

# JF&CS Memory Café Percolator Quarterly Idea Exchange

June 14, 2023



JF&CS

For more than 150 years, Jewish Family & Children's Service has been helping individuals and families build a strong foundation for resilience and well-being across the lifespan.

# Today's Agenda

1. Housekeeping
2. Announcements
3. Sara Masoud, memory café research, SA Amigos Café and Texas Café Network
4. Funding your café – results from the Percolator survey
5. Next meeting: **Thursday, September 14, 1:30 to 3:30 pm ET**
  - *Café de Los Recuerdos, Gail Borden Library, Elgin, Illinois*
  - *Café Chats: impact so far, with Dementia Action Alliance*



# Housekeeping

- This meeting is being recorded. The recording will be available at [www.jfcsboston.org/Percolator](http://www.jfcsboston.org/Percolator) in 1-2 weeks.
- Please activate your video if you are able to do so.
- Please keep your audio muted unless you are speaking.
- Please use the chat box or “raise hand” function to share your questions and comments at any time.

Say hello! Please type your name and location into the Chat box.



# Percolator Updates

- All Percolator resources are free and can be found at [www.jfcsboston.org/Percolator](http://www.jfcsboston.org/Percolator)
  - In-person and virtual/hybrid café toolkit (includes list of promo ideas)
  - Guide to Leadership & Meaningful Roles
  - PSA videos (English, Portuguese, Spanish)
  - Recorded how-to videos
  - Guest artist/activity facilitator directory
  - Join the email list



# Percolator Updates - MA

- **Massachusetts cafés** – PLEASE review your listing at [www.jfcsboston.org/MemoryCafeDirectory](http://www.jfcsboston.org/MemoryCafeDirectory)



**Submit a Memory Café**

To add a new café to our directory, [fill out the Google Form here](#). We will reach out to you via the email you provide.

**Name of Café \***

**Website URL**

**Location (Massachusetts only) \***  
[Building/Room] if applicable [Street address] [Town/city]

**Region that best fits your location \***

**Day of month or week \***  
If applicable, please note "the first Monday of the month," "the second Wednesday of the month," etc.

**Frequency \***

**Start time \***

**End time \***



# Your Updates



**TAKING IT TO THE STREETS**



**Reimagining  
Dementia**

A Creative Coalition for Justice

<https://www.reimaginingdementia.com/takingstreets>

# Your Updates



<https://goodwinliving.org/stronger-memory/>

# Your Updates

Please share your news –  
briefly, please!



**Memory Café Research**  
**SA Amigos Memory Café**  
**Texas Memory Café Network**

**Sara Masoud, PhD, MPH (She/Her)**

Program Manager | Caring for the Caregiver

UT Health San Antonio, School of Nursing



# **“We Don't Feel so Alone”**

**A Qualitative Study of Virtual Memory Cafés to Support Social Connectedness Among Individuals Living With Dementia and Care Partners During COVID-19**

Sara Masoud, PhD ([masoud@uthscsa.edu](mailto:masoud@uthscsa.edu))  
JoAnn Sharman, RN ([sharmanj@uthscsa.edu](mailto:sharmanj@uthscsa.edu))

Caring for the Caregiver  
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# Social consequences of dementia

Individuals living with dementia and their caregivers are at increased risk for loneliness and low social support.

Low social support and loneliness are associated with poorer cardiovascular, immune, and mental health.

Individuals with lower social support are at increased risk of mortality.

COVID-19 exacerbated existing barriers to social connectedness among families impacted by dementia.

# Memory Cafés for social engagement

Widely implemented intervention to provide social opportunities for families living with dementia.

Memory Cafés provide a space to socialize without worry of stigma or judgment.

Focused on capacities that remain (ability to connect with others, creative expression, and participation in groups).

Since COVID-19, most either shut down or transitioned to virtual but little is known about how virtual models can support social connectedness.

# What is a Memory Cafe?

Originated in Europe, widely implemented globally since late 1990s.

Guided by continual dialogue with attendees.

Activities are typically creatively-focused; planned around a goal to facilitate connection among attendees.

Staff are 'dementia aware' and typically have some professional training (Dementia Friends) or personal experience (past caregiving role).

No requirement to share a diagnosis; inclusive space for people of all abilities.

Since 2019, Caring for the Caregiver has hosted the SA Amigos Memory Cafe.





# **“We Don’t Feel so Alone”: A Qualitative Study of Virtual Memory Cafés to Support Social Connectedness Among Individuals Living With Dementia and Care Partners During COVID-19**

*Sara S. Masoud<sup>1\*</sup>, Kylie N. Meyer<sup>1</sup>, Lauryn Martin Sweet<sup>1,2</sup>, Patricia J. Prado<sup>1,2</sup> and Carole L. White<sup>1</sup>*

# Project framework

## COMMUNITY PARTNERSHIPS



Caring for the Caregiver



The **Caring for the Caregiver Program** partnered with the **Alzheimer's Association** and **UT Rio Grande Valley** to establish the Texas Memory Cafe Network.

A space to work together to accomplish shared goals, workshop ideas and challenges, and develop shared resources.

The Network provided the infrastructure needed to conduct the activities of this Project.

Adapted quickly post-COVID to meet goals (new partnerships, transitioned activities and interviews to virtual, amended program and IRB to accommodate Spanish-speakers)

The Network meets on an as-needed basis to provide collaborative support for Memory Café coordinators in Texas.

# Project Objectives



## **Describe characteristics of Memory Cafes to develop a Toolkit**

To create a **checklist** of Memory Cafe characteristics, we conducted a **literature review**, compiled observational **fieldnotes** at different Memory Cafes, and **confirmed final checklist** with the Texas Memory Cafe Network.

The checklist was later used to develop a **Toolkit**.



## **Describe the experiences of social connectedness among attendees when attending a Memory Café**

We conducted **in-depth individual interviews** with attendees to learn about their perceptions of how the Memory Cafes impacted their experiences of **social connectedness**.

People living with dementia and caregivers were both included in interviews.



## **Adapt and implement new Memory Cafes to meet the needs of underserved populations**

Partnerships were leveraged to establish **two new Memory Cafes** in Texas and the adaptation of the SA Amigos Memory Cafe to support families in other regions of South Texas.

**Trainings** were held for coordinators and volunteers.

# Memory Café Checklist

## Memory Café checklist

The following table was generated after reviewing the existing literature on memory cafés. Those identified as “required” are criteria that are typical of most memory cafés globally. Those identified as not required are criteria that are typical to memory cafés but are not essential to meet the definition of a memory café.

Criteria	Required	Notes
Welcoming for persons living with dementia <u>and</u> care partners	Yes	Memory Cafés are for both the family caregiver and the person living with dementia to attend together. It is not respite for caregivers or a day program for persons living with dementia.
“Open” and accessible to anyone	Yes	Persons living with dementia and caregivers who are interested in attending the memory café should be welcomed without discrimination.  Virtual memory cafés should be hosted using platforms that do not require attendees to pay for software (Zoom, Skype, Hangouts, Blue Jeans, etc.).
Location & atmosphere	Yes	In-person Memory Cafés should be hosting in accessible community locations. They should strive to create an atmosphere more like a social gathering rather than a clinical program or class.  Virtual memory cafés should also foster an atmosphere that is more socially inclined (use of video, calling people by name, encouraging use of chat box, and allowing time for attendees to speak)
Scheduled regularly	Yes	Can be weekly, bi-weekly, or monthly but all memory cafés are repeated and regularly scheduled events (typically on a fixed rotation <i>i.e.</i> , <i>second and fourth Fridays of each month</i> )
Activities focused on socialization	Yes	All memory cafés have a primary goal of promoting social interaction between persons living with dementia and caregivers with others in their communities. However, other goals might include educational, creative expression, physical activity, etc.  Virtual memory cafés should encourage socialization within households as well as between other participants in the virtual memory café.
Designated facilitator	Yes	All memory cafés are staffed by at least one “professional” facilitator. This term is loose and includes trained volunteers who are sometimes former caregivers
Tailored to attendee interests	Yes	All true memory cafés are designed to be receptive to the needs and interests of their attendees. Some attendees might prefer a less active role in planning but are regularly consulted on their preferences for activities, meetings times and dates, etc.

Coffee, tea, refreshments	No	All in-person memory cafés should offer some form of refreshments which contribute to a more relaxed atmosphere.  Virtual memory cafés do not require this criteria though participants can be encouraged to prepare a cup of tea or coffee before sitting down for the virtual event.
Registration	No	Some memory cafés do not require registration and focus on encouraging people to just show up. Most memory cafés, though, have some formalized system of registration to keep track of who is attending.
A range of diverse activities	No	Most memory cafés will explore a range of entertaining, education, and/or creative activities. While this is the typical model for a memory café, some prefer to stick to one or two activities each time.
Planned activities	No	Not all memory cafés have structured activities. Many simply meet to chat and share coffee with others
Part of a Memory Café “Network”	No	Many memory cafés participate in Memory Café Networks to share their experiences and lessons learned with other facilitators.
Volunteers	No	Many memory cafes are staffed by volunteers in addition to a designated facilitator though smaller groups might not need the extra support
Funded by donations and grants	No	Most memory cafés are funded by grants and/or donations though some are funded by private organizations as part of their community service/engagement budgets.
Documenting attendees	No	Not all memory cafés take attendance but most do. A sign-in sheet, roll call, and even demographic data collection might occur before, during, or after the scheduled memory café gathering.
Evaluation	No	Many memory cafés will have some way to evaluate whether their gatherings are meeting the needs and interests of their attendees.  This might be in a questionnaire given annually, periodically, or after each gathering. Some are collected online and some are collected during the gathering. Many simply “check in” with their attendees before ending their event to see if the event was enjoyed.

# Study Timeline

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## **LITERATURE REVIEW (MONTHS 1-2)**

Two members of the team conducted independent reviews of the literature to find any publications assessing Memory Cafes. Meetings with Co-PIs were held periodically to refine keywords and compare findings. The review informed the initial draft of the checklist components.

## **FIELDNOTES (MONTHS 2-4)**

Co-PIs observed five Memory Cafe sessions hosted by three members of the Texas Memory Cafe Network. Notes were thematically analyzed and findings were used to refine the initial checklist. The checklist was reviewed at a quarterly Network meetings to invite feedback and recommendations.

## **CREATING THE TOOLKIT (MONTHS 8-11)**

Findings from the literature review, fieldnotes, and thematic analysis of interview data were used to develop the toolkit. The outline of the toolkit was presented to the Network for insight in January 2021. A subgroup of Network volunteers will review and refine the final version of the Toolkit.

## **PUBLISHING FINDINGS (MONTHS 10-12)**

A manuscript of findings was published in *Frontiers in Public Health* and shared in community presentations, including with the TMCN.

# Individual Interviews



# Research Participants

17 in-depth individual interviews from three Memory Café partners in the TMCN.

For perspective, interviewed individuals who stopped attending post-COVID (n=2).

Interviews conducted via Zoom, recorded, transcribed, thematically analyzed by two independent coders.

Preliminary findings shared with Network for their insight

Table 1. Participant demographic details

N = 17	n (%)
<b>Persons living with dementia</b>	5 (29.4)
<b>Care partners</b>	12 (70.6)
Spouse	8 (66.7)
Adult children	4 (33.3)
<b>Gender</b>	
Female	11 (64.7)
Male	6 (35.3)
<b>Language</b>	
English	15 (88.2)
Spanish	2 (11.8)
<b>Format</b>	
In-person only	2 (11.8)
Virtual only	9 (52.9)
Both	6 (35.3)

# Thematic Analysis

FIVE FINAL THEMES & SUB-THEMES

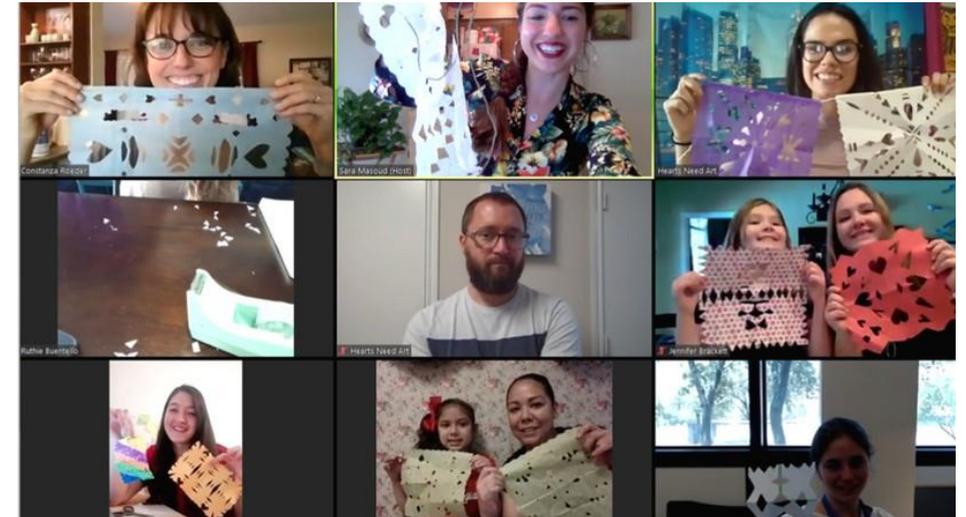
- **REPRIEVE**
  - Something to look forward to
  - Break from daily life
- **WHAT IS STILL POSSIBLE**
  - Highlighting capacities and strengths that remain when living with dementia or caregiving
- **CONNECTEDNESS**
  - Feeling of belonging (part of the group)
  - Sense of community (shared experiences; peer support)
- **INCLUSIVITY**
  - Accessibility (planning; staff; responsiveness)
  - Diversity (culture; language)
- **VALUE ADDED**
  - Cognitive stimulation
  - Education
  - Resources
  - Helping others





*“I get to talk to other caregivers. He gets to talk to people in his situation... it helps because we don't feel so alone, so isolated I guess, and the understanding of what we're going through each one of us when we go into the groups, we just - okay, we're accepted.” – Spousal care partner*

*“I think it's the social part that it's helped with. I would have to say that's the biggie. You're not so isolated.”  
– Person living with dementia*



# Conclusion

**Findings from this study establish a framework for future evaluation of the specific mechanisms that influence the social connectedness experiences of Memory Café participants.**

Virtual models may meet important needs for social connectedness, but are often not accessible to everyone (digitally excluded households and persons living with more advanced dementia).

Increased intentionality in planning online models is critical to the facilitation of meaningful engagement between participant households.

**Findings have implications beyond COVID-19, especially when trying to extend resources and support to other geographic regions and communities that are excluded from health and service infrastructure and resources.**

Future research should investigate the experiences of persons living with dementia who attend Memory Cafés and quantitatively evaluate the extent to which participation improves the health and quality of life of participants.

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# Project Summary



**CREATE MEMORY  
CAFE CRITERIA  
CHECKLIST TO  
DEVELOP  
TOOLKIT**

**ASSESS IMPACT  
ON EXPERIENCES  
OF SOCIAL  
CONNECTEDNESS**

**ADAPT & ESTABLISH  
NEW MEMORY  
CAFES TO SUPPORT  
UNDERSERVED  
POPULATIONS**

**SUBMIT  
MANUSCRIPT OF  
FINDINGS FOR  
PUBLICATION**

**PUBLISH TOOLKIT  
TO SUPPORT THE  
SUSTAINMENT OF  
VIRTUAL  
MEMORY CAFES**





# TEXAS MEMORY CAFÉ NETWORK

## Virtual Memory Cafe Toolkit

Members of the Texas Memory Café Network collaborated to develop this resource to support the establishment and sustainment of virtual memory cafés. Our efforts were supported by the UT Health San Antonio Institute for the Integration of Medicine and Science through a Community Engagement Small Projects Award. Our hope is that this toolkit will offer insight and guidance needed for community partners to develop programs that improve the well-being of families living with dementia through opportunities for social engagement.

**Toolkit development overseen by:**

Sara Masoud, MPH  
Founder, Texas Memory Café Network  
Community Outreach Coordinator, Caring for the Caregiver  
UT Health San Antonio, School of Nursing  
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[masoud@uthscsa.edu](mailto:masoud@uthscsa.edu)

**THIS TOOLKIT WAS DEVELOPED BY THE TEXAS MEMORY CAFE NETWORK (TMCN)**  
The TMCN is a group of Memory Cafe coordinators, community partners, and families living with dementia who work together to improve the quality and quantity of Memory Cafes in Texas.

### Memory Café Resource Pack:

<https://drive.google.com/drive/folders/10XdseU8WjW0dnuBJLbMLLuS0klnF5OWA?usp=sharing>

# Project Team

Carole White, PhD, RN, FAAN (PI)  
Sara Masoud, PhD (Co-PI)  
Kylie Meyer, PhD (Co-I)  
Ginny Funk, MS (Co-I)

JoAnn Sharman, RN (Program Manager)

Lauryn Sweet Martin (Research Assistant)  
Patricia Prado (Research Assistant)

Noe Garza, DDS, MPH, DPH (UT RGV Consultant)

# Texas Memory Cafe Network

Arden Courts Memory Cafes  
Camille's Memory Cafe  
SA Amigos Memory Cafe  
The Forget-Me-Nots  
Alzheimer's Association  
The Glenn Biggs Institute  
Catholic Charities of San Antonio  
WellMed Charitable Foundation  
Dementia Friendly San Antonio  
Memories International

# Acknowledgements

The **Percolator Network** provided the foundation for the start of all this work. In 2018, our program joined the Percolator Network before starting the only Memory Café in San Antonio at the time.

We continue to turn to Beth Soltzberg and the Percolator Network for guidance and support as we try to adapt our programs to meet the needs of our communities here in Texas.

Thank you!



# Discussion



# Stretch break!



# **Funding Your Café**

**Results from the  
Percolator Funding Survey**

**...and sharing our pearls of wisdom!**

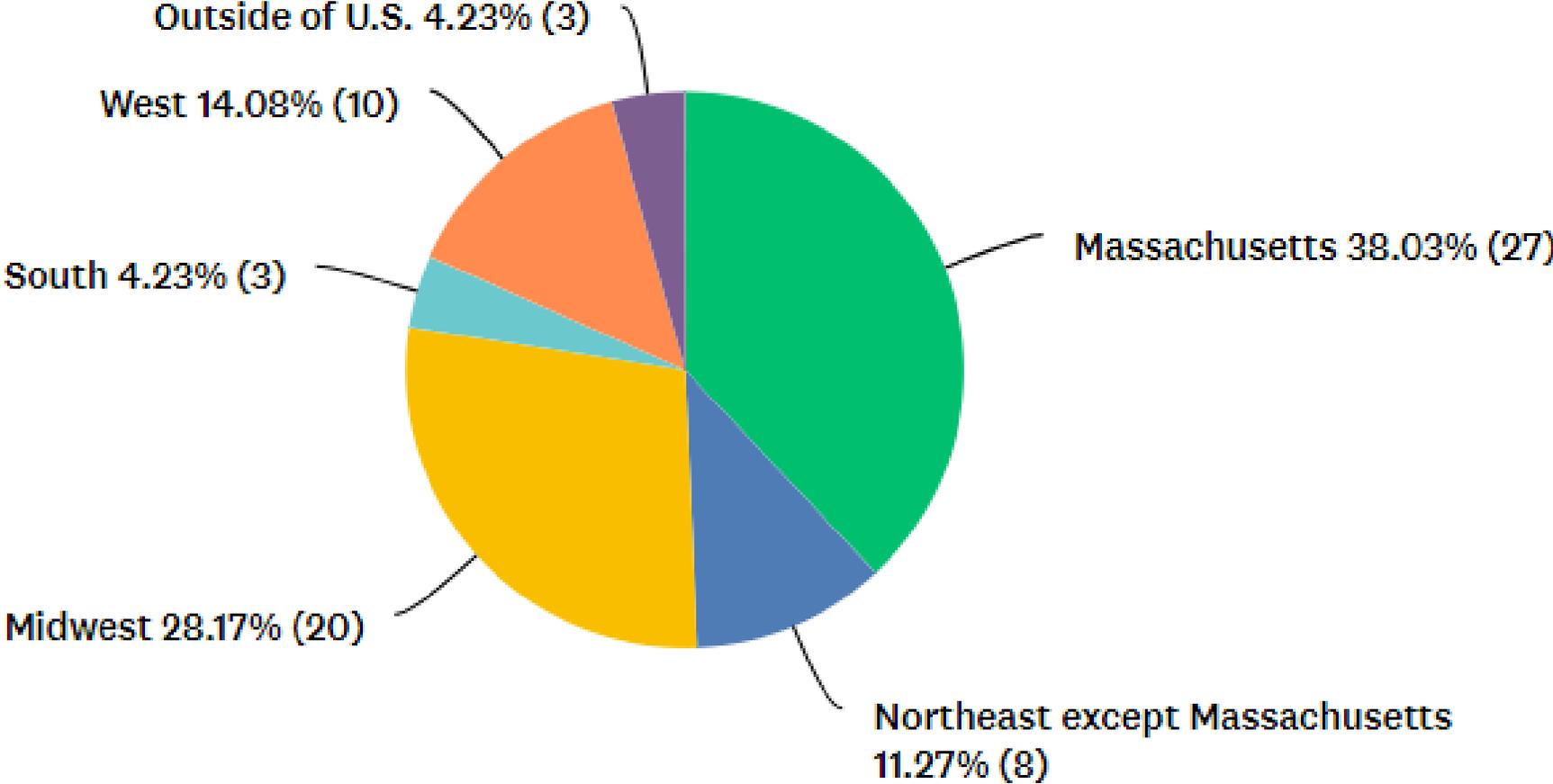


# Let's talk about FUNDING!!

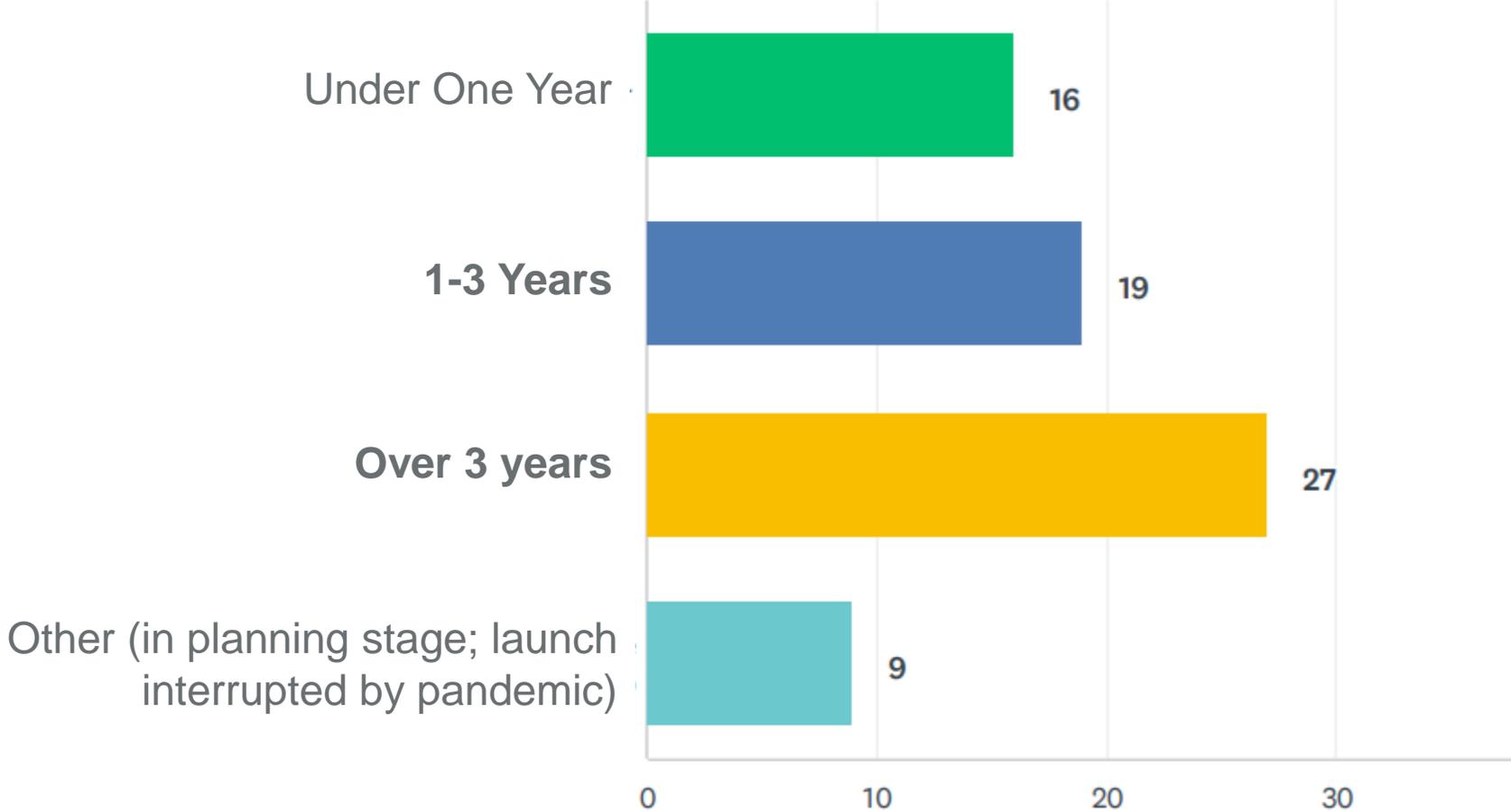
- Results of Percolator funding survey
- Pearls from several café coordinators:
  - Nicolette Farmington, Hummingbird Memory Café, Nevada
  - Gail Sonnesso, Harmony Café, North Carolina
  - Kathi Hayen, Memories in the Making, Wisconsin
  - Vicky Pitner, Engaging in Life!, Florida
  - Mary E. MacDonald, Rest.Stop.Ranch, Massachusetts
- Laundry list of café funding sources
- Open discussion!



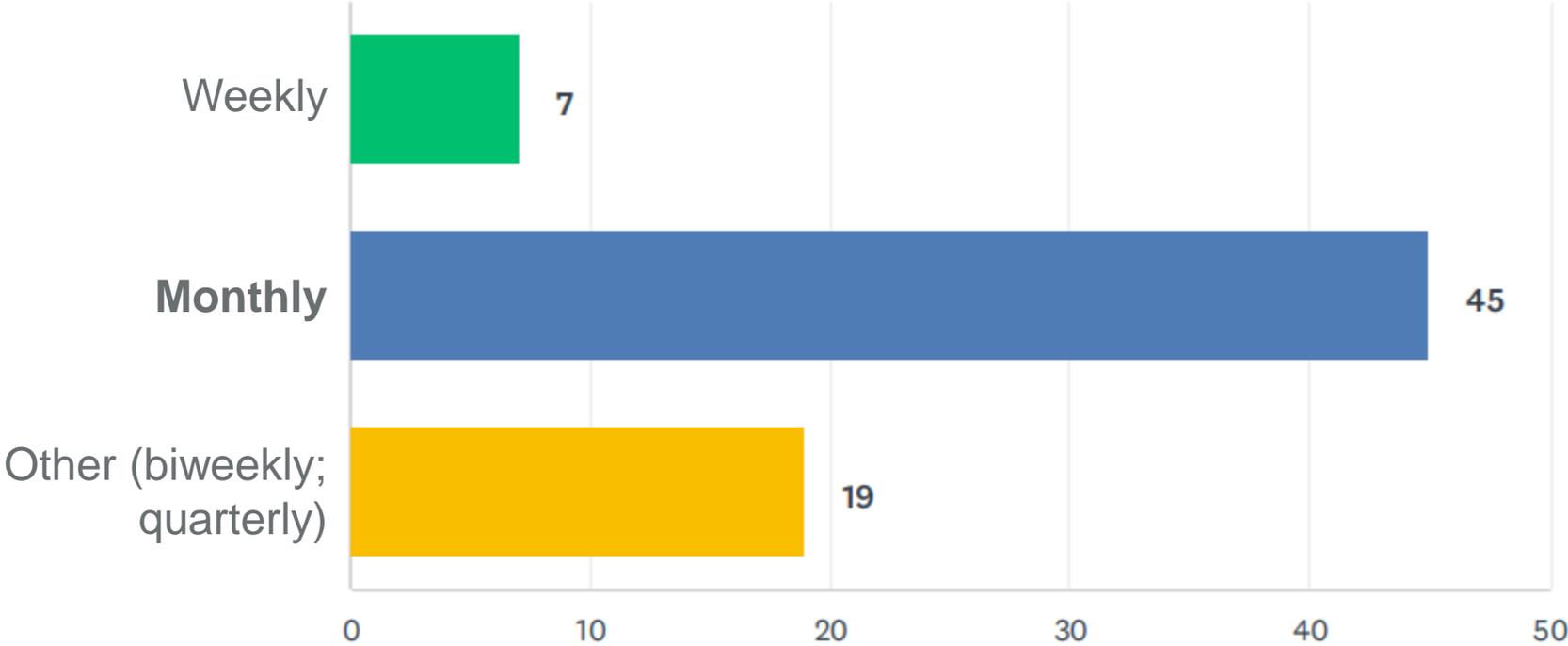
# Percolator Funding Survey (n=71)



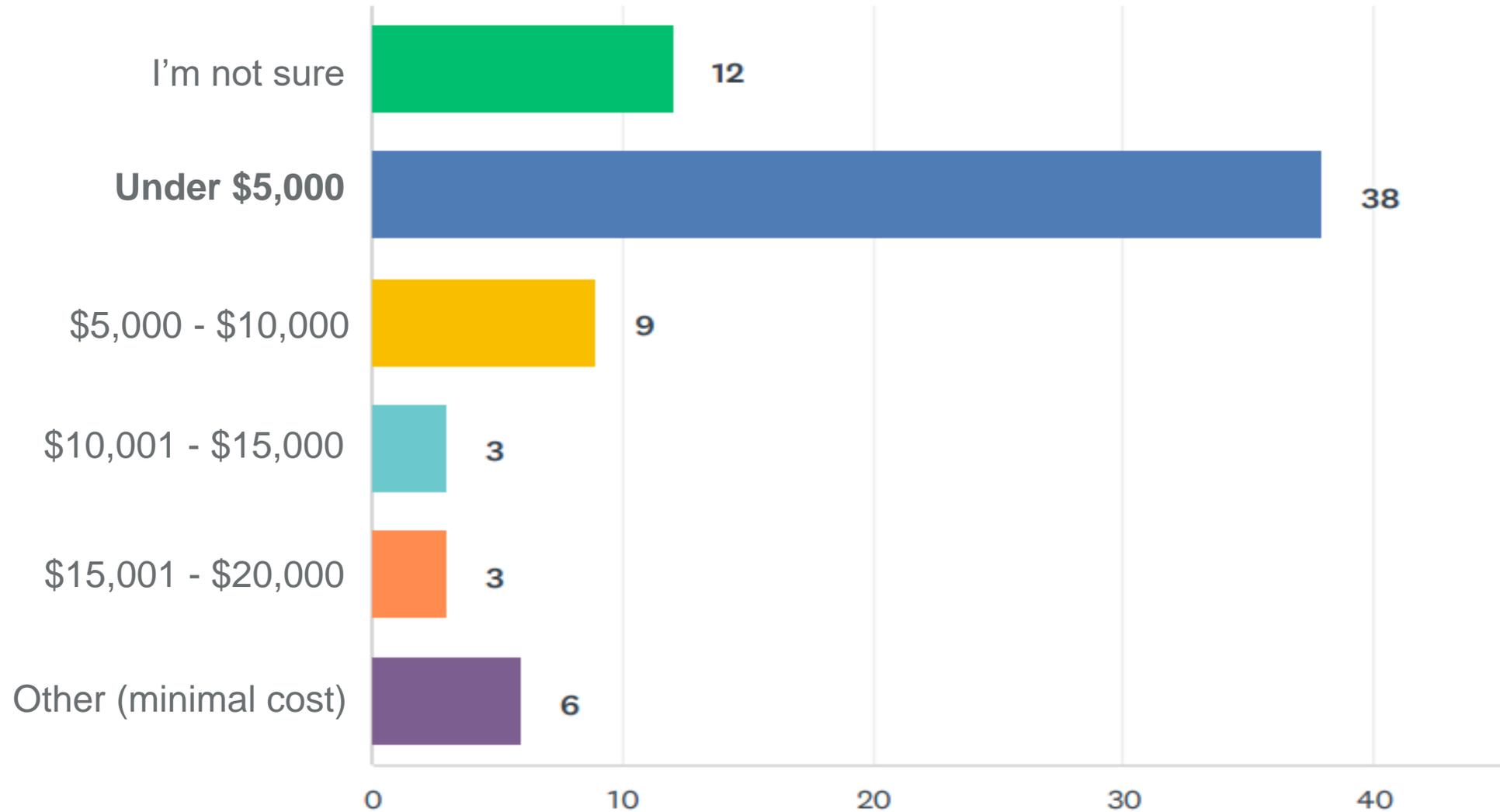
# How long has your café been running?



# How frequently does your café meet?



# Approximately how much does your café cost per year, including staff time?



# Accounting for cost of Coordinator's time

Estimates based on 2-hour meeting once per month

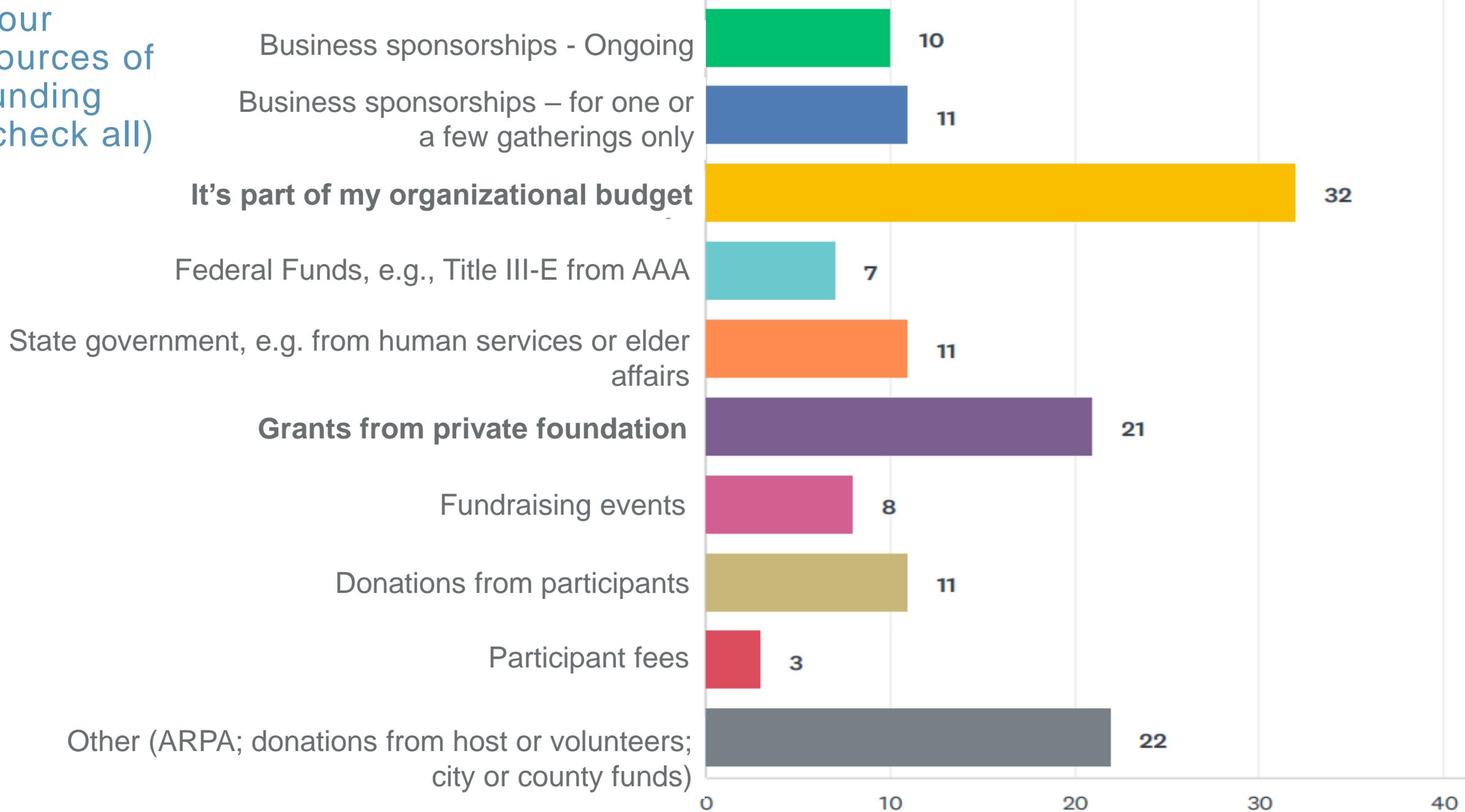
Task	Hours per month	Notes
Purchasing food for café	1.5	
Setting up for café	2	
Hosting café		
Cleaning up from café		
Planning program for café sessions		
Updating flyer		
Mailing to café guests and providers		
Entering new guests' information in mailing list		
Miscellaneous, such as developing and writing policies, answering questions from callers		
Outreach	1	this requires 5+ hours in the early months
Volunteer coordination	2	
<b>Total hours per month</b>	<b>20.5</b>	

<b>Estimated cost of Café Coordinator's work</b>			
Hours of work per Café gathering	Hourly Rate	Total per gathering	Annual labor cost
20.5	\$20	\$410	\$4,920

English: [www.jfcsboston.org/MemoryCafeToolkit](http://www.jfcsboston.org/MemoryCafeToolkit)

Spanish: [www.jfcsboston.org/GuiaCafeDeMemoria](http://www.jfcsboston.org/GuiaCafeDeMemoria)

Your sources of funding (check all)



# Sources of funding reported to be a **significant** part of the café budget\*

- Line item in organizational budget
- Grant from private foundation
- State or federal funds
- ARPA funds
- Donations from volunteers, and honorary/memorial donations from families (including donation of volunteer time to run the café)
- Business sponsorships

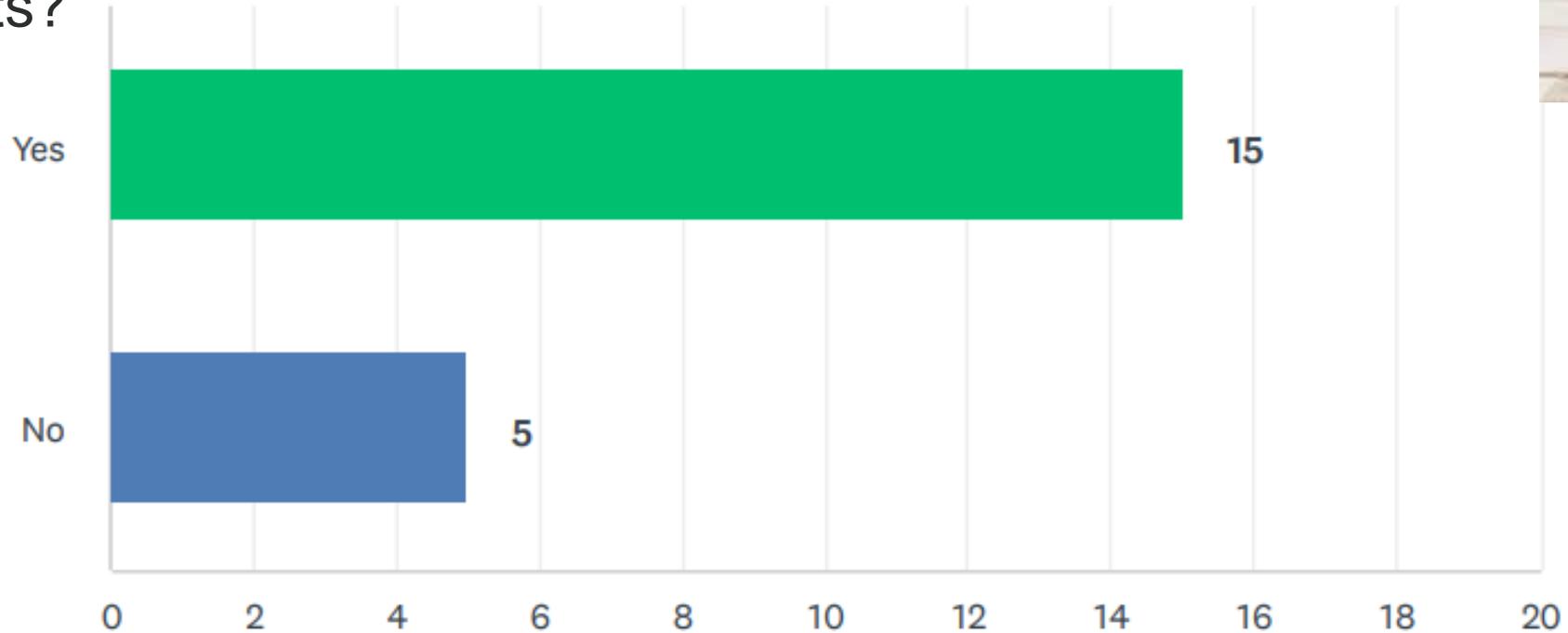
\*At least some respondents reported that this source of funding comprises a medium part or most of their café budget

# Sources of funding reported to be a **smaller** part of the café budget

- Participant fees
- Participant donations
- Fundraising events

# It's not just about the dollars

Do your business sponsors give you in-kind donations, such as refreshments?



# Your pearls of wisdom

- Search Pro Publica (free!) and look at 990s ([www.propublica.org](http://www.propublica.org))
- Ask community foundations for grant-writing assistance and to suggest other funders to try.
- Seek a planning grant to start a café.
- If your grant proposal is rejected, ask why. Get feedback!
- Connect with your local branch of Association for Fundraising Professionals and other non-profit marketing groups.
- Consider partnering with other nonprofits to seek a grant together.
- Be prepared to network and establish contacts over time, and to educate potential funders about cafés and dementia friendly concepts.



# Your pearls of wisdom

- ASK! Reach out to clubs (Rotary, Lions, etc), local colleges, businesses. Many people have a connection to dementia and talking about it reduces stigma!
- Keep your café simple and sustainable.
- If you hold a café at a bakery or restaurant, participants can purchase their own food.
- Many people will donate their talents and lead programs for free.



# Your pearls of wisdom

- Collaborate with other organizations to help with outreach and other resources.
- Some cafés get few donations from participants. Some get sustaining funds from volunteers or families in memory of a participant.
- Tell your story. “When you tug at the heart strings, you pull the purse strings.”
- Social isolation is in the news. Explain how cafés help to connect people.
- Set written guidelines for business sponsors.



# Your pearls of wisdom

- Some café providers have seen significant budget cuts and need to simplify their program.
- One café charges \$5-10 per person and finds that people are more likely to show up if they pay for it.
- Some large businesses have foundations. Speak to a manager.
- Community banks have small foundations, and may connect you with family foundations.
- Some regions and cities have foundations.



# Laundry list of funding sources for cafés



- **Federal, state, county government:** ACL (federal – large grants), Area Agency on Aging (National Family Caregiver Support Program-Title III-E; won't cover food), state Council on Aging organization
- **Foundations:** corporate foundations (banks, supermarkets, assisted livings, etc.), private/family foundations, community foundations, town foundations
- **Charitable organizations:** United Way, Area Agency on Aging, Alzheimer's Association
- **Service Clubs:** Rotary, Elks, Lions, Knights of Columbus, etc.
- **Business sponsors:** home care companies, residential communities, "Main Street" businesses, etc.
- **Collaborating organizations:** library, residential community, dementia friendly community initiatives, YMCA, faith-based organizations
- **In-kind:** food (ask grocery stores, restaurants, residential communities), art supplies, guest artist honoraria
- **Participant donations:** in honor/memory of; donation jar or donation envelopes at café gatherings, annual or bi-annual solicitation
- **Participant fees**
- **Fundraising events:** annual pledges, gala events, etc.

# Pearls from Café Coordinators

- Nicolette McDermott-Ketchum, Hummingbird Memory Café, Nevada
- Gail Sonnesso, Harmony Café, North Carolina
- Kathi Hayen, Memories in the Making, Wisconsin
- Vicky Pitner, Engaging in Life!, Florida
- Mary E. MacDonald, Rest.Stop.Ranch, Massachusetts



# Discussion



# Save the date!

**Next Percolator Idea Exchange is Thursday, September 14,  
1:30 – 3:30 EDT**

Learn about:

- Café de los Recuerdos, Elgin, Illinois
- Dementia Action Alliance: debrief from Café Chats; promoting leadership and engagement among your café participants

*Coming in December:*

- *Memory Café Nova Scotia – launching a network of rural cafés*
- *Update on Alzheimer’s Association resources for your café*

Please let Beth know if you’d like to present your café or suggest a topic for a future idea exchange!



# JF&CS Memory Café Percolator Quarterly Idea Exchange

Wednesday, June 14, 2023



JF&CS

For more than 150 years, Jewish Family & Children's Service  
has been helping individuals and families build a strong  
foundation for resilience and well-being across the lifespan.