# Access to Care: Everyday Challenges for Women With Heart Disease

#### **EDUCATION MODULE**



## Access to Care: Everyday Challenges for Women With Heart Disease



#### TO VIEW THE ACCESS TO CARE VIDEO

Download the video from your flash drive.

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## **Agenda**

## **Access to Care: Everyday Challenges for Women With Heart Disease**

#### 1. Introduction and overview: 5 minutes

- ♥ Welcome all participants to the session.
- ▼ Introduce yourself and tell a brief version of your story—your experience with heart disease, your experience with WomenHeart, or a fun fact about yourself, such as the latest recipe you've tried or your favorite color. Include a different fact at each meeting.
- ♥ Invite participants to introduce themselves. Depending on the group, you may want to use a quick icebreaker. See the Quick Tip for suggestions.
- ♥ If you have first-time participants, introduce them to WomenHeart, your meeting schedule, etc.
- ♥ Share the meeting format—video, presentation, Q&A, and any regular meeting business.
- ▼ Introduce today's presentation topic: Access to Care: Everyday Challenges for Women With Heart Disease.

#### 2. Show the video: 5 minutes

- ♥ You'll find it on your flash drive.
- 3. Objective 1: 15 minutes
- 4. Objective 2: 15 minutes
- 5. Ask participants to share questions or concerns. Discuss. 15 minutes
- 6. Thank everyone for coming. Share the time and place for future meetings.

#### QUICKTIP

Try this quick **icebreaker**, which works for groups that are well acquainted or groups with new members. As participants introduce themselves, ask them to include a descriptive term that starts with the same sound as their first name. For example, "Hi, I'm *Isabelle* and I'm *interested* to learn about this topic" or "Hi, I'm *Sarah* and I'm feeling *strong* today."

## **Access to Care: Everyday Challenges for Women With Heart Disease**

#### **Purpose**

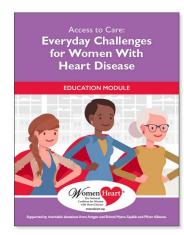
This session provides research-based information showcasing the challenges that women with heart disease encounter as they pursue the treatment recommended by their doctors.

#### **Estimated time**

60 minutes. Group size and type affects this, so complete the module at your own pace.

#### **Before the meeting**

- ♥ Review the information, including the education module, video, handouts, and infographic.
- ♥ Print or photocopy the handouts for attendees. These are in this booklet and on the flash drive for Access to Care.
- Test any technology you'll be using. Play the video on your flash drive and test your laptop or projector.
- ♥ Provide paper and pens so attendees can write questions and comments.



#### Here's what in this kit:

- Meeting agenda
- Talking points for each objective
- ▼ Two handouts to copy for participants (page 14 and page 15)

Display the paper version or project the infographic onto a whiteboard or wall using a projector linked to your laptop or directly from the flash drive.

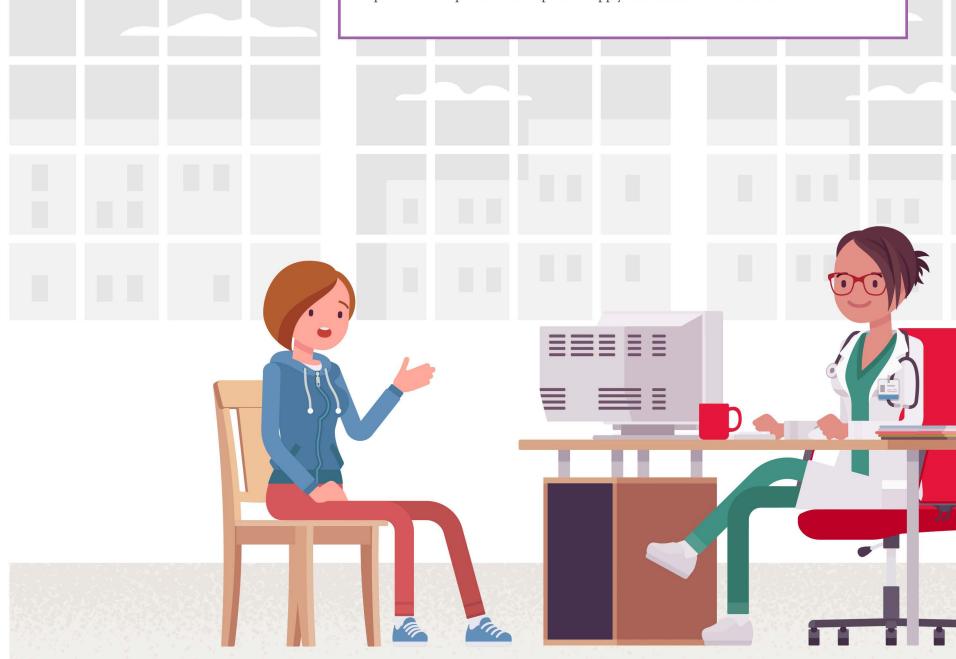




All printed resources and the video are on the flash drive.

#### QUICKTIP

Adult learners are eager to **apply information to their own situations**. Encourage meeting attendees to make notes about how they plan to use the information being presented. Writing notes on paper will work for some, while others will want to put notes right in the calendar or notes app on their phones or tablets. Let them know it's not rude to pull out their phones if it helps them apply information to their lives.



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## **Education Module**

#### **Video Presentation: Access Now!**

Time: approximately 60 minutes The video is on your flash drive.

#### 1. Introduce the video.

This video features new information showing the challenges women with heart disease encounter and the choices they sometimes have to make as they seek care.

#### 2. Watch the video.

Invite attendees to jot down notes or questions that come to mind.

#### 3. Discuss the video.

Find out more about what attendees saw, how they perceived the information, and what questions or relevant experiences came to mind.

## 4. Make a list of What We Saw and What We Learned.

Ask individual attendees to make a two-column grid with the headings Saw and Learned at the top and make notes in each column. Or if you prefer, draw the grid on a whiteboard and have the group work together to make a list.

Saw	Learned

#### QUICKTIP

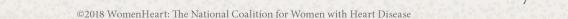
Give attendees a quick **verbal preview** of what they'll be seeing on the video. Ask them to think about what they know about the topic and their own experiences related to it. This is referred to as "activating prior knowledge," which helps attendees make connections between the video and their own experience.

#### QUICKTIP

Want to encourage more discussion? Ask attendees questions like these:

- ♥ How would you summarize the video for a friend?
- ♥ What one piece of information surprised you most?
- ♥ If you gave the video a title, what would it be?

THERE HAVE BEEN
SEVERAL TIMES
I COULDN'T
AFFORD MEDICATIONS.



### **Objective 1:**

**Explore and discuss WomenHeart's latest research** on the connection between women having insurance and getting the care they need.

#### 1. Share the background on the research.

The research has two parts:

- ♥ an online survey sent to members of the WomenHeart community and partner organizations.
- ♥ three focus groups to get feedback specifically from members of the WomenHeart community.

Explain that the groups don't reflect the overall population of the United States or the overall population of people with cardiovascular disease.

#### 2. Share one of the survey's main findings: Having insurance doesn't necessarily mean women get the care they need.

Ask for a quick show of hands: How many participants have encountered challenges in getting the medicine, treatment, or device that their doctors recommended?

Record how many participants raise their hands. If you have a whiteboard or paper available, write the results so everyone can easily see them.

Display Infographic #1 and pass out the handout. Discuss these points from the research:

♥ Of the participants who answered this question on the survey, 25% said that there is a specific medicine, treatment, or device that they have had trouble obtaining.

Looking more closely, the survey showed that, within that group, women had these challenges:

- ♥ 49% had trouble obtaining the medication their doctor prescribed.
- ♥ 26% had trouble obtaining care at a cardiac rehab facility.
- ♥ 7% had trouble obtaining medical supplies.
- ♥ 6% had trouble obtaining some other medicine, treatment, or device.

Women mentioned various other challenges, including getting INR home-testing machines to test clotting times, getting prompt medical appointments, getting access to specialists who didn't have offices in the area, getting follow-up care, and other issues.

Compare the research results with your informal survey of the group. Are the results similar? Different? Discuss why that might be.







#### 3. Getting the name-brand drugs that their doctors prescribed presents the most common challenge for the women who participated in the survey.

Women in the focus groups shared that the common insurance company practice of favoring generic drugs isn't always appropriate for cardiovascular disease patients. Read to your participants these statements from women in the focus groups:

- ♥ "I didn't take drugs I needed because they were too expensive; \$300 for one medication alone, and I couldn't get government assistance, so I waited until I desperately needed help. I can't take generics because they change what is in them and I am sensitive to the changes."
- The doctor doesn't want to put me on generics. The name brands are working. Why take the risk to change it?"
- ♥ "I didn't take [a brand name drug] for a long time because it was too expensive. Now it is generic."

Ask participants if they can relate to these statements. Reread the statements one by one and invite attendees to share their experiences.

#### **OUICKTIP**

If you don't know the answer to a question, put it in the "parking lot," meaning you'll make a list of questions to find answers to later. If you have participants' email addresses you can send answers after the meeting. If not, revisit the information at the next session.

## **Objective 2:**

Discuss the difficult and dangerous decisions women sometimes have to make when they encounter challenges in getting access to care.

#### 1. The need for heart care can cause a serious financial strain even for women with insurance.

Many people might assume that women without insurance could find themselves in the position of deciding to delay or skip care but that those with insurance get the care they need. However, the survey showed that women with insurance are concerned about out-of-pocket costs and may delay or skip care for that reason.

- ▼ The survey showed that 26% of women responding to the survey have skipped or delayed part of their treatment to reduce out-of-pocket costs.
- ♥ Revisit the information on the infographic that showed 25% of women responding to the written survey said that there was a specific medicine, treatment, or device that they had trouble obtaining. Within that group 75% went on to say that cost was a factor in skipping or delaying treatment.

See how those results compare to your group participants. Ask attendees to raise their hands if they have skipped or delayed treatment because of concerns about out-of-pocket costs (stress that this is optional, as some attendees may not be comfortable sharing this information). Record how many participants raise their hands and determine if the percentage is higher or lower than the research results.

Share with participants that one focus group attendee, a psychotherapist, commented that she has "more and more CVD [Cardiovascular Disease] patients coming in with anxiety and depression over access to CVD care."

#### 2. Women with certain types of insurance report more delays in accessing care—or skipping care altogether.

Display Infographic #2 and pass out the second handout. Discuss these points from the research:

Income seems to play a role in determining whether women delay or skip care.

- ♥ Within the focus groups, women whose income was below \$50,000 had a strong relationship with skipping or delaying treatment to reduce out of pocket expenses, with 34%–38% reporting that they had skipped or delayed treatment.
- ♥ However women with higher incomes were delaying and skipping treatment too:
- 24% of those making \$50,000-\$99,999.
- 17% of those making \$100,000-\$149,999.
- 21% of those making \$150,000 and up.



Besides income, the type of insurance focus group members have impacts skipping or delaying treatment to reduce out-of-pocket expenses.

- ♥ Women who were most likely to delay or skip treatment to reduce out-of-pocket expenses had Medicare (39%).
- ♥ The next most likely to delay or skip care are those with with private insurance and Medicare (31%) and those with only employer insurance (31%).
- ▼ Those with other insurances or combinations of insurance (24%) came next. Explain to attendees that "other insurance" means these insurances plus combinations of other insurances, such as Medicare, employer, or military insurances.

Women who were least likely to delay or skip treatment to reduce out-of-pocket expenses had

- Employer-provided insurance plus Medicare (13%).
- Medicare plus other insurances or combinations of insurance (13%) (see the list of what these insurances might be, above).

#### 3. Women grapple with the financial impact of cardiovascular disease.

Women in the focus groups shared examples of care that they skipped and significant expenses they had encountered. Read to your participants these statements from women in the focus groups:

♥ "I stopped doing stress tests because my costs were significantly higher than what insurance would cover. It would have been thousands of dollars out of pocket." ♥ "There have been several times I couldn't afford medications, which were \$180-\$200/month. Sometimes I try a medication for a

♥ "I owed \$100K on a \$480K bill."

♥ "My life right now is just focused on doctors and meds and what I need to do to stay healthy. The cost has impacted financials for my retirement."

few days and it makes things worse,

♥ "I sacrifice to have the supplemental insurance."

After you read these statements aloud, ask participants if they can relate to them. Invite them to share comments and stories.



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## 4. Insurance company prior authorizations and other rules present yet another challenge for women and for healthcare professionals.

- ♥ 23% of survey respondents indicated that insurance company prior authorizations caused delays or prevented them from accessing cardiac rehab, receiving implantable devices, or obtaining prescribed medications.
- ♥ Patients and emergency personnel don't always know what an insurance company will consider as an emergency. Read to your participants these statements from women in the focus groups:
- "I went code blue, and the (private) health care insurance turned the ambulance away; 911 called the fire department and it took 2 rounds of nitro to get my heart to where they could safely transport me."
- "My first incident was when I collapsed at work; they thought I was having a heart attack, and I was airlifted to a hospital. The local hospital has no cardiologist. My insurance company investigated the case and said it was not necessary to have been airlifted. I had to pay an \$11K bill."



#### Wrapping up

♥ Work with the group to come up with one point related to the materials presented that starts with each letter in "HEART." If you have access to a whiteboard, write the letters in HEART down the left side of the board and then write the words participants suggest by each letter. For example:

- Happy to learn that...
- Eager to know more about...
- Already knew that...
- Ready to make a change in...
- Timely to find out that....

#### **QUICKTIP**

Some of the best sources of information, tips, and strategies for women come from other women. That's the kind of **support** WomenHeart is here to provide. As your meeting wraps up **encourage women to share** what has worked for them, and foster the **after-the-meeting conversations** when women exchange information and support. Your WomenHeart community will be all the stronger!



## Getting What the Doctor Ordered



25%

of women struggled to get the medicine, treatment, or device that their doctor prescribed

#### What types of care did they have trouble getting?



prescription

medication

care at a cardiac rehab

facility



medical supplies



other medicine, treatment, or device

All data based on participants who answered this question on the written survey. Supported by a grant by Amgen and by a charitable donation from Bristol Myers-Squibb and Pfizer Alliance.

Our next meeting is:

## Difficult & Dangerous Decisions

insurance skipped or delayed their treatment to reduce

out-of-pocket costs

What insurance do they have?



Medicare



private insurance and Medicare



employerprovided insurance



insurance or combinations of insurance



employerprovided insurance plus Medicare



Medicare plus other insurances or combinations of insurance

**Note:** "Other insurance" means these insurances plus combinations of other insurances, such as Medicare, employer, or military insurances.

#### Is delaying or skipping affected by income?



34%-38%

income below \$50,000

> \$150.000 and up

24% \$50,000-\$99,999

**17%** \$100,000-\$149,999

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