



## **Complex Chronic Disease Program (CCDP) Patient Engagement Findings**

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## Background:

A World Café style patient engagement event was held with the BC Women's Complex Chronic Disease Program (CCDP) patients on May 27, 2017. The World Café event was designed to focus on identifying opportunities for further patient and community engagement in the CCDP, as well as, identify opportunities for ongoing program improvements. Four main topic areas were determined and a number of questions were posed to patients, families and community partners including:

- How CCDP can provide support for caregivers and families of patients in the program?
- What could we do to ensure your primary care provider's understanding of your health concerns is better?
- What are the priority topics for education?
- What matters to you as a patient/family member of CCDP? What needs are important to you that are not being met by CCDP?

Seventeen patients participated in the World Café event and provided responses to the above questions. Responses which were captured via field notes were subsequently summarized by the CCDP program staff.

An online survey was also sent to participants who had not participated in the World Café event. In total, 29 surveys were obtained from CCDP patients via an online survey. Three surveys were blank or responses were not in relation to the survey questions and as such were omitted from further analysis. In addition, feedback was received from two individuals via email.

Survey and email data were analyzed thematically -comments were analyzed and categorized based on themes. The World Café field notes summaries were incorporated into the themes generated from the survey/email data

The CCDP intends that the World Café framework for engagement will become an ongoing, annual event to continue to facilitate patient, family and community engagement in the program, as well as, other types of engagement and partnership activities.

## Findings:

### Q1. Describe supports that CCDP could provide to caregivers and families

Please note this question was responded to broadly – the answers did not solely pertain to caregivers/family members.

- **Information/Education**

- General

- Research trials
    - Medical information
    - List of treatments
    - Canadian guidelines/consensus criteria for ME/FM
    - BC and National ME/FM websites
    - Facts/stats
    - Address stigma and misconceptions among the public and providers
      - Chronic Fatigue or CSS does not reflect the disease
    - Map of patient journey through the program
    - Information is needed for those on wait-list
    - Information sent to GP
    - Suggested modes/methods:
      - Online resources
      - Tool free help telephone line
      - Books/brochures/flyers
      - Use story telling approach – “Love letters from ME/CFS”
      - Community of knowledge – online community
      - OT classes to set up home

“...In order to address support for families, you must address stigma and contempt in the health care (physicians) and in society. You are a provincial program. You have the power to recommend education to the drs., the good kind of education, not the holistic kind.”

- Caregiver

- Emphasize the importance of partnership in care
    - Information on expectations of caregiver support
    - Address misunderstanding and misperceptions among family members/caregivers
    - Educate caregivers on signs of depression – for self and patient
    - How other agencies provide support to caregivers? (e.g., Cancer Agency)
    - Suggested modes/methods:
      - Handbook/brochures for caregivers –explaining disease, legitimizing and providing practical suggestions

- Provide patients with a standard script “elevator speech” to use with caregivers/families – short, concise, factual
- Info video to share with family/friends
- Share CCDP journey map with caregivers

*“...facts about ME/CFS for family members who still remain “doubters” of the disease. There’s so many generic info sheets, that the same ole words are glossed over. Hard-hitting facts are good. (i.e. during CCDP family and friends session – stats given for money given to AIDS/HIV research compared to ME/CFS...And fact that ME was more debilitating was really good!”*

- **Family engagement**

- Orientation video that includes family members/caregivers
- Intake meeting with family/caregiver to legitimize disease and discuss caregiver role
- Bring support person/advocate to all CCDP meetings – open-communication between CCDP and caregiver provides a better understanding of the level of support the patient receives at home
- Continue with Friends and Family nights
  - Needs to better advertise/market the event
- Support-groups/counselling – acknowledge that it is hard on partner/many couples break up.

*“Intake meeting with primary support person (partner, parent, etc.) to help explain the disease and the limits to patients’ abilities. Especially in terms of legitimating the illness and educating about the options.”*

- **Access**

- Follow-up call
- Better communication flow between GP and CCDP – GP should be able to contact the person as needed
- Program not being time-limited
- Support for patients/families/providers outside of Vancouver/remote communities
  - Conference calls/videoconferences
  - Community outreach teams
  - Professional education
  - Telehealth meetings
  - Education kits for GPs, health units, pharmacy, etc.

- **Community Resources**

- List of physicians familiar with these diseases

- Respite care
- Resource list for rural communities
- List of support groups
- Home care or home help programs
- How to access services
- **Treatment and multilayer support**
  - Not just diagnostics or symptom management, but medical treatment
  - Address all the areas impacted
  - Address the needs of patients first
- **Break/day-off/help for caregivers**
  - Respite care so caregivers can take a break
  - Emergency home care assistance
- **Financial support/Resources**
  - Financial avenues of support
  - Tax breaks
  - Home support services to help with daily tasks/government funded home care
  - Support with travel costs
- **Collaborate with leaders in the field**
  - Partner with other leaders
  - Conduct leading research
  - Host international conferences

*“Financial avenues of support. Disaster on the financial front leads to threat of nutrition, housing, living resources, healthcare, affordability of therapies recommended by the CCDP. Lack of financial resources leads to increased distress to patients and caregivers. Fear of the unknown and anger between family members. This leads to marriage break ups, homelessness and suicide.”*

**Q2. What could we do to ensure your primary care provider’s (PCP) understanding of your health concerns is better after each CCDP visit?**

- **System gaps**
  - Health care providers lack knowledge about complex chronic disease
  - Primary care providers (PCPs) need incentives to become more informed about ME/FM; increase accountability
    - Need to increase PCP engagement – willing to learn, be informed and work with patients

- Patients often feel that they have to educate PCPs, but they are seen as not “credible” sources
- ER providers lack understanding of illness and patients often feel disregarded, not believed and pushed away
- When patients change PCP, new providers need to be brought up to speed
- PCPs often do not follow recommended guidelines
- Recommendations from CCDP do not stand out in the current reports to PCPs
- PCPs are sometimes unable to provide support with disability paperwork
- PCP visits are short – not much time to discuss illness
- CCDP is diagnostic only – there are no treatments available
  - Use proven treatment models that work
- Need a medical speciality dedicated
- Need patient advocates

- **Education for Primary Care Provider (PCP)**

- Information to PCP regarding any tests or treatments that can be done while on wait-list; info on what is available in the US
- Basics of ME/FM
- List of tests that could be done
- Latest research (e.g., Dr. Lily chu’s article)
- Standard of care (if available)
- Canadian Consensus Criteria overview
- More information on chemistry
- Educate on approaches
  - Need to work within the patients’ “aerobic zone”
  - POTS and the 10 min stand/b.p. test
- Better understanding of their roles
- Make sure they speak the same language – consistency of care between CCDP and PCP is important
- Address misconceptions/misdiagnosis/validation of symptoms with patients
- Modes/methods:

*“You assume that physicians and primary care providers are willing participants here. It has been my and other’s experience that it is not the case. The GPs cannot even describe how to diagnose ME. This said, I expect CCDP to clearly express that this is not a psychiatric illness...”*

*“Again, stating brief hard-hitting facts about ME/CFS is great. Example....give the doctor the usual follow-up notes on patients....but add a few juicy points (bullet form) in the realm of “did you know?” A lot of great info concerns how ME/CFS compares to other more well-known disease...”*

- Open-discussion/consultations/office visits
- Information nights for providers (similar to Family and Friends night)
  - Screen the film “Unrest”
- Improve access - ability for GP to follow-up with CCDP
  - Have a dedicated education staff at CCDP so PCP can contact for education/support
- Continue with the practice of asking PCP to sign a form stating that they would follow recommendations of the CCDP
- CCDP information documents/package to accompany the visit summary sent to PCP

- Send a link to online resources – latest research, patient support groups, etc.
  - Send link to educational videos
  - Add few facts about ME/CFS on each follow-up note – “short, concise, scientific facts”
  - Cheat sheets
  - Publish articles in the BC physician publications
  - Fund training for PCPs/lobby for courses
- **Education for other health care providers**
  - Information to all GPs on what conditions and symptoms can be referred to CCDP; and/or any tests that should be performed prior to referral
  - Send proactive information to case workers and insurance companies
  - Pamphlets in doctors’ offices and hospitals
  - In-service/education for all ER doctors and RNs; provide credible, scientific and easily accessible information
- **CCDP Written reports**
  - Send reports/updates in a timely manner
  - Copies of reports sent to patients so patients can follow-up with PCP; email patients key points
  - Clear and concise updates provided to both patients and providers/ highlight diagnosis and recommendations on top of the report (easily seen)
  - Patients can provide insights that could be incorporated into the report
- **Information on disability claims**
  - Claims deadlines and urgency must be communicated to PCPs
  - Advocate for PCPs to go to a lawyer-sponsored letter writing course for disability insurance and/or CCDP physicians to share letter-writing tips
- **Take on an advocacy role**
  - Support patients when they are liaising with health care providers
  - Follow-up with care providers to ensure they provide the care needed
  - Speak for the patient when they have no voice

**Q3. What are the priority topics for education videos/tools/materials? What are the priority audiences?**

**Priority topics:**

- **Illness specific**
  - Science of illness

- Available diagnostic tests – biomarkers and objective tests
    - Barriers to testing (e.g., costs, invasiveness, etc.)
    - How to follow-up on abnormal tests
  - Available treatments
  - Disease burden - what it means to live with it daily – chronic nature/ impact on quality of life; calculate burden of disease (similar to US); impact on finances and work
  - Range, severity and progression (e.g., from moderate to severe/home bound, bedridden)
    - Create clear outline of the “four different phases of ME”
  - Link to other health complications (e.g., suicide, depression, potential for cancer, etc.)
  - Understanding that it is not a death sentence
  - Statistics – demographics, prevalence, % not working, cost to individual and system, etc.
  - History
- **Information about CCDP**
    - Range of services and support - what CCDP offers and does not offer
    - Diseases and conditions
    - Referrals
    - Patients on wait-list to have access to information:
      - Tests need to be completed prior to initial appointment
      - Treatments that can be pursued prior to initial appointment
    - Dates of groups and information sessions
  - **New diagnosis**
    - Information for those with new diagnosis
      - How to begin to manage the illness
      - What are the strategies that may help
      - What not to do when you have ME/FM
  - **Management of illness by providers outside of CCDP**
    - What tests, medications and/or treatments to pursue
    - ME/FM guidelines; practice guidelines and therapies
    - How to fill out disability forms; writing letters to insurance companies
  - **Validation of the reality of the illness**
    - Address stigma, misconceptions and false beliefs
    - Acceptance of illness - it’s a physical illness – not just in our heads
    - Scientific evidence would give credibility and legitimacy
    - Need validation in order to get disability insurance and government support
  - **Current research from around the world**

*“Priority topic: the basic definition of ME and FM to dismiss all rumours and misinformation out there, that this is chronic condition with no cure that needs to be studied more, that it is a serious condition affecting many lives.”*

*“It is not just about educating them [health care providers], it is about convincing them how serious and legitimate the condition is. As a role model the CCDP should present our case. (As a patient of the CCDP*



- Link all providers with latest publications
- Not just about education but about convincing them that it's real
- **Alternative treatments and coping skills**
- **Resources**
  - How to apply for a disability income
  - What resources are available and how to access them
- **Relationships**
  - Need for family/friends support
  - Support when talking to primary care provider
  - Support when talking with family/friends about “crashing”
    - What is it; what does it feel like; what does it look like
  - Support with partners
    - Physical intimacy; high rates of divorce/separation; strain on relationships; and coping
- **Communication and information sharing in community**
  - Connection between GP offices, other programs, Specialists and between Health Authorities
  - How CCDP communicates with primary care providers
  - Health care providers awareness
  - Public awareness building efforts
- **Politics of complex chronic disease**
  - Research dollars spent
  - Policies that impact patients
- **Suggested resources**
  - IOM survey
  - Dr. Lily Chu’s article: US ME/CFS Patient Survey – April to May 2013
  - Dr. Jarred Younger’s work
  - UBC PIE group and PAC
  - OMI – in US
  - Dr. Byron Hyde – You Tube videos
  - Unrest and Forgotten Plague video
  - Information about naturopaths
  - “Hard hitting facts”
  - Video of sample support group
  - Meditation and mindfulness videos

*Quick, hard hitting facts...website links, videos (but they have to look/feel like someone cares enough to make video look good. Videos that are poorly shot, recorded, blustery make it look like certain diseases aren't worth the effort). I think introductory video of CCDP nurse chatting with patients is good because there was effort put into video.”*

- Dental visit pointers
- Paper on somatic illness should NOT be given to patients – delegitimizes the illness
- **How (Modes & Methods)**
  - Simple to understand, but medically and scientifically proven information/simple highlights
    - “Elevator speech” – translating the science into understandable and easy to communicate language
  - Information be accessible in different languages
  - Videos
    - High quality videos – similar to CCDP introductory video
    - Short videos
    - Easy to understand messaging
    - Educational You Tube series
  - Story telling approach/case studies – human interest stories
    - Drives the message regarding impact of the illness; creates connections within the patient community
  - CCDP to send bulletins to GPs – with clear instructions and recommendations
  - Case conferences with patients, GP and CCDP
  - More collaborative information sharing between all providers
  - CCDP to send information to patients electronically (via email)
  - Online tool kit
  - Pamphlets in all doctors’ offices
  - Educational forums and events
    - E.g., library education nights
  - Family and friends only event (without patients)
  - Live streaming through social media (Twitter , Facebook)
  - Educational podcasts for credits via medical mobile app for health care professionals
  - CCDP patient blog – to share information and experiences
  - Tap in to group discussions in patient forums – contribute to the discussion and/or use that as model
  - In-service and outreach teaching
  - Patients desire to be involved in development of education materials
    - Gather feedback from patients on the appropriateness of content on CCDP website and Health Link BC
  - Conduct needs assessment of primary care providers; community needs assessments

**Priority audiences:**

- **Patients**
- **Medical community**

- Primary care providers (PCPs)
  - Need to be able to do diagnosis and disability assessment
- Emergency room providers
- Nursing – home care support
- Specialists, programs and health authorities
  - Policy makers
- CCDP physicians and staff
- **Teaching, research and professional institutions**
  - Medical schools
  - Medical College of Physicians and Surgeons
  - Nursing organizations and schools
  - Researchers
  - Research funding bodies
- **Caregivers/friends and families**
- **Community at large**
  - Politicians
  - Journalists
  - Insurance companies and lawyers
  - Families and children and teen

*“GPs are the priority audience since they see patients first. Right now the most important things are diagnosis and disability assessment. Work with BCMA or College of Physicians and Surgeons to develop materials that contribute to professional development goals.”*

*“The top priority is to educate the physicians and the scientists at UBC who want to expand their research to open field.”*

#### Q4. What matters to you? What needs are important to you that are not being met by the CCDP?

##### What matters to you?

- **Access to CCDP**
  - Knowledgeable staff
  - Caring and attentive staff
  - Non-judgmental
    - Treated with respect and dignity
    - Sensitive treatment
  - Hopeful
  - Access to latest research
  - Control over symptoms
  - Learned new things
- **Proper testing, diagnosis and treatment**
  - Latest research, clinical trails

*“That CCDP exists!! That I am being seen by knowledgeable doctors, medical professionals and caring staff. That I am treated with care and dignity; that I am not being judged and shamed for my limitations the way I was being treated by some doctors in my own community; that I am being kept informed of new research and opportunities to try new treatments and trials successful in other countries; it give me hope when I find myself at the end of the rope...”*

- Adequate funding for research
- Not just coping skills, but real treatment
- Less focus on CSS, CBT, and emotions and more focus on medical treatment
- **Validation of illness**
- **Improved quality of life**
- **Patient engagement in care process**
- **Good communication with health care providers and patients**
  - Trust and respect
- **Access to care**
  - Remote access
  - Ongoing access to care/support
  - Multidisciplinary approach
  - Access to community resources
- **Advocacy**
  - Educating people/society
  - Champion the cause
  - Leadership in the field

*“I have completed the program at the CCDP. I did learn a few things, particularly where my aerobic level is now compared to when I was first ill...I also learned of some supplements that might ease symptoms....some of the staff were very aware of my limited abilities and offered me a place to lay down and be cooler than in the waiting area...”*

*“It matters to me that others like me with ME/FM will not be treated by health care members, co-workers, or family members as incapable, lazy, depressed, anxiety ridden or hypochondriacs.”*

### Gaps in CCDP

- **Flow**
  - Triage patients on wait-list
  - Long wait-lists
  - Need access to information while on wait-list (e.g., list of tests, what is covered by MSP, what is not covered, etc.)
  - Work with primary care providers for an earlier diagnosis
  - Provide a roadmap for what is going to happen –journey map from referral to discharge
  - Regular communication (e.g., email) with patients and primary care provider
  - Challenging to schedule appointments (calls not returned promptly); options for later appointments
  - Improve discharge process
    - Improve discharge form
    - Ask patients come for their exit interview if possible
  - Stay in touch with patients who have been discharged

- **Treatment and care**

- Need medical care (treatment); complex disease specialists; not just support with managing symptoms
- Need Neurologist
- Neuro-feedback
- Massage
- Helpful supplements
- Ongoing support groups
- Ongoing support to patients who have been discharged
  - Follow-up visits every 6 months
  - Invite patients to participate in groups, events, etc.; send them information
- Ongoing updates to GP on latest research and treatment – after patient discharge

*“ME is a lifetime illness for most of us. One year of access to the program does not consider this illness has changes and stages. We need ongoing support....”*

*“I found that the support was good. In terms of counselling, nutrition, info, etc. but really not much medical attention. I don’t think it’s realistic that our doctors are taking care of our needs. Unfortunately I think it should be treated like going to a specialist...the GP makes the referral (i.e. kidney specialist) and that specialist provides actual medical care. I don’t think much medical care was provided for me at CCDP and that surprised me. There was an in-person initiation appt, then an exit phone call...I would very much like to see an MD CFS specialist at the clinic...”*

- **Resources**

- Subsidized or affordable home support for those living alone or need additional help
- Support with disability paper-work/claim
- Respite program for spouses/partners
- Emergency number for GPs, ER providers
- Help-line to ask questions
- Provide patient advocates
- Comprehensive list of resources – including costs and details
- Secure more funding for CCDP

- **Remote access to care/support for those not living in Vancouver**

- Satellite clinics
- Secured video link consultation appointment
- Set up social connections in rural communities (e.g., informal co-links)
- Model of care rolled out to other clinics around the Province
- CCDP Travel and parking costs are barriers to care

*“I found it extremely difficult to make it to my appts at the CCDP. It was prohibitively expensive for someone who has been on disability for 15+ yrs both to get there and for parking. Also, due to my ME I find it physically prohibitive as well.”*

- **Education/information**

- CCDP to provide outreach education to providers
  - Conduct needs assessment (e.g., surveys, focus groups)
- Facts – memorial, scientific, hard-hitting
- Stories – relatable
- Info about tests not covered/not available at CCDP
- Info about latest treatment
- Use simple language (e.g., newsletters had too much jargon)
- Program language and structure should be inclusive e– ME/FM, MCS, and Lyme patients
- List of FAQs available online and in print

*“I want ammunition for being able to educate people/society about ME/CFS. Easy to understand facts to give people a bit of a jolt (things they hadn’t realized about the severity of ME/CFS). I want facts that will captivate and engage people. Facts that are easy for them to remember and pass on. Patients with ME/CFS identify with other patients’ descriptions/examples/stories of having the disease...”*

- **Patient engagement and relationships**

- The Community Advisory meetings should be open to all who want to attend; minutes should be shared with all stakeholders (including patients)
- CCDP to fully cooperate with the Patient Advisory Group and the ME/FM BC Society
- Have a CCDP quarterly newsletter – on plans, progress, addressing patient concerns, etc.
- Improve patient-provider communication

- **Community building**

- Facebook page
- Live streaming of fundraising and fun events
- Fund raising activities (e.g., gala opera, art auction)
- Website that supports online communication – each patient having their own login id (e.g., similar to weight loss programs)
- Have a ME/FM community centre facility (like AIDS Vancouver)
- Look at other communities and learn from them (e.g., MS, Cancer)

*“With an ME label it excludes us and we are left alone....you [CCDP] need to be our voice. Our defenders. Don’t let GPs get away with...not doing their job. Put pressure on government for funding, for testing and for clinical trials...”*

- **Advocacy**

- “You need to be our voice”; “defend us”; “speak for us when we can’t”
- Public awareness campaign
- Take the stigma away from the ME label – getting help from the health care community becomes difficult with the ME label
- Advocate for more research and testing


- **Re-branding CCDP**

- Not just a disease exclusive to women
  - Relocate to UBC
- Not just CSS or chronic fatigue

*“The one year discharge is not realistic. Wait lists are far, far too long. Out of Vancouver access is negligible and cost prohibitive for many. CCDP needs to be far broader base than simply diagnose, stabilize and exit. Remote access is critical. Ongoing research...is CCDP doing any?”*





## Summary

Key emergent themes:

	<p><b>Treatment</b></p> <ul style="list-style-type: none"> <li>• More focus on treatment, as opposed to diagnosis and management of symptoms</li> </ul>
	<p><b>Access</b></p> <ul style="list-style-type: none"> <li>• Remote access to appointments/clinic</li> <li>• Information to patients while on waitlist</li> <li>• Shorter wait-list</li> <li>• Caregiver/family involvement</li> <li>• Continued support to patients after discharge</li> </ul>
	<p><b>Medical community engagement &amp; education</b></p> <ul style="list-style-type: none"> <li>• Formal and informal education and training</li> <li>• Improve communication between primary health care providers and CCDP</li> <li>• Work with educational institutions and professional organizations</li> </ul>
	<p><b>Validation of the illness and addressing stigma</b></p> <ul style="list-style-type: none"> <li>• Self-validation</li> <li>• Family/friends/caregiver education</li> <li>• Rebranding – CSS or Chronic Fatigue does not reflect the illness</li> </ul>
	<p><b>Resources</b></p> <ul style="list-style-type: none"> <li>• Online and print resources (e.g., videos and brochures)             <ul style="list-style-type: none"> <li>○ Science of illness, range/severity, tests, treatments, research, journey map, etc.</li> <li>○ Simple language, scientific and relatable</li> </ul> </li> <li>• Help lines for patients and providers</li> <li>• Patient advocates</li> <li>• Support with disability paperwork</li> <li>• Affordable/subsidized home support</li> </ul>
	<p><b>Advocacy</b></p> <ul style="list-style-type: none"> <li>• Be the patient voice</li> <li>• Increase public awareness</li> <li>• Build a community</li> <li>• Seek patient and community involvement</li> <li>• Advocate for more funding, research and improved treatment options</li> </ul>

## Goals

Following the World Café, the CCDP commits to focusing on the following goals over the next 6-12 months to improve care in the program in the short term. The CCDP also commits to continuing to incorporate the priorities identified through this process in setting longer-term goals.

	<p><b>Access</b></p> <ul style="list-style-type: none"> <li>• Work with the Provincial Health Authority to identify and advocate for opportunities for remote access to appointments/clinic through video-conferencing to patient's homes</li> <li>• Further develop website to improve information that patients on the waitlist have access to based on needs identified through this process</li> <li>• Develop family/caregiver support groups, starting with surveying family members and caregivers to determine best method for this</li> <li>• Expand access of 'Family and Friends' Education Session to offer online access for those who cannot attend in person</li> <li>• Work with team to develop strategies and actions to reduce wait-times for patients in the program to access various specialists and disciplines</li> <li>• Implement electronic version of Patient Experience Feedback cards to ensure that patients have ability to provide feedback on their experience in the program</li> <li>• Implement youth support group for patients 18-30 years of age</li> </ul>
	<p><b>Medical community engagement &amp; education</b></p> <ul style="list-style-type: none"> <li>• Continue to increase the number of medical students and residents completing rotations in the program</li> <li>• Better promote ability for PCPs to access consultative services of the clinicians in the program, including better promotion of resources available on the CCDP website to support community providers</li> <li>• Continue to expand capacity building activities conducted by the program in the medical community (educational sessions, continuing medical education activities etc.)</li> </ul>
	<p><b>Resources</b></p> <ul style="list-style-type: none"> <li>• Review online and print resources (e.g., videos and brochures) to further develop resources available based on priority topics identified through this event</li> <li>• Further develop suite of educational videos available to the public (including PCP)</li> <li>• Implement blog-like tool on website that will be updated on a quarterly basis with various topics, research, treatments and tools</li> <li>• Implement patient library for patients in the program to have access to resources on various topics that have been identified as priorities</li> </ul>
	<p><b>Advocacy</b></p> <ul style="list-style-type: none"> <li>• Work with Community Advisory Committee to identify opportunities and priorities for advocacy.</li> </ul>