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Co-Creating a Responsive, Sustainable, and Equitable Community Health Model for Older Adults with Chronic Diseases

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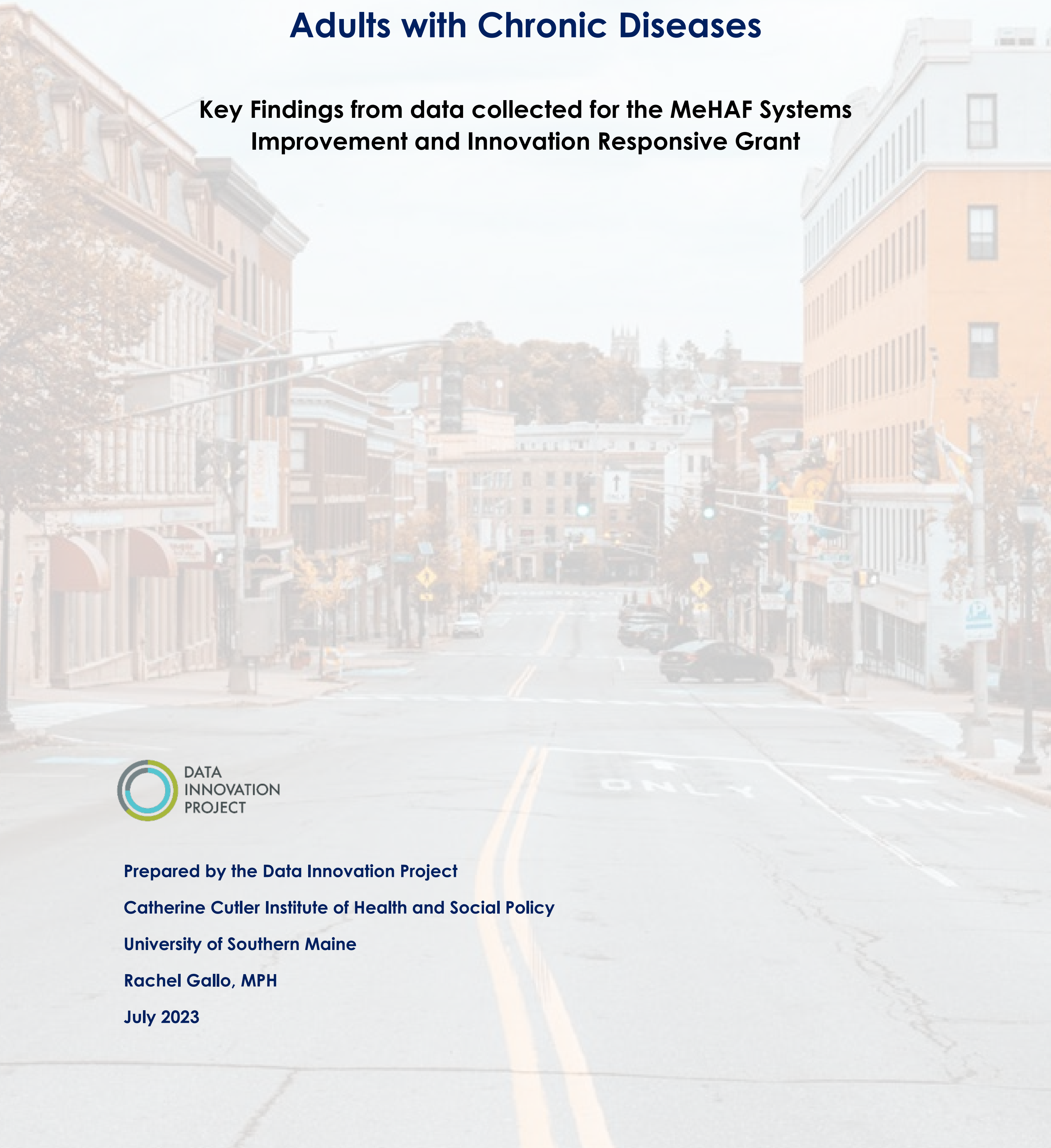
Co-Creating a Responsive, Sustainable, and Equitable Community Health Model for Older Adults with Chronic Diseases

Key Findings from data collected for the MeHAF Systems Improvement and Innovation Responsive Grant



DATA
INNOVATION
PROJECT

Prepared by the Data Innovation Project

Catherine Cutler Institute of Health and Social Policy

University of Southern Maine

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Acknowledgments

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Introduction

In 2022, the Bangor YMCA received a grant from the Maine Health Access Foundation's (MeHAF) Systems Improvement and Innovation Responsive Grants Program for their "Co-Create Responsive, Sustainable, and Equitable Community Health Models for Older Adults with Chronic Diseases" project. The University of Southern Maine's Data Innovation Project (DIP) at the Catherine Cutler Institute of Health and Social Policy was brought on as a contractor to support data collection and analysis for this project.

Purpose

As stated in the project's proposal to MeHAF, the aim of this project was to "engage older adults with chronic disease conditions and their care partners to collectively identify new ways to connect people to community resources and to co-create community-based continuum of care systems to support the physical, emotional, and mental well-being of people in [their] communities of focus". To work towards creating a community-based continuum of care, leaders in the community need to have a better understanding of the current system and where there are opportunities for improvement.

The project had five research questions, as shown in Figure 1. The research questions were utilized to frame the design of the survey, focus group, and interview protocols described in the next section. This report focuses on the results of the focus group and interviews; however, some survey results are integrated into this report to support the findings from the qualitative data collection. A summary of the survey is provided in the Appendix.

1. How are individuals with chronic disease connected or not connected to community health resources?
2. How can a trusting continuum of care be created?
    a. Where are there gaps in the continuum of care (i.e., Where does it break down?)
3. What are the current gaps in palliative care?
4. What incentivizes people to commit to managing their chronic diseases through community programs like YMCA evidence-based classes?
5. How has the pandemic impacted the care experience?

Figure 1. Project Research Questions

Methods

The DIP and YMCA collected data through a survey, a focus group with community members who had at least one chronic condition, and interviews with YMCA partners. It should be noted that the original planned methodology was to collect data from YMCA partners through a focus group, but due to the inability of finding a time that most partners could meet, the focus group became a series of interviews. Additionally, the original goal was to collect survey responses from 70 community members, however only 52 community members filled out the survey despite numerous distribution methods. A copy of the survey and the data collection protocols are provided in the Appendix of this report.

Evidence Based Programs Survey

In the fall of 2022, a Data Innovation Project researcher and a YMCA staff member co-designed a survey to gather information from community members who either had a chronic condition or were a care partner to someone with a chronic condition. After the survey was developed, the DIP collected feedback from YMCA partners regarding the survey's design and content. The survey was electronically deployed using Qualtrics software and a paper version was also available at the YMCA. The survey was distributed via emails, listservs, and handed out after some YMCA programming between the dates of October 14, 2022 and January 9, 2023. Respondents were eligible to receive a gift card as a thank you for their participation.

The survey received 52 responses, of which 43 respondents had at least one chronic disease and 8 respondents identified themselves as a care partner. In February 2023, a summary of the survey results was created and shared with the YMCA and their community partners.

Community Member Focus Group

A community member focus group with 8 participants was held at the YMCA on March 31, 2023 and was facilitated by a YMCA staff member. A DIP researcher participated virtually and took notes during the 1-hour session. The focus group was recorded and transcribed for analysis.

YMCA Partner Interviews

In May 2023, YMCA partner interviews were conducted by the DIP researcher, a YMCA staff person, and a former YMCA staff person who volunteered their time to complete interviews. A total of five interviews were completed with two medical providers and three community organizations. The interviews, 15-30 minutes in length, were recorded and transcribed so that the DIP researcher could summarize and compile the findings of the interviews.

Key Findings

All the data collection for this project was framed around the chronic disease continuum of care. Focus group and interview participants were all informed about the definition of the continuum during data collection activities. As shown in Figure 2, the chronic disease continuum of care has three defined parts:

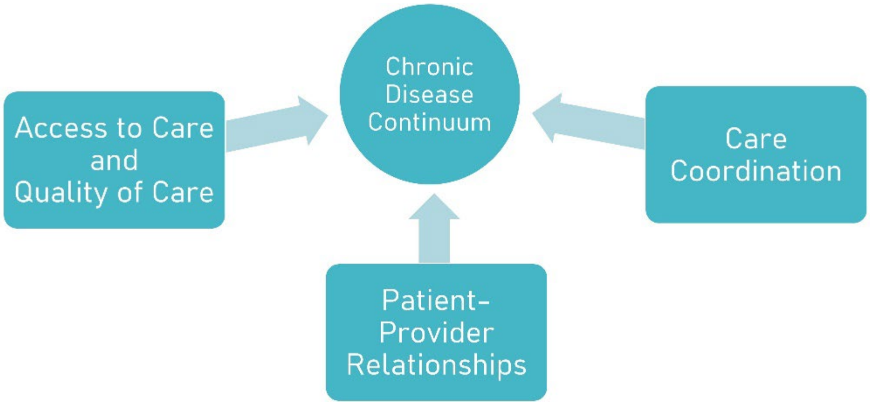

Figure 2. Chronic Disease Continuum of Care

1. Access to care and quality of care over time (from diagnosis to management of disease)

2. Patient-Provider relationships

3. Coordinated care between medical providers and community health resources

Access and Quality of Care

Accessing Medical Care

Most focus group participants (i.e., community members) discussed their difficulties in getting the medical care they need. Participants discussed traveling long distances to care, meeting others during appointments who had driven long distances, or regularly leaving early in the morning to get to an appointment which resulted in having to wait long periods of time before the treatment or appointment started.

Community Member and Provider Perspectives:

Barriers to Accessing Medical Care

- Long travel distances and transportation challenges
- Difficulty in finding trustworthy doctors
- Provider Shortages; Long wait lists for PCPs and specialists
- Insufficiently staffed doctors' offices
- Financial constraints

One focus group participant discussed how, over the course of three years, they had four different oncologists. Another participant discussed having three different rheumatologists in a short period and eventually that third rheumatologist was replaced with a nurse practitioner. Respondents to the Evidence Based Programs survey indicated specific shortages of:

- nutritionists,
- geriatric medicine care specialists,
- behavioral health specialists,
- rheumatologists, and
- oncologists.

A few of the interviewed YMCA partners also noted issues with access to medical care in the Bangor area. One provider discussed how patients often cannot get the care they need and, therefore, end up seeking care from the Emergency Department or Urgent Care. This leads to patients getting "piecemeal" care because the provider at that location does not have a person's full medical record and is only looking at the presenting complaint. This ultimately affects a person's quality of care.

Quality of Medical Care

While most YMCA partners focused on the lack of access to care in their interviews, there was still discussion on the gaps related to quality of care. Specifically, partners talked about untimely care due to a lack of available appointments and a lack of integrated care due to a shortage of resources. The COVID-19 pandemic also affected quality of care. This was indicated by survey respondents in their quality of care ratings, specifically, that they rated quality of care lower during the pandemic. When discussing the concept of quality, one provider shared that it is their practice to continually prioritize discussions with patients based on what is important to the individual patient, even if it is not what is "at the top of their [own] list." The sentiment of this conversation was that this approach is not a "norm" for providers likely because most do not have the time to prioritize the things patients perceive as indicators of quality of care (i.e., spending sufficient time with the patient, minimal usage of electronic medical records during an appointment).

Patient-Provider Relationships

When community members were asked what could be done to improve their relationship with their health care providers, all responses were related to time management or technology. One community member felt that their provider was under pressure to spend less time with patients. A provider partner also discussed time management, saying "primary care time constraints are very real. And it can be extremely tough for patients needs to be met and I think it … potentially can erode the patient provider relationship, which I think is key to success in keeping people healthy and well."

One focus group participant noted that technology could be a positive aspect of their relationship with their provider because utilizing email allows their cardiologist to quickly respond to their inquiries. However, most participants discussed negative aspects of technology. For instance, they discussed issues with electronic medical records systems and providers spending too much time looking at screens. One provider partner shared, "I use the chart then as a reference, I do not type people's answers … I do not complete any notes when I'm in front of a patient. Makes me, according to the employers, much less efficient. But I just don't feel like I can… connect well with patients if I'm looking at a computer and I'm not looking at the patient."

73% of survey respondents used telehealth in the prior year, however their experiences varied

Care Coordination

Between Medical Providers

> *"Sometimes it seems that once people have left the hospital or left the doctor's office, they're kind of on their own with setting up and accessing some of those resources that might make their lives a little easier"*
>
> *– YMCA Partner*

One YMCA partner believed that the medical community does a wonderful job of getting people into appointments and diagnosing patients. However, a different YMCA partner provided the perspective that some primary care providers are either reluctant to or unable to give a specific diagnosis, like Alzheimer's or dementia, if further testing is needed. Primary care providers often need to refer to specialists with long wait times and it is possible that a provider can believe a patient is just getting forgetful. This provider explained that even though the testing for dementia and Alzheimer's can be intense, "we need to be advocates, we need to teach our families, our constituents, to be advocates for themselves and … really ask for that follow up and the ruling out of other things going on."

Between Medical Providers and the Community

Most YMCA partners who were interviewed discussed the disconnect between the medical providers and community health resources. YMCA partners discussed not knowing what all the community health resources are, how to connect to them, and not having enough time to connect patients. One partner acknowledged that patients need to be made aware of what resources exist in the community, saying "For instance, I hear all the time. Oh, I didn't know about, you know, the free education programs that the Alzheimer's Association offered. I didn't know that there was all this information on your website … I didn't know that there was an adult day program." Focus group participants also suggested the need for community information and advice, including lists of what services are available. Several partners discussed how having accessible community programs provides opportunities for patients to get education and support, especially when the opportunities are offered at various times of day and with remote or in-person options.

While a few focus group participants discussed how some of their medical information is shared between different hospitals, most discussed that there is a lack of information sharing between providers. There was a general agreement among participants that shared information and systems would save time and increase collective communication. Participants described anecdotes about specialists not sharing information with PCPs or other specialists, how information from surgeries had been lost, and the difficulties in figuring out which providers could assist with their care. However, one partner provider explained, "you can be an extremely diligent provider and try to get as much information as you can. But the bottom line is you've got a lot of people stacking up behind you so if you're taking an hour to call the patients primary care doc, you're talking to the pharmacy, you're really trying to put together the whole picture. It's just, unfortunately, not a very realistic workflow in today's care delivery."

A few participants suggested that self-advocacy might be the best way forward for care coordination. One participant stated, "Maybe we need to know more about how to make sure our doctors are talking to each other. Make sure we know how to advocate for ourselves, manage our own cases," while another shared, "You really need to have you. You need to be your own patient advocate. Otherwise, things don't happen."

Exemplar Quotes Related to Care Coordination from Focus Group Participants

"I just went to my primary care guy at 8:30 this morning, and I'd had an appointment with a specialist who never reported back to him with the results. And I know I gave the other provider the information, so there's some slack communication. And then the other thing that happens is cardiology is looking at my heart and my primary care is looking at my thyroid levels and they don't really seem to be talking to each other either with respect to the medication."

"It gets frustrating because they don't share information between Eastern Maine and Saint Joe, and so if one of your doctors is with St. Joes and the other one is with Eastern Maine, they will never communicate either on the computer or in person or on the phone. They just don't share information between the two places, at least from what I've seen."

"I had my surgery at Eastern Maine and I was having real bad problems that following weekend and so I called Eastern Maine and they said well, you're no longer our patient because we did the surgery. Where's your cardiologist? Well, he was over at Saint Joe. Thank God I got ahold of the cardiologist at Saint Joe to help me with the issue. But they weren't talking to each and that doesn't make any sense. Saint Joes referred me to the hospital for the surgery."

Chronic Disease Management

Individual Care

Most survey respondents (38%) thought their chronic disease was managed "moderately well", with fewer (29%) saying it was managed "very well" and even fewer (15%) saying "extremely well." Respondents felt that caregivers and health care professionals managed their chronic disease better than themselves or wellness providers.

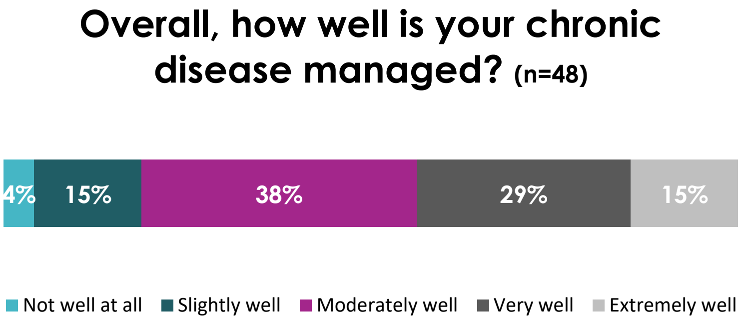

Figure 3. Responses to Evidence Based Programs Survey

Focus group participants were also asked about the management of their chronic disease. Participants most frequently mentioned exercise as the thing that helps them manage their chronic disease to the best of their ability. While discussing exercising at the YMCA, one participated stated, "I come because I'm going to meet the people I exercise with in our group and there's a group identity. There's a sense of belonging, and we're all in it together and we share our path, our journey." Several participants discussed information sharing as helpful in the management of their chronic disease(s). Examples of sources of information included websites (i.e., HealthLine, WebMD), information from hospitals and insurance providers, and programs (i.e., *Anti-Cancer Lifestyle Program)*.

> "As a physician, I feel like I am a partner in patients care. I am not the person who runs the show. Very important to meet people where they are at and recognize that. At the end of the day, people are going to do what they're going to do, but my job is to present them with my professional opinion and then work with them accordingly."
>
> *– YMCA Partner*

Beyond exercise and information sharing, participants also discussed the importance of primary care providers, face-to-face appointments (versus telehealth), diet, support from specialists, additional income, and vitamins/supplements as helpful to their chronic disease management.

Alternative Therapies

During the community member focus group, participants were provided with a handout with a list of alternative therapies. All participants in the focus group checked which alternative therapies they were most interested in accessing. Two-thirds of respondents were interested in nutrition/diet support and half of respondents were interested in massage, meditation, tai chi, and yoga. Additional interests are shown in the figure below.

Most participants were interested in nutrition/diet support as an alternative therapy

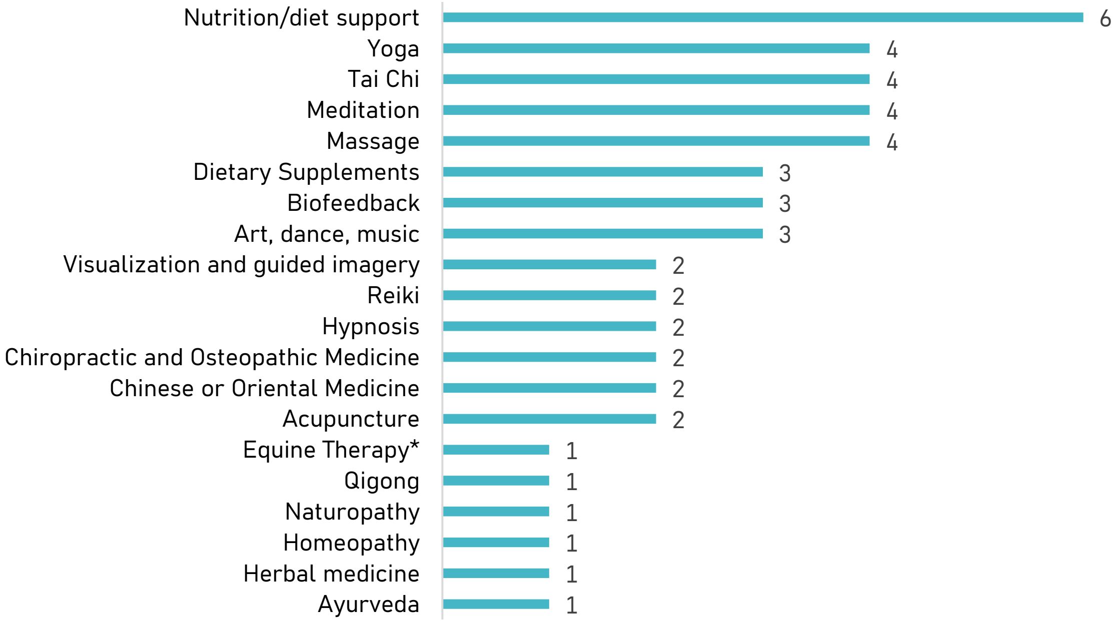

Figure 4. *Alternate Therapy Interests*

*Equine Therapy was a write-in response.

Community Care

When asked how the community can better assist with their efforts to manage their chronic disease, a few community members discussed the need for support during appointments. One participant stated, "*there are a lot of people who could use an outside person as their advocate to go with them to their appointments because it's difficult to understand what's being said, and sometimes you're just too depressed to hear it. You know, it's enough stress to have the chronic disease, trying to remember all that everybody says about it. It's really difficult, and especially on certain days, you hurt more than others. I would love to see more patient advocates that we could actually contact and say, 'I need somebody to go with me to this appointment.' You know I don't know whether that would be a volunteer program or that would be an insurance covered program or not. But it really would be a useful thing for a lot of people, I think*."

One YMCA partner discussed the need for more support groups that meet outside of the hospital. They believed it would be beneficial to have involvement from a case manager or resource manager who is aware of the resources and programs available in the community. The support groups could help with social connectedness and provide a space for older adults to ask questions they may not have asked during a medical appointment or to get clarification around medical aspects of their care. The YMCA partner explained, "*for many of our older folks, I think they go back to a home where there's very little contact with folks, and they often don't ask the questions or don't comprehend what's been told to them about their diagnosis and the course of their illness. So having sort of those informal groups, I think can be helpful.*"

Another partner discussed that even when they believe the patient understands something related to their health, the patient often does not, and it would be helpful to have a non-medical person provide education and support with the patient and their care partner. Community members also noted how taxing it can be to find medical information. One survey respondent stated, "It is extremely difficult and time consuming to search through the plethora of medical information advertised on a daily basis and even more time to research the accuracy of this information. Having one contact, to act as a 'clearinghouse' and to help vet this information is the most helpful thing I can think of. This would be especially helpful for seniors who have mobility or other conditions that may make finding medical support difficult."

During YMCA partner interviews, community care was discussed by asking about beliefs related to what patients need to manage chronic diseases to the best of their ability and what partners need from the community to improve the health outcomes of people with chronic diseases. As shown in the infographic below, several of the responses overlapped. Additionally, partners referred to past successes of intergenerational activities that help address social isolation, having community programming with diverse timings and locations, as well as the availability of meaningful activities for older adults. One provider noted that communities can benefit when there is

> *"Sometimes you know treating those illnesses is bigger than going to the doctor and taking the medication. It is around being connected to community, having a place that that is comfortable to live, having the food that you need, all of those other connectedness pieces."*
>
> *– YMCA Partner*

a focus on overall wellness, not just exercise. This includes walking, healthy eating, and having social gatherings.

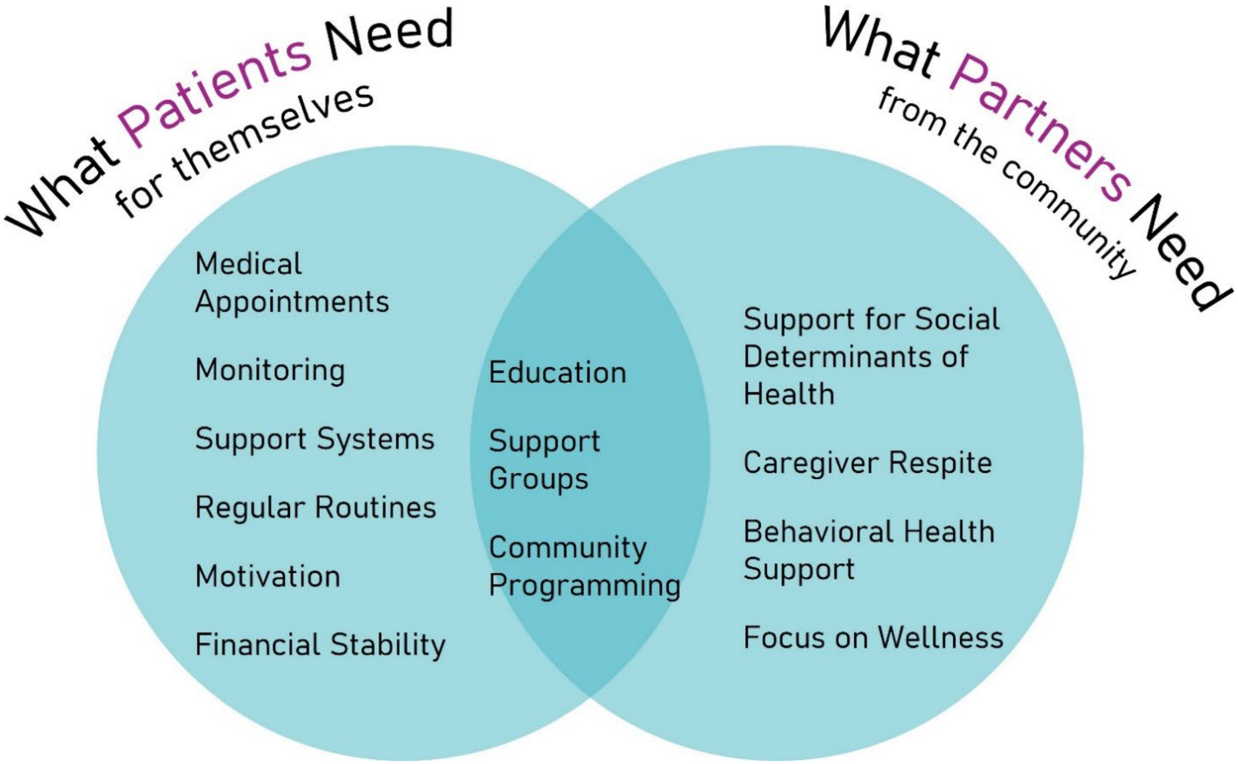

Figure 5. Community Care Infographic

Palliative Care

Palliative care is “specialized medical care for people living with a serious illness” and focuses on providing relief from the symptoms and stress of an illness to improve the quality of life for patients and their families.[1] During interviews, a few YMCA partner providers commented they believe that colleagues and the general public are unaware of the concept of palliative care and are likely to believe that it is the same thing as hospice care. One YMCA partner suggested that it could be useful for community organizations to provide information about palliative care that differentiates it from hospice care. Further, one partner noted that palliative care should start from medical providers, but, because they are overworked, that is not likely to happen. Transportation and care partner support were the two aspects of palliative care discussed during partner interviews.

Transportation

Community members and YMCA partners discussed issues with transportation. Community members indicated that it is a problem for people to get to services. For example, regarding

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[1] Center to Advance Palliative Care. “About Palliative Care” https://www.capc.org/about/palliative-care/. Accessed July 2023.

outpatient services and surgeries, it can be a burden to find someone who will drive to the appointment, wait, and then pick the person back up. One YMCA partner mentioned patients may have difficulty getting transportation to programs that are non-medical (e.g., support groups), as these are often not MaineCare reimbursable. This partner, who is able to provide transportation services, mentioned they could provide transportation for community members to non-medical appointments if the timing was mid-day. This is an opportunity for community partner collaboration.

Care Partner Support

A YMCA partner mentioned that while care partner support groups are helpful for building community, what care partners really need is respite and help giving care. While that is beyond the capacity of the YMCA, it may be beneficial to investigate whether care partner support groups could be expanded. Further inquiry in this area may show a strong need for this given that the Evidence Based Programs survey results showed that care partners rated themselves as having lower mental health ratings compared to those who identified as having a chronic condition.

YMCA Programming

Community Member Perspectives

Focus group participants discussed how YMCA exercise programs are helpful. In particular, participants highlighted the ability to participate in programs geared towards older adults, variability in programming, positive interactions with staff, and opportunities for socialization. Participants expressed that exercise teachers are excellent at being encouraging and finding new exercises, while all YMCA staff members really seem to care about YMCA members. Several focus group participants noted that exercise instructors often recognize the physical limitations of individual participants. However, there were also discussions about how more class time could be allocated to discussing physical limitations. Further, several participants mentioned that the YMCA's physical building has limited overall participation (e.g., broken elevator, lack of space for gathering) and they were looking forward to a new building as they believed a better space would encourage more program participation.

> *"A membership at the Y is not very much money and it covers an awful lot of the things that you want to do so it'd be it'd be good to get more publicity about that out."*
>
> – Focus Group Participant

A few recommendations for improvements included having classes at different times because sometimes classes overlap, accepting Silver Sneakers, and adding more virtual classes. One participant noted a lack of in-person cancer connections groups, and another identified the need for more socialization activities for older adults.

> *"I was beginning to feel old and decrepit. And you know this, I was limping around and I said, I think I need to do something. So, we enrolled in healthy bones and joints here … And then I feel better overall. I feel like, in a way, I'm warding off something. I'm trying to stay as mobile and as healthy as possible, and this helps. It really does. There's a noticeable change in my body by participating here…"*
>
> – Focus Group Participant

Advertising and Sharing Information about YMCA Programming

Focus group participants and a few YMCA partners acknowledged that there are a lot of services provided by the YMCA, yet had concern that community members were not taking full advantage of them due to confusion around costs. Focus group participants also suggested that they thought community members were not participating in YMCA programs due to uncertainty as to whether insurance would reimburse for YMCA services, a lack of referrals, and due to transportation issues. Participants recommended making it clear that programs are affordable by clearly defining YMCA membership costs and participation benefits, as well as noting the availability of grants or sliding scales.

Community members and partners had suggestions for advertising and sharing information about YMCA programming. For example,

- Having brochures about YMCA programs in hospitals and waiting rooms
- Making sure partners have copies of the *Health Happens at the YMCA* brochure
- Creating YMCA branded postcards with a QR code that would bring patients directly to a current and updated list of YMCA offerings
- Having spotlights on offerings featured on the local news

Referral Pathways and Community Coordination

Partners enthusiastically agreed that the YMCA has been easy to work with. However, there is difficulty with maintaining referral pathways because of competing time priorities within hospital and primary care settings, the lack of a central repository of community resources, and staff turnover both at the YMCA and within provider settings.

YMCA partners were asked how referral pathways could be expanded or strengthened. The partners offered suggestions of how to strengthen informal referral pathways:

- Host quarterly meetings for organizations who work with older adults to share upcoming programming and initiatives, with a specific focus on inviting case managers, behavioral health professionals, and others "who are really doing the work"
- Reach out to new nurse practitioners and doctors to make sure they are aware of the YMCA's offerings
- Add doctors and other healthcare professionals to newsletter email lists

One potential referral pathway to focus on would be with physical therapists' offices. Community members mentioned they were confused about the relationships between physical therapists' offices and thought that clarifying the relationship between physical therapy offices and the YMCA could be beneficial.

Recommendations

Advocate for or Create Support Groups

YMCA partners and community members both spoke of the need for and importance of support groups for individuals with chronic diseases. Respondents to the Evidence Based Programs survey indicated a preference for support groups led by a trained facilitator rather than a peer-led support group. By advocating for or creating more support groups, individuals and care partners may feel more supported and motivated to manage their chronic condition(s).

Additionally, medical partners may want to consider shared medical visits, where persons with similar health needs meet together with health care providers to “concentrate on patient education, resource sharing and disease management.”[2] Although it may be difficult to implement due to provider shortages, “the American Academy of Family Physicians believes that group visits are a proven, effective method for enhancing a patient’s self-care of chronic conditions, increasing patient satisfaction, and improving outcomes.”[3]

Strengthen and Expand Referral Pathways

While there are likely barriers to creating formal referral pathways from medical providers to the YMCA, there is opportunity for improvement with community programs. One recommendation is to facilitate quarterly meetings with community partners to share what programming and community initiatives are forthcoming. This could also be a platform to discuss how referral pathways can be improved and will ensure that community partners are able to connect with each other.

Community members and YMCA partners both spoke about the need for increased visibility of YMCA programs, as well as community supports and resources. Expanding the distribution of the *Health Happens at the YMCA* or other advertising materials may bring more awareness of the YMCA’s programming. Any materials should include information on membership pricing. Further, creating a centralized listing or repository of community resources related to chronic disease supports or directing community members to 211 Maine may help connect people to the services and programs they need.

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[2] Vanderbilt University. “Program studies impact of shared medical visits on loneliness and other issues” https://news.vumc.org/2023/04/06/program-studies-impact-of-shared-medical-visits-on-loneliness-and-other-issues/. Accessed July 2023.

[3] American Academy of Family Physicians “Shared Medical Appointments/Group Visits” https://www.aafp.org/about/policies/all/shared-medical-appointments.html Accessed July 2023.

Conclusion

It will take coordination and systems change at multiple levels to co-create a responsive, sustainable, and equitable community health model for older adults with chronic diseases. While the Bangor YMCA may not be able to address the high-level factors that are affecting the chronic disease continuum of care (i.e., provider shortages, communication between providers), they may be able to bolster parts of the continuum which will ultimately increase the quality of life for many older adults with chronic disease, as well as their care partners. Strategically implementing programming in coordination with community partners and continuing to foster relationships with providers and community partners will ultimately lead to improvements in the chronic disease continuum of care.

Appendix A:

Evidence Based Programs Survey

Bangor Region YMCA Survey

The Bangor Region YMCA wants to have a better understanding of how individuals with chronic disease and their care partners feel about their current experience with their disease management, health care and our YMCA programming, as well as improvements or changes they might desire. The information you provide will help the YMCA make improvements and better serve the community.

Taking this survey is voluntary and all responses on this survey are optional. You may skip any questions. After you complete the survey, you may provide your contact information to receive a $25 gift card from Buoy Local as a thank you. The first 60 persons to complete the survey will be eligible for a gift card.

This survey will take approximately 15 minutes to complete. While this survey is accessible via a smart phone, **it will be easiest to complete this survey on a computer or with a paper version available at the YMCA.**

This survey is only for persons living with chronic disease(s) and for persons who care for those with chronic disease(s). If you are a health or wellness provider, we would still appreciate your feedback! Please email Vanessa Newman (vnewman@bangory.org) for information on how to provide your thoughts in the upcoming months.

If you have any technical issues while taking this survey, please e-mail Rachel Gallo (rachel.gallo@maine.edu)

Q1. **Which of the following best describes you:**

○ I have one or more chronic diseases

○ I provide care for someone with one or more chronic diseases

○ Neither of these descriptions apply to me (if this is applicable, please discontinue)

Q2.1 **Which of the following chronic diseases have you or the person you care for been diagnosed with?**

☐ **Cancer**

How many years ago did you or the person you care for learn about the Cancer diagnosis?

☐ Less than 1 year ago

☐ 1-2 years ago

☐ 3-5 years ago

☐ 6-10 years ago

☐ More than 10 years ago

☐ **Diabetes**

How many years ago did you or the person you care for learn about the Diabetes diagnosis?

☐ Less than 1 year ago

☐ 1-2 years ago

☐ 3-5 years ago

☐ 6-10 years ago

☐ More than 10 years ago

☐ **Dementia or Alzheimer's**

How many years ago did you or the person you care for learn about the Dementia or Alzheimer's diagnosis?

☐ Less than 1 year ago

☐ 1-2 years ago

☐ 3-5 years ago

☐ 6-10 years ago

☐ More than 10 years ago

☐ **Parkinson's disease**

How many years ago did you or the person you care for learn about the Parkinson’s diagnosis?

- ☐ Less than 1 year ago
- ☐ 1-2 years ago
- ☐ 3-5 years ago
- ☐ 6-10 years ago
- ☐ More than 10 years ago

☐ **Cardiac Disease**

How many years ago did you or the person you care for learn about the Cardiac Disease diagnosis?

- ☐ Less than 1 year ago
- ☐ 1-2 years ago
- ☐ 3-5 years ago
- ☐ 6-10 years ago
- ☐ More than 10 years ago

☐ **Arthritis**

How many years ago did you or the person you care for learn about the Arthritis diagnosis?

- ☐ Less than 1 year ago
- ☐ 1-2 years ago
- ☐ 3-5 years ago
- ☐ 6-10 years ago
- ☐ More than 10 years ago

☐ **Other Diagnosis (please list) ____________________**

How many years ago did you or the person you care for learn about this diagnosis?

☐ Less than 1 year ago

☐ 1-2 years ago

☐ 3-5 years ago

☐ 6-10 years ago

☐ More than 10 years ago

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Q3.1 **We are interested in understanding where you receive support for chronic disease and your feelings about chronic disease care.**

Where do you or the person you care for currently **receive support for or gather information about** managing chronic disease? (check all that apply)

☐ Civic or community group (e.g., senior center, rotary club)

☐ Urgent Care clinic

☐ YMCA

☐ Fitness Center

☐ Primary Care Provider

☐ Church or religious organization

☐ Medical Specialist

☐ Online apps or programs

☐ Employer sponsored programs

☐ University or college published research or program

☐ Other (please list below)

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Q4.1 Health care providers are doctors, nurse practitioners, physician assistants, or other primary care providers.

Which of the following responses best describe how you feel about the health care providers that manage chronic disease?

Q4.2 **I trust health care providers so much I always try to follow their advice**

☐ Totally Disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Totally Agree

Q4.3 **I trust health care providers judgments about medical care**

☐ Totally Disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Totally Agree

Q4.4 **I feel health care providers do everything they should for my medical care (or for the person I care for)**

☐ Totally Disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Totally Agree

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Next Page →

Q4.6 We are interested in understanding which community organizations/professionals you trust the most to provide care that helps you manage chronic disease(s).

Of the following choices, which do you trust the most? (select up to three)

☐ Civic or community group (e.g., senior center, rotary club)
☐ Urgent Care clinic
☐ YMCA
☐ Fitness Center
☐ Primary Care Provider
☐ Church or religious organization
☐ Employer sponsored programs
☐ Online apps or programs
☐ University or college published research or program
☐ Medical Specialist

Next Page →

Q4.7 **We would like to know what types of community programs you are most interested in.**

How likely are you to do the following for managing chronic disease?

	Extremely unlikely	Somewhat unlikely	Neither likely nor unlikely	Somewhat likely	Extremely likely
Attend an **in-person** educational session	○	○	○	○	○
Attend a **virtual** educational session	○	○	○	○	○
Go to an **in-person** exercise class	○	○	○	○	○
Go to a **virtual** exercise class	○	○	○	○	○
Attend a support group led by my peers	○	○	○	○	○
Attend a support group led by a trained facilitator with expertise in chronic diseases	○	○	○	○	○

Q4.8 Think about the ways you receive support for chronic disease from the community. Are there any community services or programs missing?

____

____

____

____

____

We are interested in learning about your experiences in the management of chronic disease.

Q5.2 How well do you feel your chronic disease is managed? (or the chronic disease of the person you care for)

	Not well at all	Slightly well	Moderately well	Very well	Extremely well	N/A
Overall	○	○	○	○	○	○
By health care professionals	○	○	○	○	○	○
By wellness providers	○	○	○	○	○	○
By yourself	○	○	○	○	○	○
By your caregiver	○	○	○	○	○	○

Q5.3 How often would you say **lack of time** prevents you from managing chronic disease to the best of your ability?

○ Never

○ Sometimes

○ About half the time

○ Most of the time

○ Always

Q5.4 How often would you say **money** prevents you from managing chronic disease to the best of your ability?

○ Never

○ Sometimes

○ About half the time

○ Most of the time

○ Always

Besides time and money, what else prevents you from managing your chronic disease to the best of your ability?

____

____

____

____

____

____

Q5.6 Are you interested in using apps to assist with managing chronic disease(s)? For example, exercise/calorie tracking, blood pressure monitoring.

○ Yes - I already use apps

○ Yes - I would like to learn more

○ Maybe

○ No

Q6.2 **We are interested in learning about the costs associated with chronic disease care.**

What would you say the **monthly out of pocket expense** is for managing your chronic disease? (or for the person you care for)

Out of pocket expenses include coinsurance and deductibles, prescriptions, medical supplies, and services not covered by insurance.

○ Unsure

○ $0

○ $1-$100

○ $101-$500

○ $501-$1,000

○ $1,000-$2,000

○ More than $2,000

Q6.3 With your current financial situation, how much money would you (or the person you care for) be willing to spend on activities to support mental and physical health per month?

$ _______ for mental health each month

$ _______ for physical health each month

Next Page →

Q7.1 Health insurance can be helpful in covering chronic disease expenses.

Do you (or the person you care for) currently have health insurance?

○ Yes (please skip to question 7.3 on the next page)

○ No

Q7.2 Why do you (or the person you care for) not currently have insurance?

☐ Too expensive

☐ Not eligible for coverage

☐ Do not need or want

☐ Signing up was too difficult or confusing

☐ Cannot find a plan that meets needs

☐ Unemployed or between jobs

☐ Another family member has health insurance, but it does not cover person with chronic disease

☐ Unsure

Q7.3 Who is the primary health insurance provider?

If you have more than one type of provider, please choose the one you primarily utilize for managing chronic disease

○ Aetna

○ Anthem Blue Cross Blue Shield

○ Cigna

○ Harvard Pilgrim

○ Maine Community Health Options

○ United Healthcare

○ MaineCare (Medicaid)

○ Medicare

○ Military related health care

○ Indian Health Service

○ Other (please list) ____

Q7.4 What health and wellness benefits does this insurance cover? (select all that apply)

☐ Unsure

☐ Gym membership

☐ Mental health support (i.e. therapy appointments, stress-management programs)

☐ Discounts on virtual health or wellness programs

☐ Discounts on in-person health or wellness programs

☐ Cash incentives

☐ Health and wellness education opportunities

☐ Other (please list) ____

Q8.1 How difficult has it been to access the following services during the COVID pandemic?

	Not Applicable	Extremely difficult	Somewhat difficult	Neither easy nor difficult	Somewhat easy	Extremely easy
Medical appointments	☐	☐	☐	☐	☐	☐
Dental appointments	☐	☐	☐	☐	☐	☐
Food	☐	☐	☐	☐	☐	☐
Transportation	☐	☐	☐	☐	☐	☐
Child Care	☐	☐	☐	☐	☐	☐
Wellness activities	☐	☐	☐	☐	☐	☐
Exercise classes	☐	☐	☐	☐	☐	☐

Next Page →

Q8.2 **Think about the care you or the person you care for receives for chronic disease management.**

How would you rate the quality of health and wellness care you received **before the pandemic**?

0 **Poor**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10** **Excellent**
☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

Q8.3 How would you rate the quality of the health and wellness care you received **during the pandemic**?

0 **Poor**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10** **Excellent**
☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

Next Page →

Q8.4 Have you (or the person you care for) had any telehealth appointments in the past two years?

○ No (please skip to Question 8.6 below)

○ Yes

Q8.5 Is there anything you would like to share about the telehealth experiences?

Q8.6 Was there anything preventing you (or the person you care for) from having telehealth appointments?

Q8.7 In general, would you say your mental health is:

☐ Excellent ☐ Very Good ☐ Good ☐ Fair ☐ Poor

Q9.1 Thinking about your mental health, which includes stress, depression, and problems with emotions, for how many days during the past 30 days was your mental health not good?

○ 0 days

○ 1-5 days

○ 6-10 days

○ 11-15 days

○ 16-20 days

○ 21-25 days

○ 26-30 days

Q9.2 **If you are a person with a chronic condition, we would like to know a little more about your health and how you would describe yourself.**

During the past 30 days, for about how many days did poor physical or mental health keep you from doing your usual activities, such as self-care, work, or recreation?

○ I am a care giver and this does not apply to me

○ 0 days

○ 1-5 days

○ 6-10 days

○ 11-15 days

Q10.1 **The following demographics questions are optional, however your responses will help the YMCA better understand the characteristics of persons who responded to this survey and utilize YMCA programs.**

Q10.2 What is your age group?

○ Under 18

○ 18-34 years old

○ 35-54 years old

○ 55-64 years old

○ 65-74 years old

○ 75 years or older

Q10.3 How do you identify yourself?

○ Female

○ Male

○ Prefer to self-describe ________________

○ Prefer not to answer

Q10.4 How long does it take you to get to the Bangor Region YMCA?

○ 0-5 minutes

○ 6-10 minutes

○ 10-15 minutes

○ More than 15 minutes

Q10.5 What is your household's total income?

○ Prefer not to answer

○ Less than $10,000

○ $10,000 to $24,999

○ $25,000 to $49,999

○ $50,000 to $74,999

○ $75,000 to $99,999

○ $100,000 to $199,999

○ $200,000 or more

Q10.6 How would you describe yourself? (select all that apply)

- ☐ Prefer not to answer
- ☐ Hispanic or Latino
- ☐ American Indian or Alaska Native
- ☐ Asian or Asian American
- ☐ Black or African American
- ☐ Native Hawaiian and Other Pacific Islander
- ☐ White
- ☐ Some other race not listed

Q11.1 Is there anything else you would like to share with us?

____
____
____
____
____
____

We will be holding focus groups in the Spring of 2023 so that we can learn more about the needs of the community regarding chronic disease support and care. Participants may receive an additional gift card for their participation. **If you are interested in participating, please provide your contact information below**.

Q12.2 What is your e-mail address?

____

Q13.1 To thank you for filling out this survey, we would like to provide you with a $25 gift card from Buoy Local. Please provide your contact information below. Your contact information will not be connected to your survey responses.

In order to collect your gift card, please call or email Vanessa Newman at the YMCA (207-914-2808 extension 338 or vnewman@bangory.org).

What is your name?

____

What is your email address? (if you did not provide this above)

____

What is your phone number?

____

Appendix B

Summary of Evidence Based Programs Survey

Bangor Region YMCA

Fall 2022 Evidence Based Programs Survey

DATA INNOVATION PROJECT

Catherine Cutler Institute
University of Southern Maine

February 17, 2023

Introduction

Survey Objectives:

To learn about how individuals with chronic disease and their care partners feel about their current experience with their disease management, health care, and YMCA programming, as well as any improvements or changes they might desire

Overall Project Research Questions:

1. How are individuals with chronic disease connected or not connected to community health resources?
2. How can a trusting continuum of care be created?
    a. Where are there gaps in the continuum of care (i.e.. Where does it break down?)
3. What are the current gaps in palliative care?
4. What incentivizes people to commit to manage their chronic diseases through community programs like YMCA evidence-based classes?
5. How has the pandemic impacted the care experience?

Survey Methods

To-date

Survey Design

- USM’s Data Innovation Project and the Bangor YMCA designed the survey together
- Feedback from external partners regarding the design was solicited before deployment
- Survey was distrusted via YMCA e-mail lists, YMCA Cancer newsletter, and through one external partner

Results

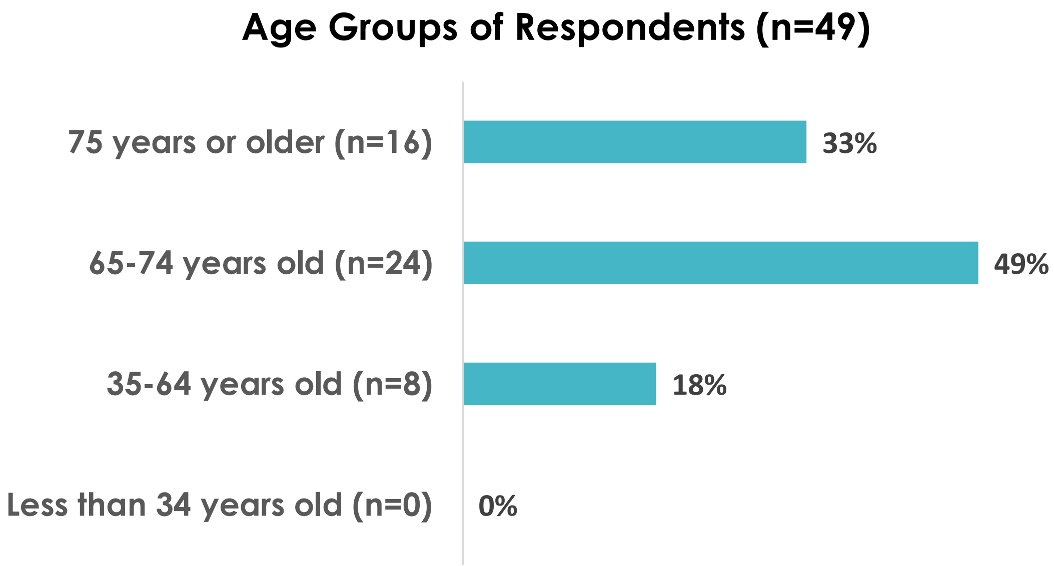
- **52 Responses**, completed on paper and via online platform
  - 49 Complete, 3 Partially completed
    - 43 with one or more chronic diseases
    - 8 care partners
- Participants were eligible for a gift card for their participation

Survey Respondent Demographics

Most respondents identified as Female (70%) and White.*

49% of the respondents were 65-74 years old

Most care partners were in the 65-74 age range

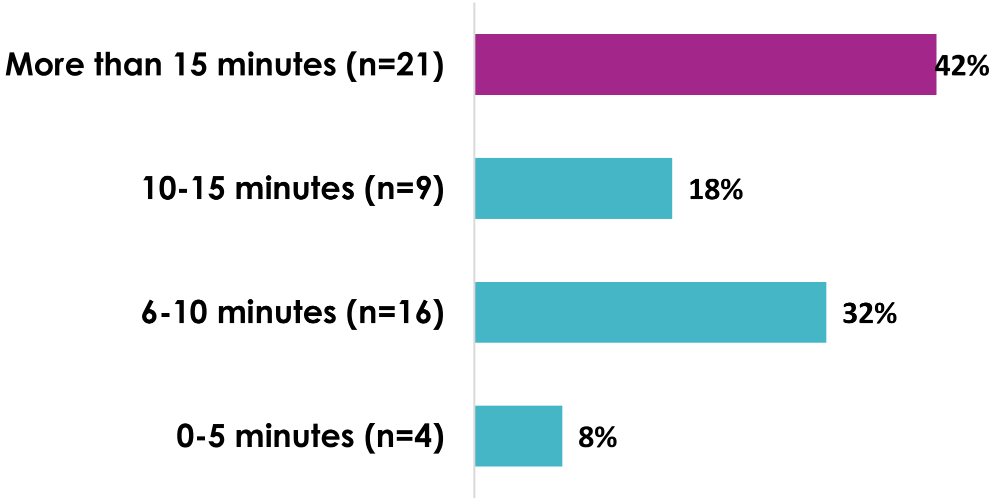


N=50, *6% preferred not to answer the gender question;
fewer than five respondents identifying as Hispanic or Latino

Survey Respondents’ Travel Times and Income

Most respondents (42%) need to travel more than 15 minutes to get to the YMCA

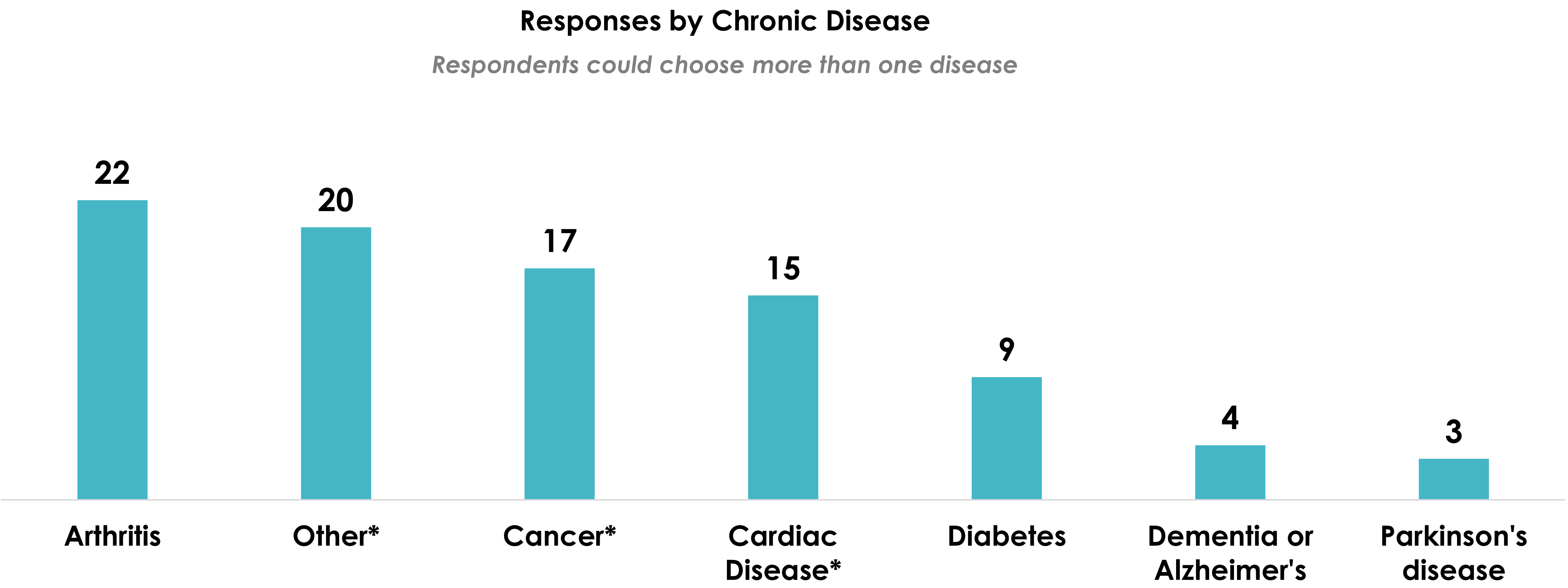
Length of Time it Takes to Travel to the YMCA (n=50)



Although most respondents chose not to disclose their income range (31%), most respondents who answered this question had an income of less than $50,000

Survey Respondents by Chronic Disease

Arthritis was the most frequent chronic disease reported



*one respondent in category partially completed the survey, therefore some data may be missing

Other included: asthma, autoimmune diseases, stroke, thyroid disorders, osteo related, chronic pain

Time Since Diagnosis

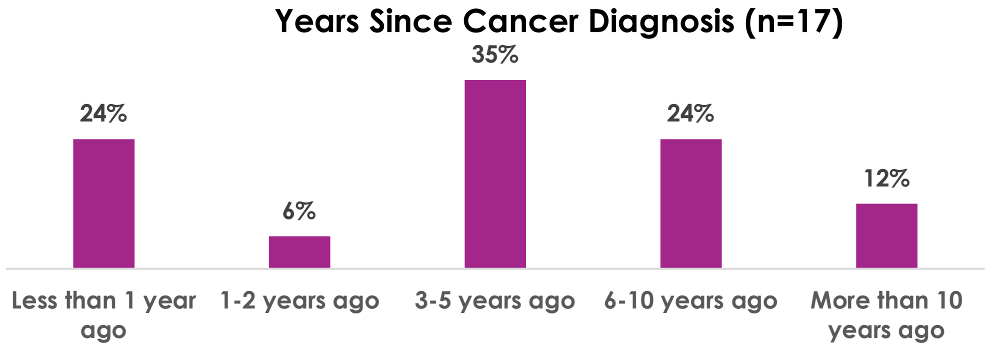
The amount of time that has passed since a person's diagnosis varied by disease

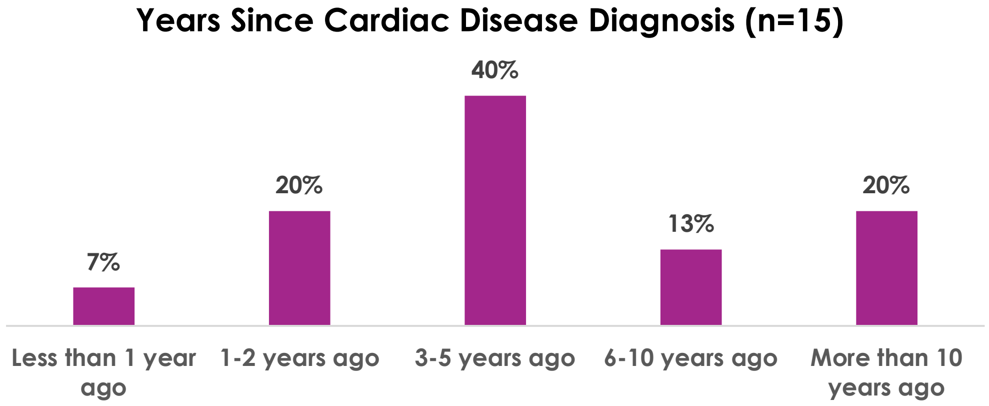
Persons with **arthritis or diabetes** were most likely to have received a diagnosis **more than 10 years ago**

Persons with **cancer or cardiac disease** were most likely to have received a diagnosis **3-5 years ago**

The Data:

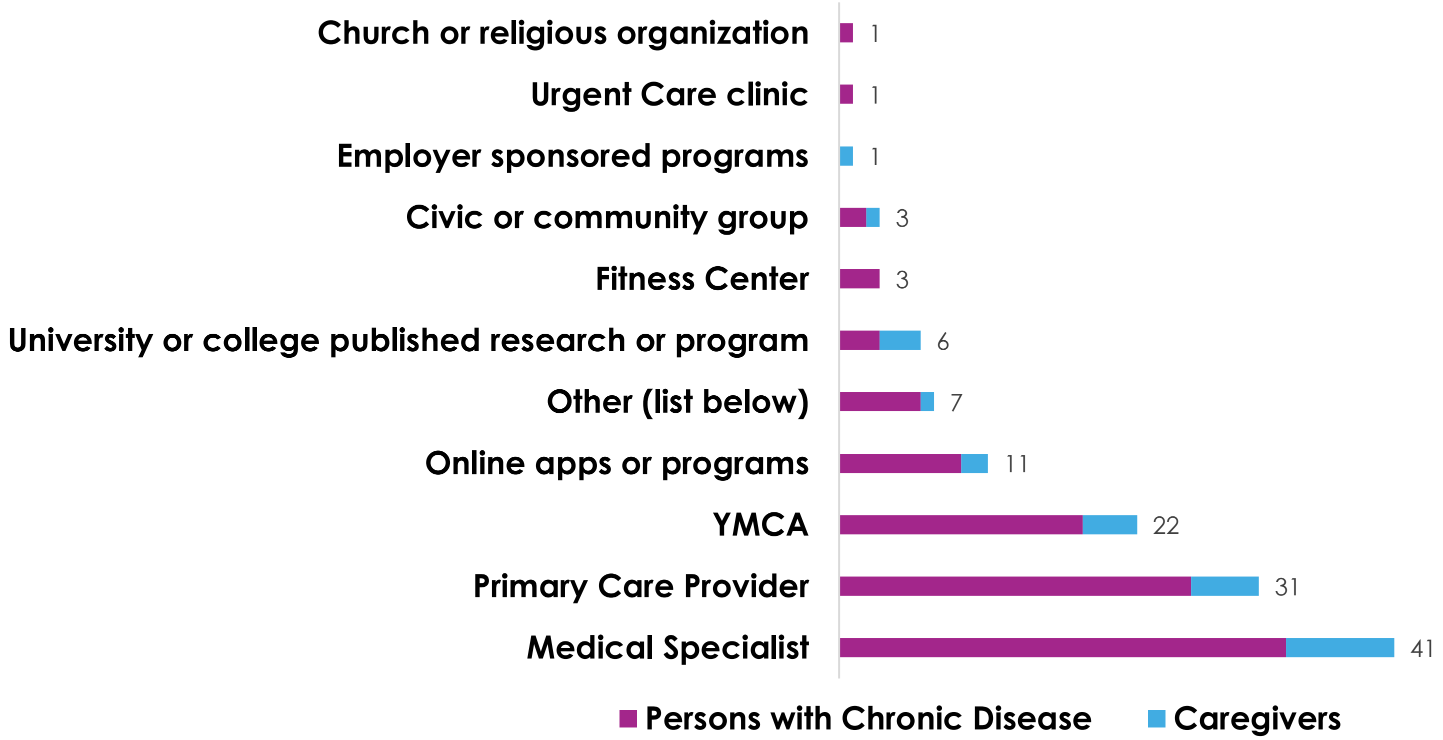
- **Arthritis**: 28% 3-5 years ago, 32% 6-10 years ago, **41% more than 10 years ago**
- **Cancer**: 24% less than 1 year ago; **35% 3-5 years ago**
- **Cardiac Disease**: 40% 3-5 years ago
- **Diabetes**: **67% more than 10 years ago**; 33% 6-10 years ago





Receiving Support and Gathering Information about Managing Chronic Disease

Most people receive support and gather information about managing chronic disease from their medical specialist or primary care provider



Other: Pain Management on Broadway; Family; NADF (National Adrenal Disease Foundation); MJFox publications; books; Internet; Friends; Clubs; Beth Wright Cancer Center

Thoughts on Health Care Providers

Overall, **most respondents felt positively about their health care providers**, many were neutral on their thoughts around trust with their providers.

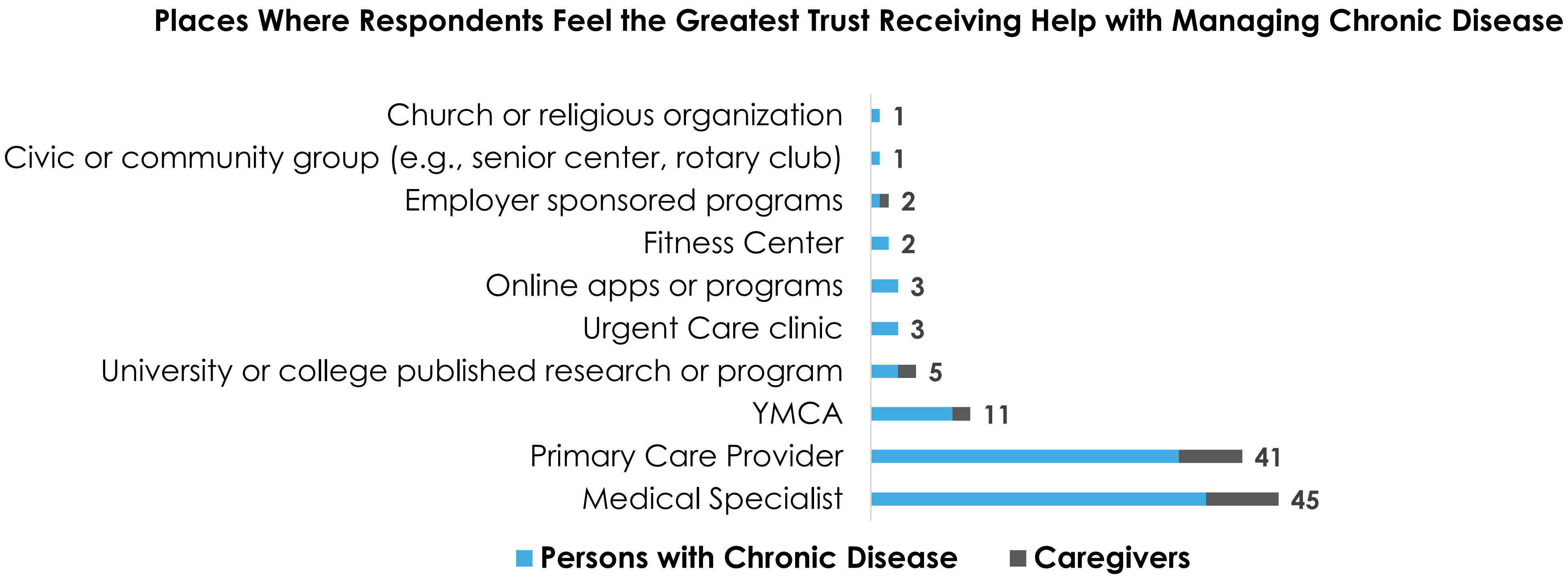
- **19% were neutral on whether they trust health care providers so much they always try to follow their advice**, while the majority said they agree (46%) or totally agree (34%)

- **17% were neutral on whether they trust health care providers judgements about medical care**, while 48% agreed and 35% strongly agreed

- **23% were neutral on whether they felt health care providers do everything they should for medical care**; 10% disagreed and 67% agreed or strongly agreed

Trust with Community Organizations

Respondents were most likely to trust Primary Care Providers, Medical Specialists, and the YMCA to provide care that helps manage chronic diseases.



Interest in Community Programs

Support Groups	Respondents **prefer to attend support groups led by a trained facilitator** (66%) with expertise in chronic disease over a support group led by peers (33%)
Exercise Classes	Respondents are nearly **twice as likely to attend in-person exercise classes** (68%) than virtual exercise classes (35%)
Educational Sessions	Respondents were **only slightly more likely to attend an in-person educational session** (58%) compared to a virtual educational session (51%)

Gaps in the Community for Receiving Support for Chronic Diseases

The most frequent responses to the question regarding missing community services and programs corresponded to:

- Integration of care for older adults (e.g., needing to get rigorous exercise, but have osteoarthritic limits)
- Lack of medical services or availability of providers, including mental health support

Additional Comments Included:

- the need for easily accessible and accurate medical information;
- sidewalks in rural areas;
- assistance with financial expenses (e.g., how to save money or find support; how to find or rent adaptive equipment);
- transportation assistance;
- directory of agencies that help with household upkeep

Note: Only 14 respondents answered this question; this question may be asked in a focus group to bolster the information gathered from this question.

Respondents noted specific medical services and provider types that were lacking

- **Types of providers mentioned included:**
    - Nutritionists
    - Geriatric medicine care specialists
    - Behavioral health
    - Rheumatologists
    - Oncologists

- **Types of services mentioned included:**
    - Community support groups (e.g., adrenal insufficiency, celiac’s)
    - Integrative therapies
    - Prehabilitation
    - Sexual health
    - Fertility support
    - Surgery
    - Hospitalizations
    - Rehabilitation
    - Skilled Nursing
    - Physical Therapy / Occupational Therapy

> “There are no rheumatologists taking patients. My oncologist is already so overworked she is exhausted and more doctors are leaving…”

Quotes Related to Missing Services

Finding Accurate Medical Information:

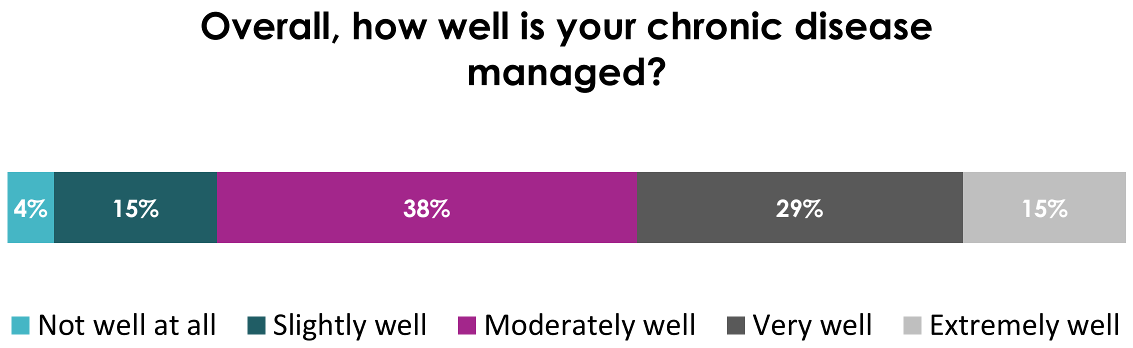
“It is extremely difficult and time consuming to search through the plethora of medical information advertised on a daily basis and even more time to research the accuracy of this information. Having one contact, to act as a "clearinghouse" and to help vet this information is the most helpful thing I can think of. This would be especially helpful for seniors who have mobility or other conditions that may make finding medical support difficult.”

Integration of Care:

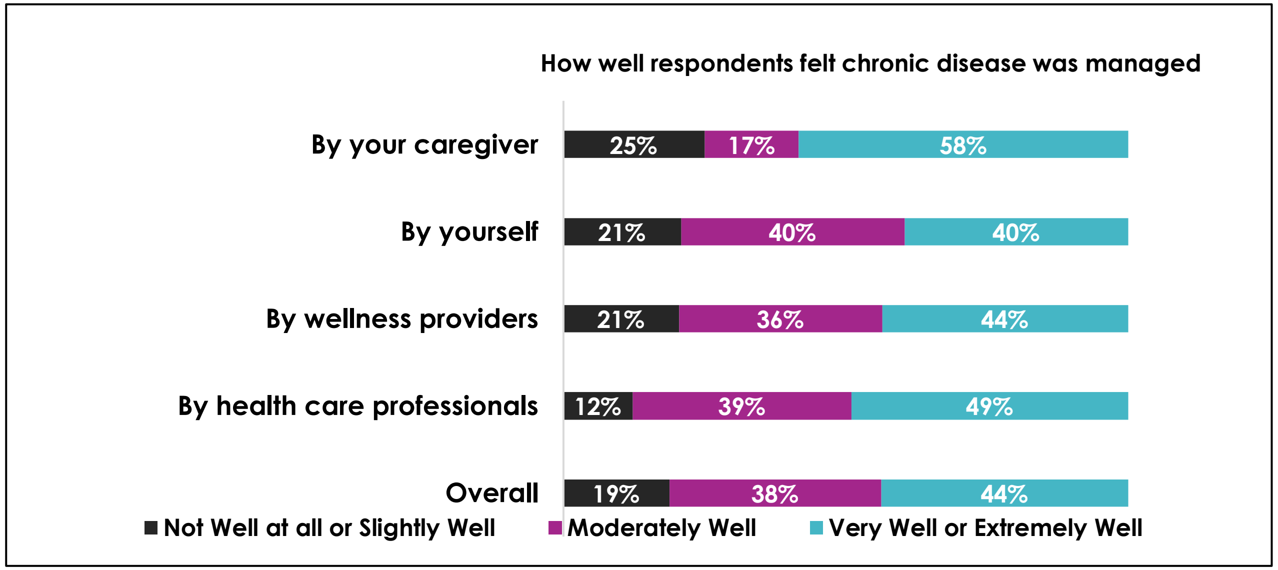
“I think that what is missing is integration of care for us seniors. For example osteoarthritic limits flexibility and from time to time, flare-ups occur; difficult at such times to meet things like cardio goals. Are there gerontologists providing advice to guide development of chronic care for us?”

Management of Chronic Disease

Overall, **most respondents thought their chronic disease was managed "moderately well" (38%)**, with fewer saying it was managed "very well" (29%) and even fewer saying "extremely well" (15%)



Looking at responses by category, ***respondents felt that caregivers and health care professionals managed their chronic disease better than themselves or wellness providers.*** Respondents were most likely to choose health care providers as managing their chronic disease "extremely well".



Management of Chronic Disease

Lack of time was slightly more likely to prevent respondents from managing their chronic disease to the best of their ability compared to money

Time

35% of respondents said a lack of time never prevents them from managing their chronic disease to the best of their ability.

47% said "sometimes", 14% said "about half the time" and only 4% said "most of the time"

Money

36% of respondents said a lack of money never prevents them from managing their chronic disease to the best of their ability.

50% said "sometimes"; 8% said "about half of the time", and 6% said "most of the time"

Management of Chronic Disease

Besides time and money, respondents mentioned the following that prevented them from managing their chronic disease to the best of their ability:

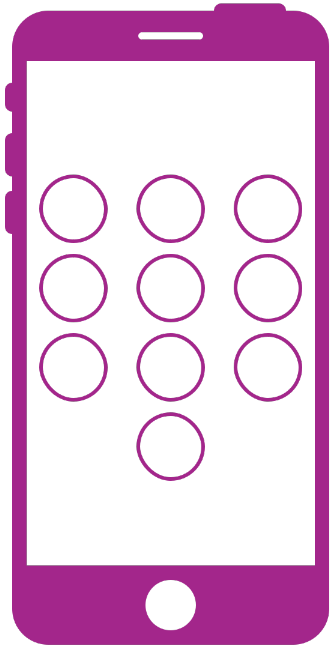
- Access to help or information
- Competing priorities
- Coordinating Care
- Health system insufficiencies
    - Service availability and wait times
    - Delays in pre-authorizations
- Motivation and Attitudes towards managing their disease
- Physical limitations (e.g., pain, weight)
- Other: insurance, internet access, bad weather

Note: Approximately half of the survey respondents answered this question; this question may be asked in a focus group to bolster the information gathered from this question.

Using Apps for Managing Chronic Disease

The majority of respondents (42%) might use apps to assist with managing chronic disease (e.g., exercise/calorie tracking, blood pressure monitoring)

- 34% of respondents were not interested
- 6% are currently using apps
- 6% would like to learn more about usings apps



Using Telehealth

73% of respondents used telehealth within the last year, however their experiences varied (n=21)

Very few respondents (n=4) noted that there was something preventing them from having telehealth appointments

5 said telehealth was helpful for some types of appointments

> “To refill a prescription it's ok.”

5 noted negative experiences

> “difficult to communicate with a provider who I have never met face to face”

3 noted neutral experiences

> “worked fine”

5 noted positive experiences

> “Telehealth counseling has been a real "Gift". No need to drive in bad weather.”

6 said they preferred in-person appointments

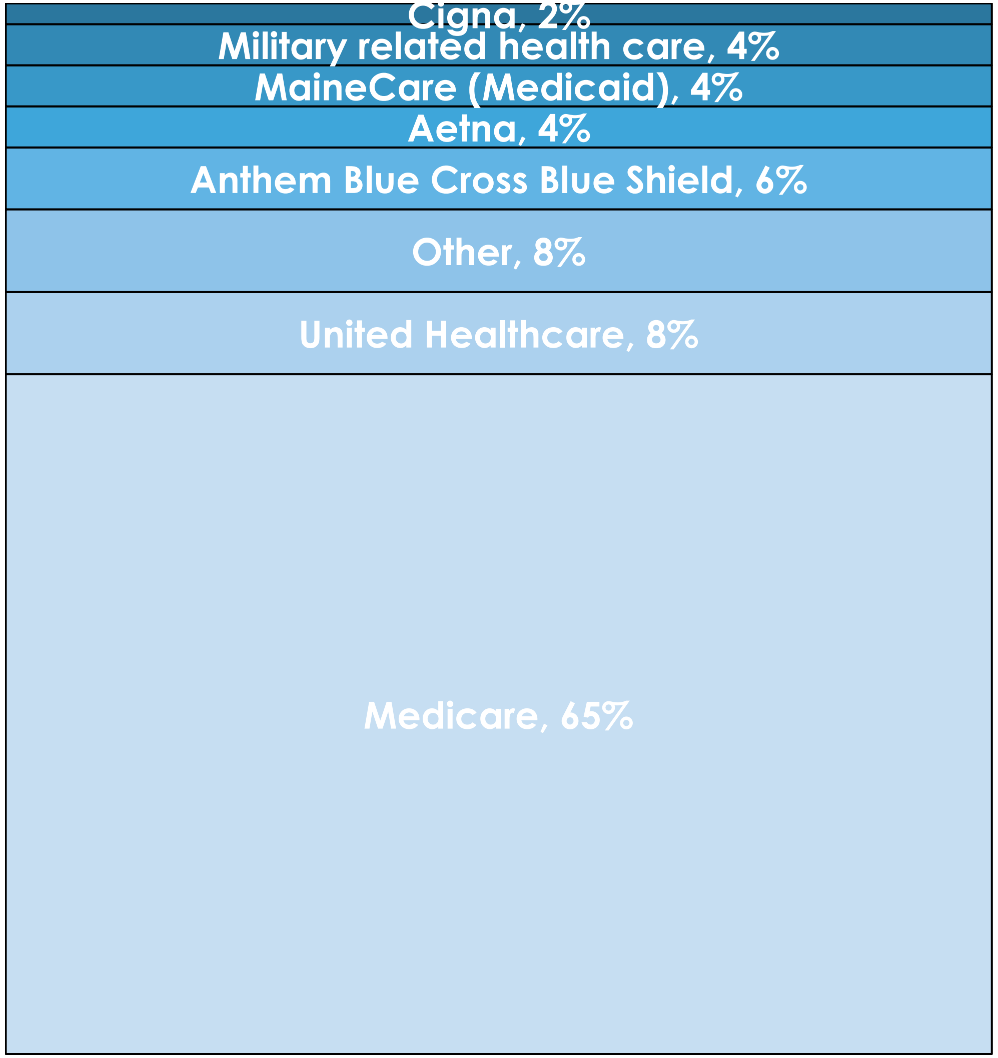
> “I prefer in person. I find it more motivating”

Costs Associated with Chronic Disease Care

All respondents on the survey had health insurance

- 65% Medicare (11 respondents specified Martin's Point, 2 specified Wellcare)

Respondents by Insurance Type (n=51)



Benefits by Insurance Type

Many respondents were unsure of the supplemental benefits of their health insurance. For those who were aware of these benefits, the following were noted:

Provider	Benefits						
	Gym Membership	Mental Health Support (i.e., therapy, stress-management)	Discounts on Virtual Health or Wellness Programs	Discounts on In-Person Health or Wellness Programs	Cash Incentives	Health and Wellness Education Opportunities	Other
Medicare	●	●	●	●	●	●	Partial reimbursement for yearly YMCA membership; Coverage for YMCA classes; Healthy Living Reimbursement
United Healthcare	●			●			
Anthem Blue Cross Blue Shield	●	●					
Aetna						●	
MaineCare (Medicaid)	Respondents Unsure						
Military Related		●					
Cigna		●					

Costs Associated with Chronic Disease Care

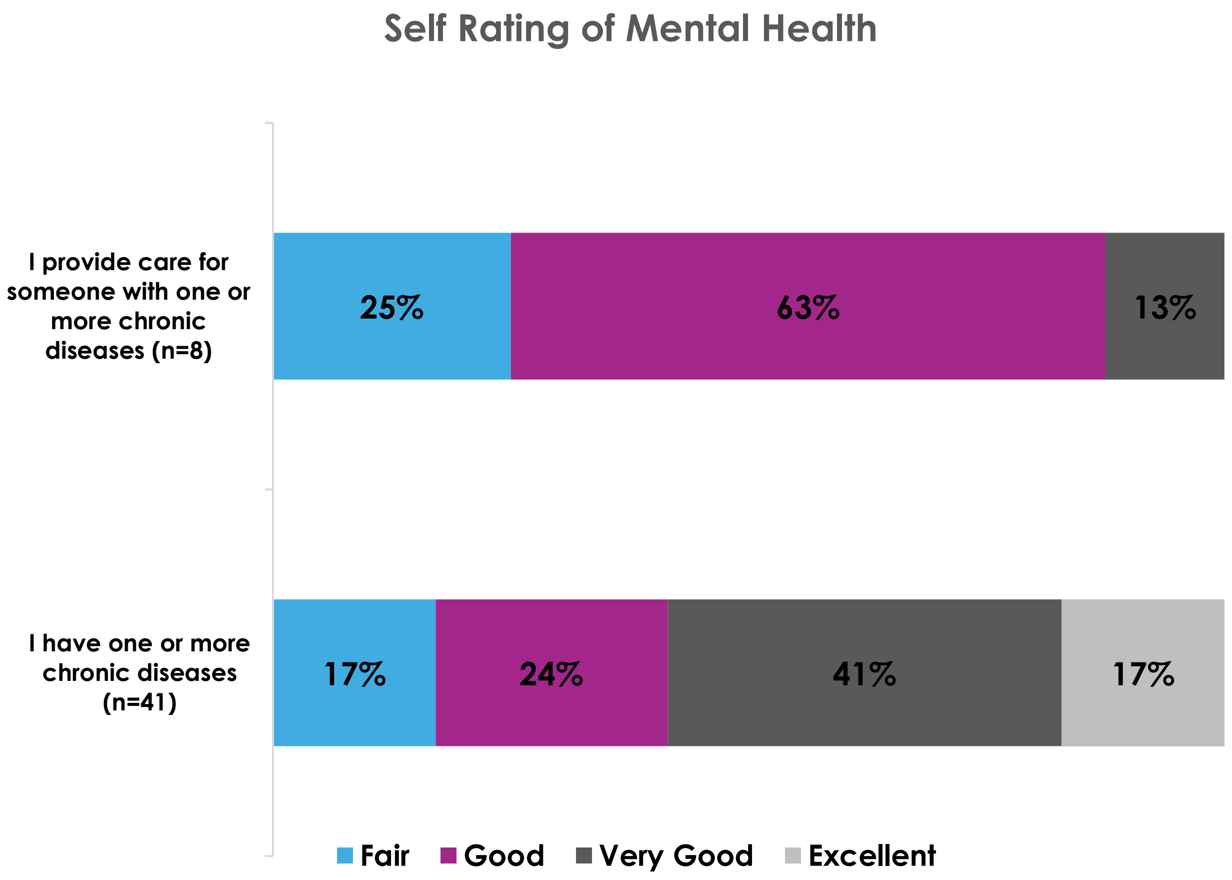
- **Most respondents (43%) spend $101-$500 out of pocket for managing chronic disease**
    - 10% do not spend anything out of pocket, while 35% spend less than $100 a month

- On average, respondents would be willing to spend **$56 per month on physical health**, but only **$28 per month on mental health**

Mental Health

Care partners rated themselves to have lower ratings of mental health compared to those with chronic diseases

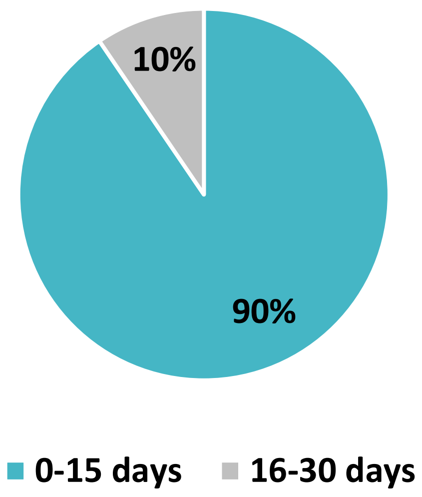
No respondents responded that they have “poor” health



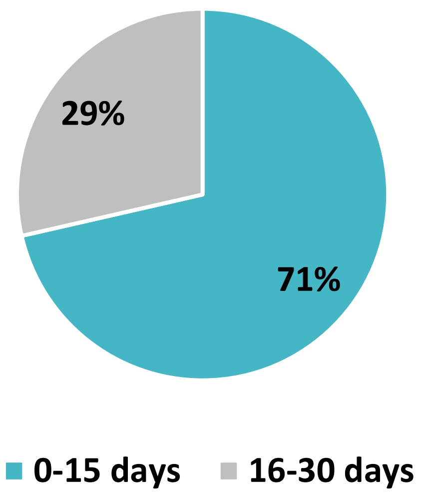
Mental Health

Most respondents said their mental health was not good for less than 6 days in the past month*

However, care partners were more likely to have more than half of a month with not good mental health



Persons with Chronic Disease



Care Partners

*Response options for this question were 0, 1-5, 6-10, 11-15, 16-20, 20-35, 26-30 days

Mental Health: Persons with Chronic Conditions

Most respondents with a chronic condition reported having no days were mental health prevented them from doing their usual activities

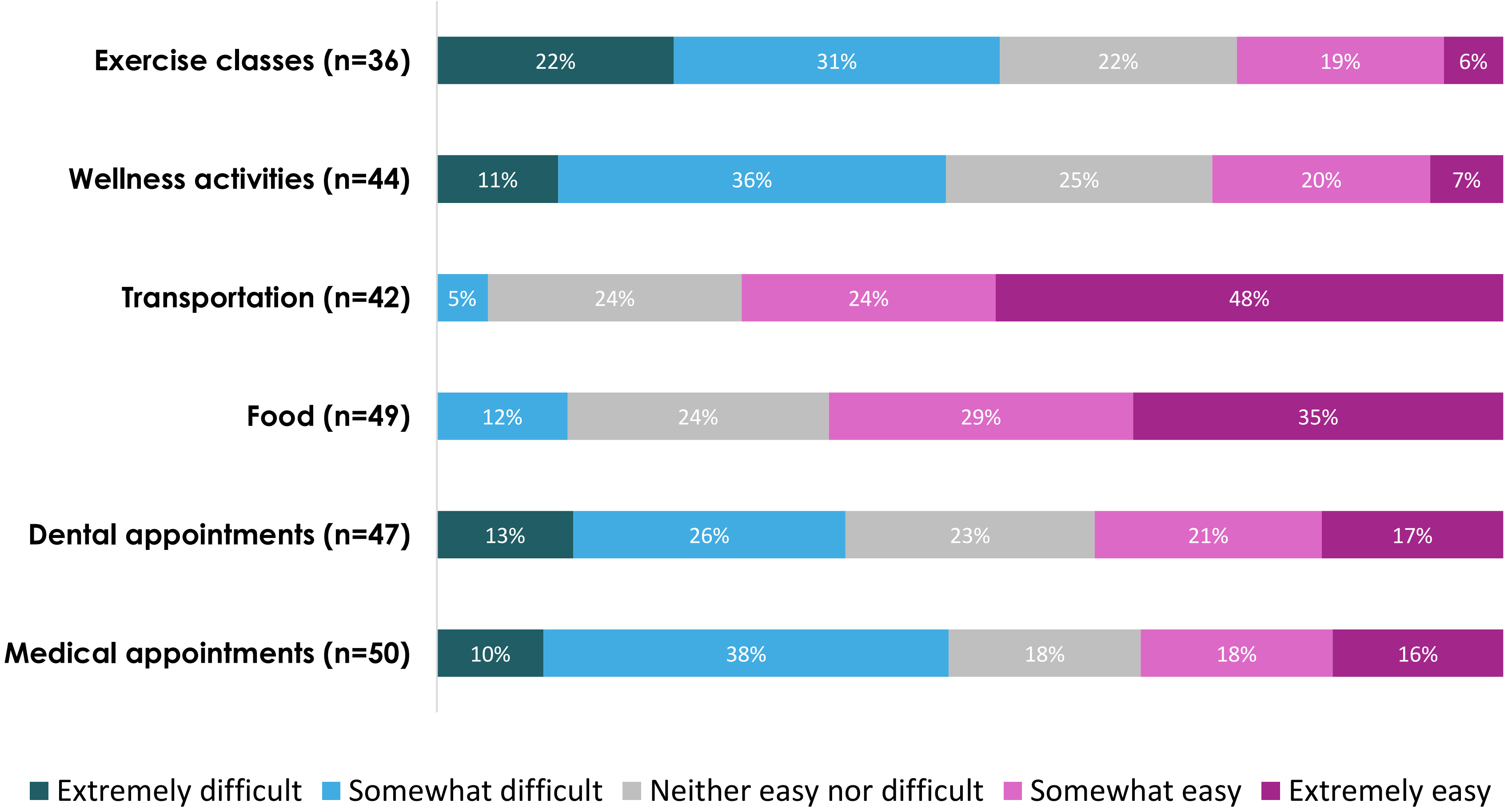
Number of days in the past month where mental health prevented respondents with a chronic condition them from doing their usual activities (n=42).

0 Days	1-5 Days	6-10 Days	11-15 Days
41%	31%	19%	10%

Accessing Services During COVID

Nearly half of respondents think accessing transportation has been extremely easy during the COVID pandemic

Exercise classes and medical appointments have been difficult for respondents to access during the pandemic


Accessing Services During the COVID Pandemic

Care Before and During the Pandemic

Ratings of health care quality have decreased during the pandemic

Before the pandemic, the mean score for rating the quality of health and wellness care was **8.06** and during the pandemic the mean score decreased to **6.61**

Recommendations

Determine how community groups or organizations can provide support to those with chronic conditions and their care partners. Most people receive support and gather information about managing their chronic condition(s) at the YMCA, primary care provider, and medical specialist. Therefore, there is opportunity for other entities to provide support or information.

Continue to provide support groups led by trained facilitators and in-person exercise classes. Respondents preferred these modalities. However, there was a minimal difference in the number of respondents preferred in-person vs. virtual educational sessions.

Provide education around the relationship between physical and mental health. Respondents said they were willing to spend more money on physical health versus mental health, however the two are related.

Provide additional support and resources for care partners. Care partners rated themselves to have lower ratings of mental health compared to those with chronic diseases.

Next Steps

Future data collection should aim to learn about:

Why persons with chronic disease and their care givers may not trust health care providers or feel that they do not do everything they should for their medical care. Nearly a fourth of respondents were ambivalent around trust with their health care providers.

Why respondents felt that caregivers and health care professionals managed their chronic disease better than themselves or wellness providers. Information should be gathered around what prevents persons from managing their chronic condition to the best of their ability.

What community services and programs may be missing from the continuum of care. Only fourteen respondents provided information about missing services or programs.

What types of apps people may be interested in using for assisting with managing their chronic disease. Most respondents (42%) might use apps to assist with managing chronic disease (e.g., exercise/calorie tracking, blood pressure monitoring).

Appendix C

Community Focus Group Protocol

Focus Group #1: Community Members with Chronic Diseases

March 31st at 10am-11am

Bangor YMCA in the Parlor

Good Morning!

We would like to thank everyone for being part of this important discussion today. My name is Kristen Pollard and I will be facilitating today's discussion. Rachel Gallo from the University of Southern Maine is here via Zoom and will be taking notes.

The Bangor YMCA has received a grant from the Maine Health Access Foundation (MeHAF) to support the identification of recommendations on how to build out more responsive, sustainable, and equitable community health models for older adults with chronic disease. In the fall we deployed a survey to gather data from YMCA members and now we are following up with a focus group to learn a bit more. We will be asking you questions about your experiences with care and the community and ideas you have for improving services and supports.

Before we get our session started, we have a few things to review:

- *Your participation is voluntary, and we greatly appreciate your feedback. Please don't feel shy—it's important for us to hear your thoughts and your experiences.*
- *If you do not feel comfortable answering a question, you do not need to provide a response.*
- *Please keep what is said today to yourself, don't repeat things outside of the session.*
- *Give each other a chance to speak and be courteous of other people's input.*
- *We will be recording the discussion today so we can capture what you have to say and not miss anything in our notes. Recordings will not be shared outside of the assessment team.*
- *We will NOT use any names in any summary of today's discussion*

Everyone will receive two $25 gift cards as a thank you upon the completion of the session.

Any questions before we get started?

Okay, if you would still like to volunteer to participate, please raise your hand.

[START RECORDER on phone and zoom]

Section 1: Individual Care

We would like to start off with discussing your perspectives related to your health. Later we will ask about providers and the community.

Question 1:

What helps you manage your chronic disease to the best of your ability?

> Examples: diet, exercise, counseling, medication management, support from specialists, etc.

Question 2:

Have you recently felt like you couldn't get the medical care you felt you needed? Please explain or provide an example.

> Probe [if you are not getting answers to the question above]:
>
> *Were you able to successfully access providers or specialists in a timely manner?*

Section 2: Provider Care

Now we would like to ask a few questions about your health care providers.

Question 3:

What could be done to improve your relationship with your health care providers?

> Probe: [if not getting responses] *What might health care providers do to earn more of your trust?*

Question 4:

Do you feel like your care and support has been coordinated between different providers?

Section 3: Community Care

The community plays an important role in providing support for individuals with chronic disease. Now we are going to discuss your thoughts on community supports.

Question 5:

What community services and programs do you wish existed to help you manage your chronic disease? That is, what community services and programs are missing from the Bangor area?

> Examples of community services and programs are: support groups, YMCA programming, palliative care, or other non-clinical places that help you manage your chronic disease

Question 6:

How can your community better assist you with your efforts to manage your chronic disease?

Section 4: YMCA Programming

Now we have a few questions specific to YMCA programming.

Question 7:

What has been the most helpful part of participating in YMCA programs?

Question 8:

What motivates you to participate in YMCA programs?

> Probe: [if not getting any responses]
>
> > *What would incentivize you to commit to a YMCA class?*

Section 5: Wrap-Up

Question 9:

Is there anything else you would like to share with us?

Thank you all for your participation! There is one handout on the table asking the question about your interest in alternative therapies, if you have a few minutes, please check off the ones you are most interested in.

Hand out gift cards

Appendix D

Community Partner Interview Protocol

Interview: Bangor YMCA Partners

I would like to thank you for being part of this important discussion today. My name is X and I will be facilitating this interview.

INTRODUCTION

As a part of the Bangor YMCA's Systems Improvement and Innovation Responsive Grant, we are trying gain a better understanding of the YMCA partners' perspectives on how we can build out a more responsive, sustainable, and equitable community health model for older adults with chronic disease.

This should take approximately 20 minutes of your time. Your participation is voluntary. No names or identifying information will be included in our summary report.

There are no anticipated risks with this interview. Your answers will help the Bangor YMCA understand gaps in the chronic disease continuum of care and identify ways to improve partnerships. Your answers will not affect your relationship with Bangor YMCA.

Do you have any additional questions before we get started?

We will be recording today's session for note taking purposes only. No one else has access to the audio recording outside of USM. Is it OK to proceed?

Okay, let's begin... [start ZOOM recording]

Section 1: Chronic Disease Continuum of Care

To start, we would like to talk about the chronic disease continuum of care. This continuum has three parts:

1. Access and quality of care over time (from diagnosis to management of disease);
2. Patient-Provider relationships; and
3. Coordinated care between medical providers and community health resources.

1. Thinking about these three components, what do you see as the biggest gaps or issues related to the chronic disease continuum of care?

2. What services do patients or community members have difficulty accessing as a part of palliative care?

Section 2: Improving Health Outcomes for Community Members

3. When a person with chronic disease leaves your medical office or community program, what do you most often feel like that person needs to successfully manage their chronic disease to the best of their ability?

   Probes: Are there specific programs or resources that are likely to help them?

4. What do you feel like you need from the community to successfully improve health outcomes for people with chronic diseases?

Section 3: YMCA Partnerships

5. The YMCA has experienced great success in direct partnerships that result in referrals to and from providers. Do you have any suggestions of how these referral pathways could be expanded or strengthened?

   Probe [if not getting enough responses to the question above]
   Can you provide any examples of how coordination between medical providers and community health programs (i.e... YMCA programs, other support groups) does or does not work?

6. As one of our partners, do you feel like you understand our offerings and programs? If not, what could the YMCA do to better advertise or share information with you?

   Probe: Do you have access to pamphlets from the YMCA? *Health Happens at the YMCA brochure*

7. [If time allows] Are there ways the YMCA could better coordinate or collaborate with community providers and organizations?

Section 4: Wrap-Up

8. Is there anything else you would like to share with us today?