SAVE BC Public Forum

Contents

Report on Patient and Community Engagement Input

A. Purpose of this Report

This report provides readers a summary of stakeholder input that was received during an in-person engagement on 22 May 2018.

B. Background and Purpose of Engagement

Study to Avoid cardioVascular Events in British Columbia (SAVE BC) is a program designed to help patients, families and healthcare professionals better identify, treat and prevent premature atherosclerotic cardiovascular disease. The research program also includes a communications and engagement component to raise awareness about genetic screening, prevention, lifestyle changes and other aspects of cardiovascular health.

The evening event on 22 May was hosted at UBC Health Sciences Centre and brought together about 70 patients and their family members to:

1. Increase public awareness and education re: cardiovascular health
2. Share the findings of the SAVE BC research project (what was heard in interviews and focus groups)
3. Receive input on the validity of the findings – i.e. validate or revise/refine
4. Expand on the findings, and identify any additional participant priorities
5. Receive input on strategies for enhanced participation in screening and genetic testing for risk factors
6. Receive input on strategies for self management (i.e. behaviour changes) – and prevention

Event participants were, for the most part, patients and their family members who have participated in the SAVE BC study and program.

C. Approach to Engagement

Planning for the event was led by the SAVE BC team of healthcare professionals, genetic counsellors and research coordinators. The organizing team also worked with the SAVE BC Patient Partner Committee to generate ideas about the format and content of the event.

In the plenary session, doctors and researchers (Dr. Simon Pimstone, Dr. Liam Brunham, Dr. John Mancini and Dr. Tara Sedlack) each made 10-15 minute presentations on aspects of the work they are undertaking and their findings. Presenters then formed into a panel to respond to questions from the audience.

After a short refreshment break, participants were invited to attend two of six different breakout sessions. Each of the sessions was facilitated using one, two or three discussion questions. The discussion questions were developed based on the findings from the SAVE BC research conducted earlier in 2018, which included one-on-one interviews with patients and family members, as well as an online questionnaire.

Sessions included:

Session Topics	Discussion Questions
Education	1. Where do you go to get information about heart disease? 2. What would an effective education program on cardiovascular health look like for you?
Social Supports	1. What are some social supports that you rely on, in relation to your experience with cardiovascular disease? 2. How does having access to your social support system affect your stress and mental health? 3. How do you think accessing social supports might affect your physical health?
Lifestyle Changes	1. What are some things that might help you make changes to your lifestyle? 2. What factors are necessary for lasting lifestyle changes?
Cardiovascular Research	What topics related to heart disease in adults under age 55 do you think are most important for researchers to focus on?
Mental Health	1. How has your emotional well-being changed after you or a loved one was diagnosed with heart disease? 2. What have you done to try to cope? 3. What resources have you accessed to cope with this?
Open Discussion	As a patient/family member interested in cardiovascular health, I think researchers and clinicians should consider…

D. Cross-Topic Summary

This summary is a qualitative analysis across all discussion topics, undertaken by one of the facilitators, to identify themes that were mentioned or referenced in three or more of the discussion groups:

1. Most participants believe there is a significant lack of awareness, even among general practitioners, about the use of genetic testing as a diagnostic tool for heart disease risks. Across several discussion groups, participants indicated more should be done to raise awareness of genetic risk factors and the role of genetic testing in advanced diagnosis.

2. There is a plethora of heart disease information available through internet sources, to the extent that it can be overwhelming. Patients and their families are seeking dependable,

practical, readily-applicable, evidence-based information. This is generally seen as coming from a credible health service provider.

3. Effective supports for people living with heart disease comes mostly from friends and family.

4. Emotional wellness for those living with heart disease is important to support motivation to undertake the lifestyle and other changes necessary to effectively manage the condition.

E. Intra-Topic Themes

Across the discussion questions, within each of the discussion groups, several themes appear to be prominent:

Education

a. Healthcare providers should be more aware of DNA testing as a diagnostic tool
b. Awareness campaigns should target the young (i.e. find out if heart disease runs in the family), and health-conscious groups (running, hockey, etc.) to raise awareness that even healthy people are at risk, so get tested for genetic makers
c. Motivation to act usually comes from a personal experience or interaction

Social Supports

a. Compassionate support from health service providers, friends and family is seen as a principal source of comfort and motivation to manage the condition
b. Emotional wellness is seen as an important ingredient to ability to make changes to effectively manage the condition

Lifestyle Changes

a. Support from friends and family is a necessary ingredient
b. Create tangible motivations (positive or negative) for changes such as smoking cessation, weight loss and higher levels of physical fitness
c. Work with a trusted and credible coach (clinician, service provider, friend or family member) to achieve realistic targets or goals to achieve over time

Cardiovascular Research

SAVE BC should work to:

a. Determine what other factors contribute to heart disease for those with a genetic disposition
b. Understand how to reverse the effects of heart disease, such as plaque reduction

c. Understand how female life events (pregnancy, stress, etc.) effect women with a genetic marker
d. Determine the role exercise plays in proactively managing the condition for those with the marker
e. See direct input from this section (below) for specific recommendations

Mental Health

a. Simply knowing you are genetically at risk causes a ripple effect of stress in one's life; self, family, friends, etc. A recommended, evidence-based approach to stress / anxiety management should be developed
b. Having workable strategies to change behaviours generally would be helpful so that patients and their families could broadly socialize the change process within a patient's sphere of influence
c. Being able to attend structured discussions, led by healthcare professionals, with others who have received a similar diagnosis would help to manage stress and support the necessary lifestyle changes

Open Session

a. SAVE BC and the heart / vascular research community generally should be "lobbying" / promoting the healthcare system to make genetic testing for heart disease more known and available

F. Next Steps

1. Share public forum presentation slides and videos
2. Create social media accounts for SAVE BC to better engage our participants, partners, and the general public
3. Integrate findings from participant interviews, online questionnaire, and public forum into research publication
4. Improve mental health support by ensuring that our physicians are asking patients about it
5. Compile and maintain a list of resources (mental health, mentoring, diet + lifestyle) that can be supplied to patients and family members
6. Explore opportunities to plan public forums and other forms of public engagement in the future
7. Expand SAVE BC to all cardiac catheterization labs in BC by 2020

Appendix A: Transcribed Input

Below are listed the discussion questions and transcribed notes captured by facilitators during the breakout sessions.

Please note: text in parentheses and italics was not recorded during the session, but added by the discussion facilitators afterwards to provide additional context / clarification based on the participant discussion.

EDUCATION

Where do you go to get information about heart disease?

- Internet *(How do we know if it is good sources?*
        - *Linked to credible sources (i.e. Mayo Clinic)*
        - *Recommendations of friends and family with lived experience)*
- Healthy heart program -> education, exercise
- How do we know if it is good sources? → linked to credible websites, family, friends
- Family, friends
- Other people who have experienced it
    - Lived experiences *(Again, must be careful about the source, but this provides comfort for participants knowing that people have survived after facing similar experiences)*
        - Knowing the symptoms
        - Experiences in the hospital
        - Speaking face-to-face
- Doctor
    - Education at the visit
    - Adequate preparation *(Poor experiences have happened due to a lack of preparation on the physician's part)*

*What would an **effective** education program on cardiovascular health look like for you?*

- 15 min medical interviews are not enough
- Approach the whole person *(Allow patients to make the decision for themselves. Give them knowledge so that they WANT to make the best decision)*
- Personalize education
- PERSONAL INTEREST *(Only way to get people to buy into education and use it in their lives)* -> How can we cultivate this? (short of having a heart attack)
    - TV shows *(The Widowmaker)*
    - Why do we think this will never happen to us? *(General lack of campaigning and awareness from the public. Compare to breast cancer, where mammograms are*

established and widespread guidelines while heart disease, a greater killer, is not well known publicly)

  - Making people aware of mortality + stats ☆
  - Having personal experience -> share with others
  - Heart problems can be managed
  - Screening for heart disease *(While potentially fatal, the public should know that heart problems can be managed)*
  - Regenerative medicine
- Targeting young people *(through social media, targeting the older generation how?)*

SOCIAL SUPPORTS

What are some social supports that you rely on, in relation to your experience with cardiovascular disease?

- Friends and social circle
  - May not understand the situation/circumstances
- Family
- Healthcare program (relied on referrals)
  - Less support 7 yrs ago for females ("syndrome x")
  - Eventually more focus on microvascular disease
- Companionship *(Clarification: meeting someone who is facing similar diagnosis and similar health issues)*
  - Matter of luck finding someone in similar situations
- Lack of formal support groups (compared to cancer for example)
  - There is support for SCAD
- Need nurse practitioners (visit homes, chat)
- Cardiologists may not be as conversational

How does having access to your social support system affect your stress and mental health?

- Badly needed to improve mental health
- Initially hard to reach out, takes time *(Initially after the diagnosis of cardiovascular disease)*
- Society promotes isolation (e.g. seniors)
- Depends on personality
- "Being open" leads to reciprocation from friends
- Social circles can cause "distractions"
  - Distractions are welcomed (take your mind off of the problem)

How do you think accessing social supports might affect your physical health?

- Emotions have impact on physical health

- Social support keeps us active
    - Get out of the house
- Healthy heart program provides valuable education (physical activities)

LIFESTYLE CHANGES

What are some things that might help you make changes to your lifestyle?

- Getting the diagnosis/adverse event
- Education on risk factors -> fear
    - Once you know you're at risk you will be motivated to make a change
    - Informal ways to communicate risks/experiences w/ cardiovascular disease *(This participant was trying to express that informal conversation about peoples' lived experiences with a disease will make others reconsider the lifestyle choices they are making. This can happen at amongst coworkers at work, teammates on a sports team, etc.)*
        - Especially the negative side → might not work for everyone *(Participants were divided on whether or not fear of the disease was a motivating factor.)*
- Support of family/friends
    - Connecting with others with the same condition
    - Attending structured programs
        - Healthy hearts program
        - Cardiac rehab program (VGH + St. Paul's)
        - Community centers
- **Governments supports** to be healthy ($$$) → penalizing people who are not living healthy? *(Some participants thought that rather than providing financial incentives for exercise programs and healthy dieting, that people might be more motivated if they were penalized for not doing this.)*
    - Subsidies or tax deductions for healthy dieting +exercise
    - **Monetary incentives** to join weight loss program
- Good informational resources that are reliable and can inform you on dietary changes, starting an exercise program, etc. *(e.g. a reliable website that doctors can send patients to)*
- 1-on-1 counselling *(More readily available counselling with dieticians, physiotherapists, trainers, doctors, etc.)*
    - Being able to see a doctor for more than 5 mins once a year to get an overall annual check-up
- Time!
- **Rewards** that come from lifestyle changes *(Communicating the non-so-obvious benefits of some of these lifestyle interventions may motivate some to change.)*
    - Quitting smoking
        - Feel better
        - Smell better

        - “Cloud over my head is gone
    - Vegetarian food
        - More interested in prepping food
        - Food tastes good
    - Wt loss/exercise
        - Easier to breath, get around and live a normal life
        - Knees stopped clicking

*What factors are necessary for **lasting** lifestyle changes?*

- Having a routine
- Resources
- **Support system**
- Seeing positive results
    - Tracking BP, weight, exercise progress
- **Goal** setting
- Having follow-up
    - Healthcare provider –> follow up appointments and testing
    - Family member
- **Shift in attitude**
    - Maintaining **motivation**
    - Everyone has their own reasons for making a change (e.g. risk of an event re-occurring). Need to find a reason that’s important for them
      (Some participants expressed that the desire to change was very much intrinsic, and people needed to figure out for themselves why it was important to make a lifestyle change.)
- Managing **set-backs**
- Patient advocating for themselves *(If they need help finding resources for lifestyle changes and maintaining those changes)*
    - **Having someone** to go to appointments with them *(If they can’t advocate for themselves)*

CARDIOVASCULAR RESEARCH

What topics related to heart disease in adults under age 55 do you think are most important for researchers to focus on?

- Genetics -> genetic markers for CVD
- Age that cholesterol begins increasing
- Lifestyle changes on reducing plaques
- Does health improve with lifestyle changes – specifically related to plaque
- Alternatives to medications (i.e. statins)
- Other alternatives to angiograms – screening version of what an angiogram offers

- What advice is important for family members/caregivers – how do they support in a positive way
- With genetics – how far back (generations) is useful
- Research around <u>accurate</u> testing – developing test closer to a gold standard *(The discussion on this point was also around finding less invasive gold standards; e.g. A less invasive form of a coronary angiogram.)*
- Utilizing big data methods to help answer question above
- When treatment conflicts with dietary preferences – what are the alternatives
- Different diet/treatment plans based on type of atherosclerosis
- Lowering rate of inflammation – also related to high cholesterol
- Develop medication that lowers Lp(a)
- ☆ More research on pregnancy and CVD event (e.g. pre-eclampsia)
- ☆ PCSK9 inhibitors – will it (decreasing Lp(a)) decrease mortality?
- ☆ Mental health connection with women and heart disease (what is it about depression that is connected to CVD)
  (Star symbol indicates the points that were selected by the second discussion group that they wanted presented during the 1-minute summary)
- What is the link between CABG and mental illness
- How much exercise makes a difference?
- Relationship between stress and exercise management – reducing secondary MIs
- What <u>kind</u> of exercise makes a difference

MENTAL HEALTH

How has your emotional well-being changed after you or a loved one was diagnosed with heart disease?

- Increased worry, heightened awareness of symptoms
- Stressful when waiting
- Loss of control
- Anxiety about "what-ifs" and path forward
- Worry about impact on rest of family
- "Bypass brain" (unsure of impacts)
  - Difficulty finding words
  - Worry about mental impacts of anaesthetics
- Coming to terms with changes in capabilities
- Impact on pre-existing conditions (e.g. depression)
- Emotional impact of heart surgery (both short and long term)
- Huge changes in relationships and roles
- Stress on family and caregivers (often ignored)
- Change in priorities
- Lifestyle changes in whole family (affecting diet, for example)

- Increased thoughtfulness regarding purpose, role in life
- Coming to grips with surgical scars – feeling forever changed

What have you done to try to cope?

- Meditation apps, yoga (things that can be slipped in) *(Slipped in to daily life – relatively un-obtrusive things)*
- Doing activities together
- Limiting Internet
- Learning (proper education – not only Google) to get sense of control -> be alert but not alarmed
- Being prepared for possibilities
- Keeping things to self
- Sharing with others *("Sharing" was given in response to "keeping things" – the overall discussion afterwards was that it depends on the person; all needs are different)*
- Change in lifestyle (diet and exercise) and was more aware of processed food
- Reduce stress *(Through other mentioned methods here)*
- Daily awareness to get used to new physical differences

What resources have you accessed to cope with this?

- Found a lack of resources (follow-ups, info)
- Internet resources
- Friends/social support – other heart patients
- Surgery rehab program (peers, professionals) for some *(As in "was helpful for some"; others did not find it helpful)*
- Group therapy
- VGH Healthy Heart Program
- SPH Healthy Heart Program
- Red wine
- Had to ask about resources + programs
- Family doctor
- Diamond Centre yoga classes, meditation classes
- Experienced confusion about resources (including lack of knowledge about what resources are trustworthy)

OPEN DISCUSSION

As a patient/family member interested in cardiovascular health, I think researchers and clinicians should consider …

- How can the medical community build bridges with the food industry + media to raise awareness about risks?
- **What can the medical community learn from the NRA (in the US) to leverage improvements (e.g. reduce salt in prepared foods) from the food industry – influence on public policy**
- Need to raise aware about testing available (i.e. 64 slice CAT scan)
- **Look for social groups (running, hockey) to spread the word**
- How to make tests that are standard in the US available here?
- Public education about risk factors, testing
- Make consumers educated consumers to ask the “right” questions
- Awareness + education @ GP level
- Star power to speak up and out – thru a public awareness campaign
- **SAVE BC to run the numbers on cost savings of hospital stays vs testing – use to [sic]**
- Benchmark how other body part NGOs have lobbied for better testing and adopt best practise
- Research treatments the [sic] target specific risk factors

Appendix B: Analysis of Participant Evaluations

Participants were asked to complete an evaluation at the end of the event. 28 of 70 participants completed the evaluation, representing a completion rate of 40%. The evaluation scoring invited participants to respond using the following response set:

- Strongly Agree
- Agree
- Neutral
- Disagree
- Strongly Disagree

The framework allowed participants to gauge each of their responses on a sliding scale from “Strongly Agree” to “Strongly Disagree”. For the purposes of analysis, this provides organizers the ability to assess if the content and process of the event was successful or not. This assessment is made by determining the percentage of participants that “Disagreed” or Strongly Disagreed” with the evaluation criteria. The logic for this simple assessment is there are always people in a group who would never assess anything as “Strongly Agree” or “perfect”, so they can still “Agree” although things, in their view, were not perfect.

On the other side of the Likert scale, participants can “Disagree” without “Strongly Disagreeing”, which would indicate they found the event useless from a content or process perspective. The middle point on the scale (Neutral) is for people who neither agree nor disagree. For these participants, the content might not have been what they expected or hoped for, or the process didn’t work for them, but they could see that others were engaged.

To assess the success of the event, we look only to one side or the other of the scale. People either agreed or disagreed and can explain their rationale. In this case we can say the event was quite successful, because nobody disagreed with any of the evaluation questions for the plenary presentations and discussion panel.

From the evaluation results, we can say everyone who completed the survey agreed (or were neutral) that the individual and panel discussions:

a. were effective,
b. questions were answered completely, and
c. there were opportunities to share experiences.

It should be noted that “Strongly Agree” was the most popular response across all three physician presentations.

In terms of the small group discussions, Lifestyle Changes, Mental Health, Education, and Cardiovascular Research were the most popular. All participants agreed (or were neutral) these discussions were effective in terms facilitating participation to share their stories in response to the discussion questions. Again, the most popular response was "Strongly Agree". Two of the five people who attended the Open Discussion disagreed this session met those objectives.

Participants were also asked to provide their feedback about the event in an open text field. From a process perspective, the most common comment related to the length of presentations and discussion forums. Those who commented would like to have spent more time in plenary presentations, panel discussions (following the presentations) and in small group discussions. Some people said, and others indicated, they were eager to have their questions answered and were more interested in hearing how research findings can be applied at the level of the patient, rather than presented as general findings. Again, many commented they appreciated the information and opportunity to connect with others and get answers to some of their questions from experts in the field.