



ICS Continence Promotion Committee Meeting Agenda

Tuesday 21st October 2014,

Venue: SulAmérica Convention Center

Room: 11

Time: 07.00-09.00

Known Attending: Tamara Dickinson (Chair), Jacky Cahill, Frankie Bates, Peter Meyers, Diane Newman, Els Bakker, Nicole Huige, Grzegorz Surkont, Diane Newman, Sherif Mourad

Also in attendance; Ran Pang, Christa Thiel

Apologies: Diane Owen, Mary Van Poelgeest-Pomfret, Stavros Charalambou, Vasani Srinivasan, Tomasz Michalek, Barry Cahill, Rowan Cockerell

1. Picture of Committee to be taken
2. Approval of Barcelona meeting and February teleconference minutes **(Attached)**
3. Terms of Reference & Terms of Office review **(Attached)**
4. Outstanding actions:
 - a) TD to discuss tagging on to education courses where possible with Education Committee.
 - b) If any committee members have YouTube videos then please notify Jenny and we can like the video so they show up on our news feed for other members to view.
5. Public forum Discussion:
 - a) Review of 2014 forum by Frankie
 - b) Group discussion on forum- plans/future actions?
6. WCW:
 - a) Review by Nicole
 - b) Group discussion-plans/future actions?
7. Continence promotion film (2010)- review/discussion
8. Meet the continence event- review/discussion
9. Evolution of the internet- Dominic discussion

10. CPC Logo discussion

11. Available funding for Committee Chair discussion

12. A.O.B



ICS Continence Promotion Committee Meeting Minutes

Monday 26th August 2013,

Venue: Centre Convencions Internacional de Barcelona (CCIB)

Room: M214

Time: 11.00-13.00

Known Attending: Tamara Dickinson (Chair), Mary Van Poelgeest-Pomfret, Jacky Cahill, Els Bakker, Nicole Huige, Stavros Charalambous, Barry Cahill, Diane Newman, Tomasz Michalek, Diane Owen, Peter Meyers, Deborah Gordon, Sherif Mourad

Apologies: Jane Meijlink, Frankie Bates, Christa Thiel, Diaa Rizk

Also in attendance: Jenny Ellis

1. Picture of Committee to be taken

Picture taken of the committee. TD welcomed members and everyone introduced themselves. TD welcomed Stavros on to the committee- this was his first committee meeting.

TD provided copies of the committee ethics to members, she would like members to review and agree to the terms (see appendix.) It's TD's expectation that is how members will conduct themselves whilst on the committee.

2. Approval of Barcelona meeting minutes, attached.

BC approved and MVP-P seconded.

3. Terms of Reference & Terms of Office to be discussed

> Committee members need to decide who would like to stay on for 1 extra year and who would like to stay on for 2 years.

JE highlighted that members due off the committee, following a 6 year term, could stay on with special permission from the Board- members need to let TD know if they wish to stay on and we will place a request to the Board of Trustees.

JC thinks the committee is currently too big. The Board will be looking at committee sizes as part of their review. BC feels committee hasn't been able to achieve as much as it could e.g. the public forum was good in Cairo but not as good since then. TD agreed in theory the public forum is an ineffective use of our time. BC felt the public forum needs to be assessed country by country- TD agreed. MVP-P agreed, -placed like Cairo were different, Spain shuts down in August so it's timing as well as location.

SM felt they we need to assess our targets; we don't have to do it all we can use other committees and organization to assist- which would help us achieve more. JC highlighted that the PCC discussed some ideas for public forum e.g. it could be sponsored. SM agreed we need to ask ourselves what we want to do- we need to have a vision.

DN stated that our vision is in our mission statement- continence awareness, so this is the CPC's function. The committee highlighted that we need funds to achieve this goal.

> Need to review the wording of the TOR in relation to specifying the patient organisation representation. Also, the wording "Conducts a Public Forum in conjunction with the ICS Annual meeting" if this is to be kept on the TOR. (See Jane comments.)

TD felt that we should remove 'conducts a public forum' from the TOR- all members agreed.



Action: JE to remove public forum from TOR and submit to Board for approval.

TM thinks the public forum should move to/for patient advocacy groups and/or general healthcare providers, and then we could encourage more sponsorship for the forum. MLVP agreed, we need to give information to local organisations who in turn can distribute this to the patients in the local areas.

The committee reviewed Jane's comments. BC does not feel that we need patient experts and advised that 1 representative on the committee would be acceptable-TD agreed. MVP-P feels, as a patient advocate, that it doesn't matter if you're a health professional but thinks it's important for patient advocate groups to be involved in the future. Committee feels that it's down to the Chair to ensure there is a fair mix of members and representatives.

4. Review of subcommittees

TD highlighted that from that the survey results showed the WCW subcommittee was the most important and fistula the least. She asked whether we should change subcommittees based on this information? TD asked whether some subcommittees should be based on the focus areas?

5. Outcome of the web survey

EB asked whether it was possible to go to 1 country a year? NH felt that it is more efficient to do a meeting where the AGM is taking place. TD highlighted that we could tag on to the education committee meeting locations. DN thinks the Board needs to give CPC money to achieve their goals. The committee questioned the budget request process, JE explained the process for clarity. The budget request was denied last year due to lack of funds which affected all committees and not just the CPC. TM felt that the ICS should fund public forum costs and ICS experts. SM highlighted that you won't get everything you request e.g. last year the fistula committee requested £32,000 and received £12,000 You therefore need to get local members and organizations involved- this therefore divides the work and costs.

BC felt that there was a struggle between the CPC and ICS, when it comes to health promotion, we haven't got the resources to do what we are suggesting e.g. public forum. BC suggested that some materials should be translated and saved on the website. EB highlighted that we have tried to do this before but it is very difficult. We need to pick 1 idea and put a business plan to the Board to get the money.

All agreed that we need to have one achievable aim and progress from there. Going forward it would be useful to tag on to education committee meetings where possible.

Action: Committee needs to select 1 achievable action for 2013-2014.

Action: TD to discuss tagging on to education courses where possible with Education Committee.

6. WCW (see additional information)

JC highlighted that the Canadian Continence Foundation (CCF) did not hold WCW this year as there is a week in Canada in November. BC highlighted that Australia aligned their week with ICS and feels the CCF should as well. JC stated that this was not possible sadly.

TD highlighted the letter sent to the World Health Organisation (WHO) for recognition of WCW- waiting for a reply.



SC thinks we should have patient videos on the ICS TV page. JE advised that we could 'like' a video and it would then show up on our news feed- so other members can view this. We have liked a number of WCW video's that were sent to the office.

Action: If any committee members have you tube videos then please notify Jenny and we can like the video so they show up on our news feed for other members to view.

SC would like video's to have subtitles, JE advised we would need to ask IT department about this.

Action: JE to ask IT department if videos could have subtitles.

7. Public Forum

See above discussion under Terms of Reference

8. AOB

MVP-P highlighted the WFIP meeting taking place in Barcelona to set up Spanish patient organization. She thanked the office for their accommodation for the request for a free meeting space and highlighted that if you put effort into arranging these meetings then outcomes can be achieved.

Minutes Teleconference Friday February 28th

Attendees; Tamara Dickinson (Chair), Frankie Bates, Adrian Wagg, Tomasz Michalek

Also in attendance: Jenny Ellis

Item	Committee Member	Minutes	Action
Welcome	Tamara	<p>FB confirmed that the conference centre was booked and confirmed for up to 300 people. This is at no cost to the CPC, the only costs to date is the AV equipment at \$300. The forum is scheduled for Wednesday 22nd October, a light meal and drinks will be available to the delegates. FB advised that the CPC want all fields covered which is why we have brought in Adrian Wagg for his expertise.</p> <p>AW asked what patient advocacy groups were involved in the forum so far? TD confirmed none at the moment but was in discussions with Jacky Cahill who has contacts with a new Brazilian continence foundation. Carlos has also advised that he will be able put the CPC in touch with local continence nurses. JE suggested Beatriz from the recent SOBEST event. TD advised that she would contact Carlos and CC Frankie into the email. JE to send Beatriz contact details.</p>	<p>TD to contact Carlos D'Anconca and copy in Frankie.</p> <p>JE to provide Beatriz contact details to TD and FB.</p>
Overview of public forum to date. (Agenda/ plan/time/venue)	Frankie	<p>AW asked what topics do we want for the forum? FB advised an overview of bladder issues and treatment from all levels of healthcare. The plan at the moment is that we will start at 17.10 until 18.20 and then stop for the food and drinks. Then we will cover incontinence in Brazil in conjunction with the local patient advocacy group (to be confirmed.)</p>	
Can we change the name "Public forum"?	Frankie/All	<p>FB would like to change the name of the forum to workshop or something similar. TD advised that, as we discussed in Barcelona, we need to re-vamp the public forum to make it more successful. TD suggested that name change should be something that symbolises the event. JE suggest that this be placed on the forum to generate idea's and then we can vote of the best suggestions.</p>	<p>JE to start a forum discussion regarding the name change.</p>
Choosing expert Speakers from ICS and topics.	Adrian	<p>AW asked if Ferring were funding the event? TM advised that he had been in contact with Ferring but the communication had gone quiet TD asked what we need funding for if the room is covered by ICS? FB advised advertising, food etc. TD asked how much the catering will cost? JE advised that she would look into this and draft a budget for all costs to date.</p>	<p>JE to confirm catering costs and draft a budget plan for forum.</p>

		<p>Group discussed that the local organisation need to advise on local promotional costs.</p> <p>AW asked who we are targeting e.g. policy makers? TD suggested having a patient panel talk about their experience.</p> <p>TD advised that we need physio's involved, Beth Shelly has previously expressed and interest in speaking, she has been chosen by the physiotherapy committee. AW advised that we need to re-think the content based on attendees- policy makers. FB advised that we always need to give overview of bladder issues etc. Also suggested that Lynne could discuss re-imbursement issues. TD suggest Donna Bliss as a speaker, she does a lot on fecal research.</p>	
Sponsorship (Ferring ?)	Tomasz	<p>TM advised that Ferring will invite patient advocacy group reps to come and speak- share knowledge with local's, 20-30 people, they will cover the costs.</p> <p>TM also advised that Astellas have expressed an interest in the event- should Ferring pull out. FB asked TM to provide an update when confirmed. TD stated that we need to utilize industry, FB will draft a letter for industry which will be signed by Adrian, and this will then be sent to industry.</p>	<p>TM to update group on the sponsorship- Ferring or Astellas.</p> <p>FB to draft industry letter and send to AW to review.</p> <p>Once confirmed this needs to be sent to Industry.</p>
Speaker on reimbursement issues /ideas?	Tomasz	<p>TM suggested that a comparison of countries re-imbursement policies are discussed which would help people learn from other countries- good and bad. Who does what better? Ferring have a lot of data on this so would be good to speak at the event. This is a hot topic- everyone agreed that it would be a good key topic for the forum.</p>	
PAG's in Brazil (Is there one and how can they help with advertising etc.?)	All	See above comments.	
Getting media involvement / interest.	All	<p>JE proposed that we could film the whole of the forum OR just the Ferring discussion, this can then be available on the ICS TV, news pages and social media. We would also make the video available to Ferring and our members to advertise on their websites. This would generate a lot of interest. JE advised that we need to do a more targeted mail</p>	

		out- focused adverts, in journals etc.	
How do we advertise the event ?	All	We need to decide who our target audience is and then look into the best avenues for marketing the event.	
General Discussion	All		

Call ends

Overview of actions;

- TD to contact Carlos D’Anconca and copy in Frankie.
- JE to provide Beatriz contact details to TD and FB.
- JE to start a forum discussion regarding the name change.
- JE to confirm catering costs and draft a budget plan for forum.
- TM to update group on the sponsorship- Ferring or Astellas.
- FB to draft industry letter and send to AW to review. Once confirmed this needs to be sent to Industry.

Continence Promotion Committee Terms of Office

Member	Role	Term Start	Term End	Term Yrs	Elected	Term details	Additional Information
Tamara Dickinson	Chair	19-Oct-12	24-Oct-15	3	Y	3 year term will finish 2015 - can renew once by formal election	
Christa Thiel	Committee Member	24-Oct-08	30-Oct-14	6	N	6 year term will finish 2014 – CANNOT renew	stepping down
Sherif Mourad	Committee Member	24-Oct-08	30-Oct-14	6	N	6 year term will finish 2014 – CANNOT renew	stepping down
Barry Cahill	Committee Member	24-Oct-08	30-Oct-14	6	N	6 year term will finish 2014 – CANNOT renew	Offered to stay on, Board would only allow 4 members to stay.
Diane Owen	Committee Member	24-Oct-08	30-Oct-14	6	N	6 year term will finish 2014 – CANNOT renew	Offered to stay on, Board would only allow 4 members to stay.
Jacky Cahill	Committee Member	24-Oct-08	30-Oct-14	6	N	6 year term will finish 2014 – CANNOT renew	Offered to stay on, Board would only allow 4 members to stay.
Lynne Poelgeest	Committee Member	24-Oct-08	30-Oct-14	6	N	6 year term will finish 2014 – CANNOT renew	Offered to stay on, Board would only allow 4 members to stay.
Tomasz Michalek	Committee Member	24-Oct-08	15-Sep-16	8	N	8 year term will finish 2016 – CANNOT renew	Staying on for 2 years
Diane Newman	Committee Member	24-Oct-08	15-Sep-16	8	N	8 year term will finish 2016 – CANNOT renew	Staying on for 2 years
Elisabeth Bakker	Committee Member	24-Oct-08	15-Sep-16	8	N	8 year term will finish 2016 – CANNOT renew	Staying on for 2 years
Frankie Bates	Committee Member	24-Oct-08	15-Sep-16	8	N	8 year term will finish 2016 – CANNOT renew	Staying on for 2 years
Nicola Huige	Committee Member	19-Oct-12	08-Oct-15	3	N	3 year term will finish 2015 - can renew	
Peter Meyers	Committee Member	26-Aug-10	15-Sep-16	6	N	6 year term will finish 2016 - cannot renew	
Stavros Charalambous	Committee Member	29-Aug-13	15-Sep-16	3	N	3 year term will finish 2016- can renew	
Vasan Srini	Committee Member	29-Aug-13	15-Sep-16	3	N	3 year term will finish 2016- can renew	
Grzegorz Surkont	Committee Member	29-Aug-13	15-Sep-16	3	N	3 year term will finish 2016- can renew	
Ran Pang	Committee Member	23-Oct-14	14-Sep-17	3	N	3 year term will finish in 2017- can renew	Physio Rep
Rowan Cockerell	Committee Member	23-Oct-14	14-Sep-17	3	N	3 year term will finish in 2017- can renew	Patient Advocacy

Nominations 2015

Nicola needs to confirm if renewing position

Key	
Colour	Meaning
	Staying on for 2 years
	Stepping down in Rio
	Will need to confirm if renewing/ positions will need to be advertised after Rio
	New member/position

ICS Continence Promotion Committee Terms of Reference

- 1. PURPOSE:** To act as a facilitator for various international continence organisations to meet and address relevant issues to do with continence promotion, awareness and prevention and to promote awareness through its national organization members, the public and government.

The principle aims are to:

- seek opportunities for networking across various countries;
- increase awareness amongst ICS members of continence related issues;
- facilitate development of continence organisations;
- facilitate exchange of information about continence awareness and promotion;
- identify opportunities for continence prevention strategies.

2. FUNCTIONS:

- Identifies broad issues through an international forum that can facilitate translation at a local national level.
- Provides input into continence awareness, promotion and prevention.
- Holds annual workshops at the ICS meetings.
- .
- Facilitates World Continence Week.

- 3. RESPONSIBLE TO:** ICS Board of Trustees and ICS General Secretary

4. COMPOSITION:

Total Members	Method of Appointment	Name	Term of Office
General Secretary	Ex Officio	See Membership	2 years
Chair:	Elected. A member must sign his/her agreement to stand. This nomination is signed by nominator and seconder, all being ICS members. The Chair would normally have served as a committee member, either current or in the past. Nominations received by April 1st as advertised. Voting regulations as stated.	See Membership	Term of office: 3 years, renewable once by Formal Election
Membership	All members of ICS committees must be active ICS members (paid for current membership year) (Bylaw 2.3.2) and have completed a disclosure form. Members are expected to attend meetings and to be active on subcommittees. The Chair may ask inactive members to step down from their position.		3 years, renewable once by Chair/committee approval. Further terms could be approved in exceptional circumstances and by referral to the ICS Trustees.

Subcommittees	Education	
“	WCW	
“	Internet	
“	Industry Liaison	
“	Fistula	
Updated January 2014		

5. **MEETINGS:** Two face-to-face meetings, one held during the Annual Scientific meeting and the second meeting heard mid-year, usually during EAU. Other deliberations, normally by email.
6. **QUORUM:** One third of committee membership plus one. For example, a committee of ten will have a quorum of four members.
7. **MINUTES:** Minutes are recorded at each meeting and posted on the ICS and CPC website in accordance to 2009 ICS Bylaw 6.1-6.4).
8. **REPORTING & ROLES:** The Chair of each committee is required to prepare an annual report to the Board of Trustees outlining achieved goals/budget requests and future objectives and strategies. The Chair is also required to be present at the Annual General Meeting should the membership have any questions over committee activities.

The committee Chair is also responsible for submitting an interim report to the Board of Trustees' mid term meeting. The date that this report will be required will be given in advance each year.

For Terms of Office Information see [Membership Page](#)