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Endocrinology Interest Group Session:

Learning from the Patient Perspective

The value of patient engagement and lived experience

Patients should be at the center of everything we do as healthcare professionals. Patient engagement means involving and empowering patients in everything from research to healthcare delivery to policy decisions.

What is lived experience?

Lived experience refers to the first-hand knowledge and expertise of a chronic condition gained from personally going through certain life experiences rather than second-hand knowledge gained through observation or academic study.

In particular, when you involve people with lived experience in health training and education initiatives, it ensures that the needs, priorities, and preferences of these communities remain front and center. It's important to remember that lived experience is its own form of medical expertise.

> *"The meaningful participation of individuals with lived experience of health conditions provides powerful expertise and narratives critical to shaping inclusive and equitable health policies, programmes and services."*
>
> Tedros Adhanom Ghebreyesus, PhD, Director General of the WHO

Hosting an interest group session focused on learning from patients can help medical students better understand the day-to-day challenges, management tasks, and impacts of people's health conditions, ultimately improving care delivery.

Description of event:

This is an interactive panel discussion designed to help medical students gain knowledge from the experience of individuals living with endocrine conditions or disorders. Students will hear diverse perspectives, ask questions in a curiosity-focused environment, and practice empathetic, stigma-free communication skills.

The session will require collaboration with individual patients and patient groups to source panelists and develop meaningful panel questions. The goal is not for this to be a general information session on a specific health condition, but a unique experience to hear from, and ask questions of, people living with a health condition – including their frustrations, aspirations, challenges, and wins.

A sample agenda for the session could be:

- Welcome and panelist introductions (5 minutes)
- Panel discussion (35 minutes)
- Audience Q&A (15 minutes)
- Wrap-up and final announcements (5 minutes)



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Collaborators for Success:

- **3-4 Individuals living with the health condition(s) you want to focus on for this session.** Aim to have a diverse representation of experiences. This might mean having people with different socioeconomic backgrounds, demographic characteristics, or management strategies and treatments for their condition.

  Helpful Recruitment Tips:
  - Many institutions like hospitals and medical schools have Patient Advisory Councils or Patient Experience departments already in place that may be able to connect you with individuals who would be intersted in participating on your panel. It may be important to ask if patients need to sign an agreement to participate, depending on your organization's rules and policies.
  - Partnering with a patient advocacy organization or a community-based organization can be helpful if you are unable to find patient volunteers within your institution.
- **1-2 Medical students to assist with planning and promotion.**
- **Panel moderator.** This could be another person with lived experience, a medical student volunteer, or a faculty member.
- **If available to you: a health stigma professional, or someone with experience working with patient communities.** While not a required collaborator, including someone with a community advocacy background and/or psychosocial expertise can help ensure that the panel content and speakers don't inadvertently contribute to or reinforce stigmatizing, inaccurate, or biased opinions.

Materials and Resources:

- **Relevant resources from patient organizations,** such as patient education and support materials, mental health resources, or information about community and support groups.
- **Sample email template** that you can use if reaching out to individual patients or a patient organization (please feel free to adjust to your needs):

Dear [Insert name/Organization] –

My name is [insert name] and I am a medical student at [insert institution]. Our endocrinology special interest group is planning a panel discussion featuring people living with [insert condition]. We are particularly interested in learning from people's lived experience and we hope that this panel discussion will help our medical students understand the nuances, challenges, and realities of living with [insert condition], as well as tips and strategies that have helped them manage their condition.

We would love to invite [you/a community member from your organization's network] to be a panelist for this event, if it is of interest to [you/your organization]. The panel will be taking place on [insert date and time] at [insert panel location]. I am happy to answer any questions you may have or share additional details.

Thank you for your time,
[insert name]

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Session Preparations/Tips for Success:

- **Conduct early outreach to potential panelists.** It can sometimes take longer than expected to find panelists who are able to participate in the discussion.
- **Meet with panelists before the event.** If time and schedules allow, having a short introductory meeting with the panelists can be really helpful. This meeting allows you to learn more about each panelist's background and perspectives, it can inspire potential panel questions, and it can help build initial trust and rapport between the patients and the organizing team and moderator.
- **Prepare the moderator to redirect questions or answers that may be stigmatizing or disrespectful.** Many health conditions carry social stigma, and it is the moderator's job to help ensure the discussion stays on topic and doesn't lean into harmful or judgmental questions. This doesn't mean censoring the discussion, but gently guiding the discussion back to the topic at hand if it goes awry.
- **Begin by thanking participants and acknowledging the value of their lived experience.** It takes courage to talk openly about living with a health condition, especially when many conditions carry stigma and judgment. A simple acknowledgment at the start of the panel can be a way to express gratitude and set the stage for a positive discussion. An example is, *"I want to start this discussion by thanking all of our panelists and everyone with lived experience of [insert conditions], for sharing their stories and expertise with us. Your insights help us provide the best care possible for all members of the endocrine community."*
- **Develop questions for an engaging and meaningful discussion.** When coming up with panel questions, these topic areas are an effective formula to help you build a well-rounded discussion that focuses on the specific expertise offered by those living with a health condition:

Sample Discussion Questions

Managing the condition day-to-day: What does a normal day look like for you as someone living with [insert health condition]?
Navigating the healthcare system: What does healthcare look like for this condition? How is the condition managed? What does a normal doctor's appointment look and feel like? Where do you run into challenges?
Insights only a patient would know or prioritize: What do you wish people knew about your health condition? What do you wish your healthcare team knew?
Celebrations and success: What does success look like for you? How do you celebrate when you have a good day? What are the types of goals or priorities you have for your health and what do you do when you achieve them?

- **Encourage students to come to the event with any questions they are curious about.** If you don't live with a specific health condition, it can be hard to understand the nuances of living with it and managing it. This panel is a great opportunity for students to lean into their natural curiosity and ask questions that can help prepare them to better care for their patients.
- **Perfection is not the goal.** Everyone makes mistakes, says the wrong word sometimes, and occasionally holds a viewpoint they didn't even know was stigmatizing. That's okay! Set ground rules during the panel discussion that help create a safe space for curiosity and learning, not judgment.
- **Patient engagement can take many forms.** For this panel, organizers are encouraged to focus specifically on lived experience. Other types of experiences, including loved (i.e. family members and caregivers), learned (i.e. healthcare professionals and researchers), and labored (i.e. advocates, community leaders, and organizational professionals), can also provide meaningful perspectives and can be considered for additional patient engagement opportunities.

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This resource was co-created in partnership with the Endocrine Society and dStigmatize, a diaTribe Foundation program, with support for The diaTribe Foundation provided by Lilly.

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