



Consumer Advisory Council Meeting Minutes

Monday, March 27th, 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 Elliott	Healthcare Lobbyist / Consultant / Planned Parenthood	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	

Staff/Guests

Via Teleconference: Nichole Sweeney, Adrienne Ellis, Kelley Gallagher

Agenda

Welcome

Nichole Sweeney welcomed Consumer Advisory Council (CAC) members and staff to the meeting, and for mutual benefit provided an overview of the agenda. Following brief discussion, members confirmed their preference to not record meetings, and Nichole Sweeney pledged to coordinate the demonstration of CRISP tools and services some members had requested during the last meeting. Actions, takeaways, and key discussion points are noted below.

Administrative

- Notes from the inaugural informational meeting were reviewed and discussed. Apart from a request to correct the spelling of a member's name and include an organizational affiliation with their title, no edits were suggested. The Council approved and accepted the notes as discussed, and the team will post the document to the CRISP CAC web page as required by state mandate.
 - **ACTION:** Staff to post notes to the CAC webpage.



- Nichole Sweeney reminded members that CRISP is required to host a CAC webpage for transparency and that artifacts such as meeting notes, member bios and photos, and charter must be posted.
 - **ACTION:** Kelley and Nichole will collect member bios and photos for CAC webpage.
- Members discussed leadership roles for the CAC and noted their strong preference for Chair/Vice Chair structure, with succession implied, over a co-Chair arrangement, and further discussed terms for these leadership roles. Members also agreed that the Chair should be a consumer advocate, while the Vice Chair can be any other member in good standing. Two members were absent, and with no candidates following discussion, attendees agreed to consider the Chair/Vice Chair roles independently and defer the election. Participants agreed that:
 - Formal actions, including elections, may be conducted via offline/email vote at the Council's request; and
 - The Chair will serve for a two-year term, with no limit on successive terms, and while succession planning is implied for purposes of continuity, this will not be codified in the charter.
 - **ACTION:** Nichole and Kelley will follow up with members offline to gauge interest in the Chair/Vice Chair roles, and based on feedback, consider holding elections via offline vote or during the next Council meeting.
 - Members also confirmed with staff that the draft CAC roster and member bios were reviewed in detail by the CRISP Board Executive Committee, with no questions or concerns raised. In following existing governance practices, CAC members will serve for one-year renewable terms, with reappointments by the CRISP Board taking place in September.

Charter Discussion

The Council reviewed provisions of the draft Charter in detail. Edits, related actions, and key discussion points are noted below.

- General. Include a provision asserting that 'new members filling vacancies are to be recommended by the by majority vote of the council, with formal approval by the CRISP Board.'

Individual provisions of the charter with discussion and/or **recommended edits** are as follows:

- Article 1 – Purpose. No changes recommended; approved as stated.
- Article 2 – Chair. Discussions and decision points above.
- Article 3 – Membership. **Consumer privacy protections; include 'and other consumer interests.'** Members also discussed what information can be considered 'confidential' to ensure all have a common understanding and can adhere to agreed-upon confidentiality standards in both CAC work and member's primary roles.
- Article 4 – Member Term. Members agreed there is no need for term limits; however Council members should contribute meaningfully to discussions during their tenure. Members



confirmed that while limits are not in place for existing advisory governance groups, attendance and active participation of members is monitored and staff will work to reengage less-active participants; if capacity is the prevailing issue, staff will work collaboratively to identify new, qualified members with more bandwidth.

- Article 5 – Meeting provisions. Members confirmed that a specific ‘tiebreaker’ provision is not needed for decisions. Staff confirmed that while a majority vote taken under quorum could pass, CRISP strives to arrive at decisions via consensus such that any issues sparking strong dissent are tabled for further discussion leading to a compromise. **Members agreed to increase the majority threshold for decisions to ‘2/3 of the voting members’ to codify our commitment to consensus.**
- Article 6 – Frequency. **Remove ‘at least 2 months in between’** as it is not needed.
- Article 7 – Confidentiality. Members affirmed that anything discussed during CAC meetings should be treated as confidential. Should individual members choose or be compelled to speak on any topics pertaining to CRISP or the CAC, including media inquiries, all members agreed that the individual should indicate that they are speaking on their own behalf and not on behalf of the Council. For formal statements, Council approval on position and content should be obtained before speaking.
- Article 8 – Membership Selection Process. Per discussion, **staff will note that the Council roster is reviewed and approved annually in September by the CRISP Board.**

General Discussion

- Regarding Council membership, staff confirmed that there is currently no provision for granting travel expenses, honorarium, or reimbursement for other applicable costs incurred. Members noted there may be instances where we need input from consumers with ‘lived experiences’ who would not otherwise be able to participate without compensation. Staff acknowledged this and as an **ACTION** will keep this as an open topic of discussion for the Council.
- The value of hosting in-person meetings was discussed, and members agreed that at least one in-person meeting per year would help foster deeper engagement between members and supporting staff.
 - **ACTION:** Staff will offline suggest opportunities/locations for later this year, including a potential summer day-retreat.
- Members discussed the importance of incorporating a diversity, equity, and inclusion (DEI) lens in the work of the CAC, as well as thought diversity, in ensuring discussions are well-rounded and all perspectives were meaningfully represented. Members suggested that adopting a DEI statement and other artifacts for the CAC and staff to follow would meaningfully affirm this position. Staff noted that while there is no formal DEI language in place at the board/governance level, CRISP Shared Services has adopted principles and statements which could serve as a starting point for CAC statements.
 - **ACTION:** Staff will share existing CSS DEI language with CAC for review and future discussion.



Opt-Out Discussion

Staff provided background on the opt-out process for CRISP within the state of Maryland, including parameters regarding timelines, ways patients can opt out, and what happens to health data after the request is completed as noted within the Code of Maryland Regulations (COMAR). Staff also shared prior feedback received on the opt-out process and CRISP's position, noting that the three key points were 1) the opt-out process should be as simple and straightforward as possible, 2) CRISP should provide more education for consumers regarding their opt-out rights, and 3) the opt-out should not be "all-or-nothing" with regards to data. Key points raised are below.

- Members shared individual experiences with opt-out, noting that they were not made aware that their provider was participating in CRISP. Members realized via discussion that providers disclose this relationship within their Notice of Privacy Practices (NPP) given to each patient (or patient representative, in the case of dependents), however this information is not prominently displayed or discussed at all during intake, treatment, or discharge. The NPP is often buried within the mountain of paperwork given to patients.
 - **ACTION:** Nichole will share NPP language with members for awareness
- Members observed that while CRISP states its commitment to patient privacy, much of the supporting language pertains to exceptions on how a patient's data must be exchanged and used by other parties even if a patient has opted out of the HIE. Staff acknowledged the confusion and frustration consumers feel and agreed that CRISP needs to work to clarify for both the CAC and the patient community at large.
 - Members discussed creating a pie chart or similar visual which types of data exchanged when opted in versus what is still exchanged when the patient has opted out. This would be more impactful for general consumers than written language.
 - Also, the opt-out form notes that patient data will not be available through the CRISP network once opted out, which in and of itself is a strong barrier to opting out. Consumers may have data privacy concerns which could be resolved by opting out, however the concern is greater that their doctors may not have access to their patient record and the potential impact to receiving informed care.
- Members agree that more thought and discussion is needed regarding opt-out policies and approaches to improving patient awareness. That, and consent management.

Next Steps

- Send email about Chair, request volunteers, feedback, and offline vote (if appropriate)
- Revise draft Charter for future discussion and approval
- Circulate CSS DEI principles and belonging statement for consideration, including whether aspects can be repurposed for the CAC
- Schedule next meetings
- Coordinate tools and services demo previously discussed



Members were encouraged to contact staff at any time with questions, comments, or suggestions for future meeting topics. With no further questions, the meeting was adjourned at 2:27pm.