



Consumer Advisory Council Meeting Minutes

Tuesday, January 24th, 2023

ATTENDEES

Members

Name	Organization	Virtual
(Chair/Co-Chair TBD)		
Gavin Taylor	US Naval Academy; Data Scientist; Research	X
Douglas (Doug) Rose	Patient / Advocate	X
Dan Martin, JD	MHA MD	X
Robyn Elliot	Healthcare Lobbyist / Consultant	X
Walter Saba	Maryland Latinos Unidos	X
Chris Peterson	Policy Consultant; former HSCRC	X
Sephora Morrison, MD	Pediatric ED Clinician/CRISP User; former CNMC	X
Linda Fischetti	Mitre; Consumer Advocate; former CHIO and Peds nurse	X

Staff/Guests

Via Teleconference: Nichole Sweeney, Adrienne Ellis, Cait Riccobono, Kelley Gallagher, Craig Behm (briefly)

Agenda

Welcome

Nichole Sweeney welcomed Consumer Advisory Council (CAC) members and staff to the inaugural meeting, and for mutual benefit facilitated introductions of all attendees. Today's meeting is an informal orientation for members, so no Minutes were recorded. Action items and key discussion points are noted below.

- Discussion on artificial intelligence (AI) capabilities in the healthcare space, including privacy and electronic health records (EHR) system considerations. Nichole Sweeney noted that a relevant whitepaper was published and she agreed to share it with anyone interested.
 - **ACTION:** Nichole to share whitepaper
- Members observed that the patient/consumer perspective has been underrepresented in governance and guidance since the CRISP's inception, and discussed deeper engagement moving forward.



- Some members expressed interest in reviewing a demo of CRISP tools and services discussed during the meeting.
 - **ACTION:** Nichole and Kelley agreed to schedule a demo for interested members
- Discussion on meeting format, including guest participation, duration, cadence, and other logistics was held to facilitate schedule planning
 - Members proposed keeping meetings closed, with only members and relevant staff participating, for the first 6-12 month to allow the CAC adequate time to establish its rhythm/cadence independently and further give members the opportunity to gel as a group.
 - Some concern that consumer voices could muted when there are non-consumer reps in the room, so we should be mindful as we consider opening the meetings
- Discussion regarding opt-out policy and concerns that patients are generally not made aware of CRISP/HIE participation at the point of care. If patients are unaware of CRISP and the role it plays facilitating the exchange of health data, they are not informed and empowered to opt-out.
 - Background on patient education and outreach activities was shared. CRISP has made meaningful progress towards being transparent about data use access and by posting info on the website, but not in ensuring docs are educating their patients regarding CRISP and their participation, as is their duty
 - Staff are committed to finding solutions to the patient access piece with CAC members and view this as a priority.
 - **ACTION:** This topic will be added to the agenda for the first formal CAC meeting.
- Discussion regarding general principles of CAC and logistical items, including establishing a charter, electing a chair, and meeting cadence (quarterly suggested).
 - **ACTION:** Kelley will circulate an email to the group regarding the following:
 - Core Principles – share the five ‘Should We [permit a particular data use]’ questions for enrichment
 - Draft Charter – share with members for review and input
 - Co-chair roles – call for volunteers
 - Next Meetings – Circulate options to CAC members and request availability
 - Services Demo and General Questions – Staff will coordinate services demos for anyone interested, and CAC members are encouraged to raise any questions, concerns, or suggestions for agenda topics to CRISP staff at any time.

The next meeting will be scheduled shortly. With no further business before the Council, the meeting adjourned at 7:00pm.