU website (mentioned the animations specifically). He felt that policy maker engagement should be the priority for 2024 rather than committing to a programme of workshops.