

Torino, Italy

Vulvar awareness in the digital era



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Chair, Canadian Network for HPV prevention

Potential Conflict of Interest : See next slide



A Taxonomy to Engage Patients: Objectives, Design, and Patient Activation

- How Health Information And Digital Technology Are Reshaping Patient Engagement
- When patients are ill, they turn to Google to learn about illnesses associated with their symptoms
- Newly diagnosed patients use online communities to seek support and information
- In recent years, communities of patients have shaped research agendas that matter to their quality of life

Patients' engagement

- Patients are moving from recipients to producers of knowledge and data
- Patients are moving from passive role of recipients of information to sharing their information to their peers and their healthcare providers
- This creates
 - Greater interaction between patients and their healthcare providers and
 - More productive discussions with their healthcare team

Patients' engagement

- *There is empowerment in feeling connected.*
- *Health care often follows a paternalistic model,*
 - *but having access to clinicians shortens the distance between patients and providers,*
 - *putting them on more of an equal footing.*
- *Providers feel more touchable.*
- *They are people too, and they want to learn from us as well.*

Patients' engagement

Objectives of Health Information Initiatives

Coproduction of health care quality improvement	<ul style="list-style-type: none">• ImproveCareNow• Swedish Rheumatology Quality Register
Peer-to-peer patient connections	<ul style="list-style-type: none">• MyHealthTeams• Breast Cancer Straight Talk Support Facebook Community
Facilitating information access and use	<ul style="list-style-type: none">• Tidepool• OpenNotes
Coproduction of research	<ul style="list-style-type: none">• IBD Partners• Health eHeart Study

Source: The Authors

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Menopause Cafés Serve Up What Women Need

- The first Menopause Café took place in June 2017 in Perth, Scotland.
- Founded by mental health counselor Rachel Weiss, Menopause Cafés are pop-up events, held wherever someone volunteers to organize one, from the smallest village to the largest metropolitan area.
- The gatherings are modeled after the popular Death Cafés that have already sprung up in 65 countries, including the United States.



The Good Hope Café in Lewisham, United Kingdom.

Menopause Cafés Serve Up What Women Need

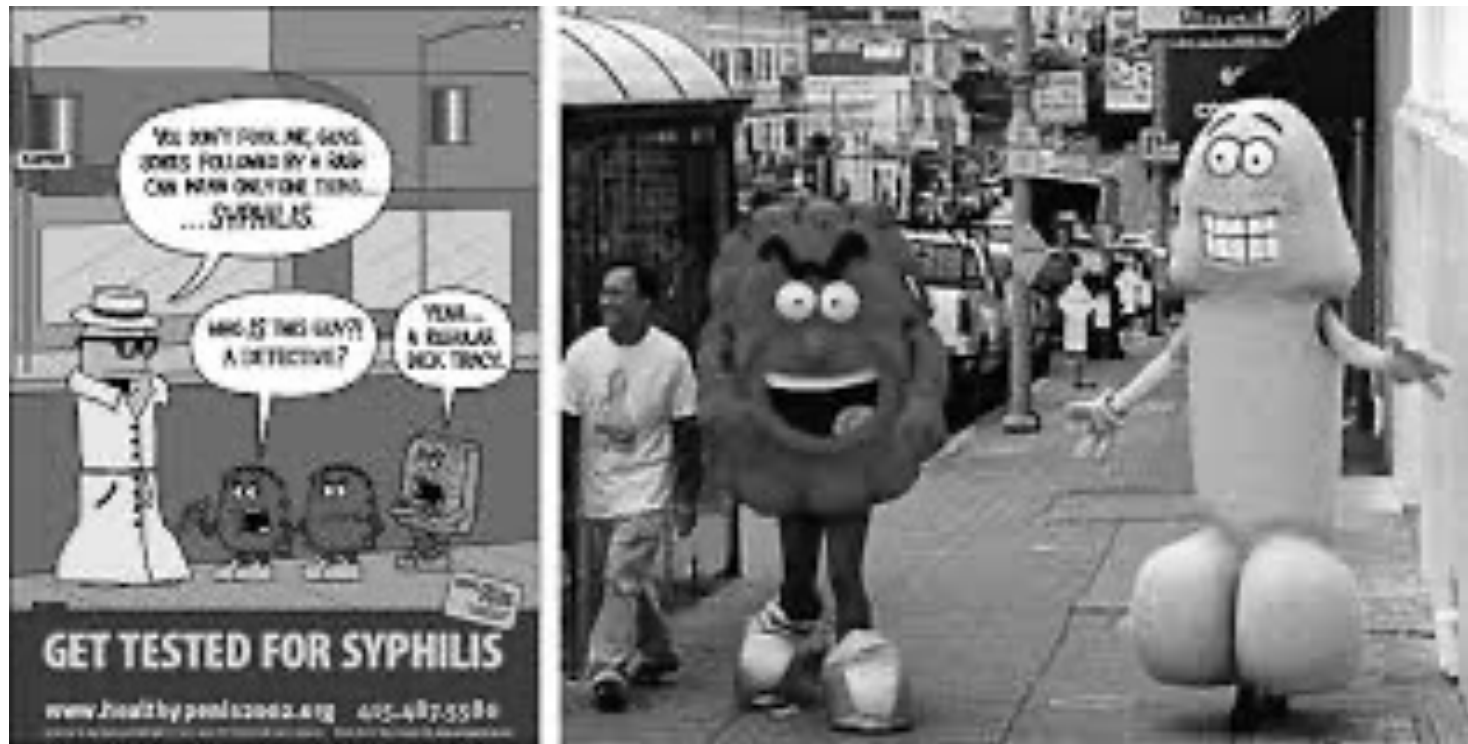
- The aim of a Menopause Café is simple:
 - To increase awareness of the impact of menopause on those experiencing it, their friends, colleagues, and families.
 - It's an open, respectful, and confidential space where people can express their views safely, without experts or expectations.
 - It's not a menopause class or information session, regardless of how useful or important that may be.
 - Nor is it a support group or counseling session. There is no preset agenda; the topics are chosen by those who attend.

Menopause Cafés Serve Up What Women Need

- Some menopause experts say these gatherings offer benefits that aren't provided through traditional healthcare settings.
- But some also worry that they could become echo chambers for bad advice.
- The fact that Menopause Cafés are growing in number suggests that women are seeking engagement on a different level.
- But do Menopause Cafés run the risk of becoming a substitute for, rather than a complement to, conventional routes of gaining health information and support?

- Overwhelmingly, the women at the Lewisham Menopause Café said that they got something positive from the event, that it was much needed, and that they found it very helpful. On the basis of this feedback, it appears that the essential concept of a Menopause Café is a good one. These gatherings allow women to be themselves, to express concerns about menopause and be listened to with respect and compassion. At a Menopause Café, women can raise menopause-related issues that they might have hesitated to talk about before, with anyone.

If we can have healthy penis on the streets of San Francisco ...



And if Ron Jones is not shy to be proud of a healthy penis



Marc Steben

I do not know why women would be shy to celebrate their healthy vulva



Marc Steben



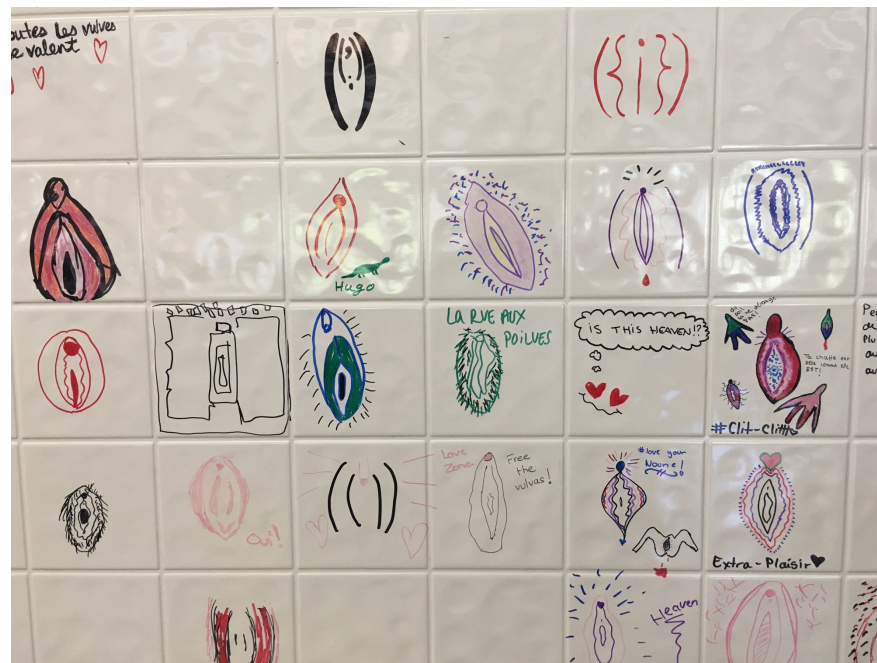
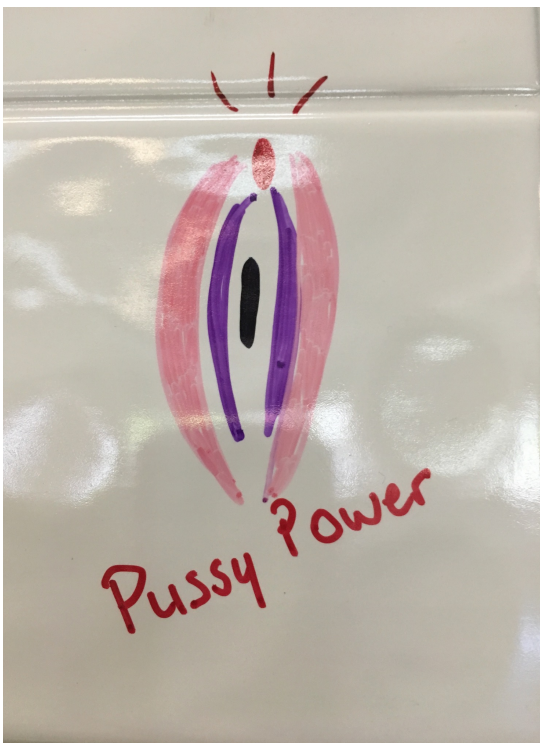
Festivulve #2 = more than 20 exhibitors and 600 women celebrating the diversity of vulvas



Marc Steben



Montréal's wall of vagina!



Marc Steben

- *The organizers hope to inspire Menopause Cafés worldwide. As a social franchise, anyone can host a Menopause Café as long as they adhere to the group's principles. A future events map displays the date, time, and location of upcoming Menopause Cafés. Of interest, the first Menopause Festival, #FlushFest2019, was held in Scotland in April 2019, where the theme was "Break the taboo, have some fun."*

Marc Steben



Women at the Lewisham Menopause Café.

Vulvar awareness

- Should be in the context of sexual health and not just disease
- Educate about functions including pleasure
- And should let women express their concerns about their vulvar health!
- You cannot join the social media world without being bold!
- Vive la santé vulvaire!

Thank You!

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