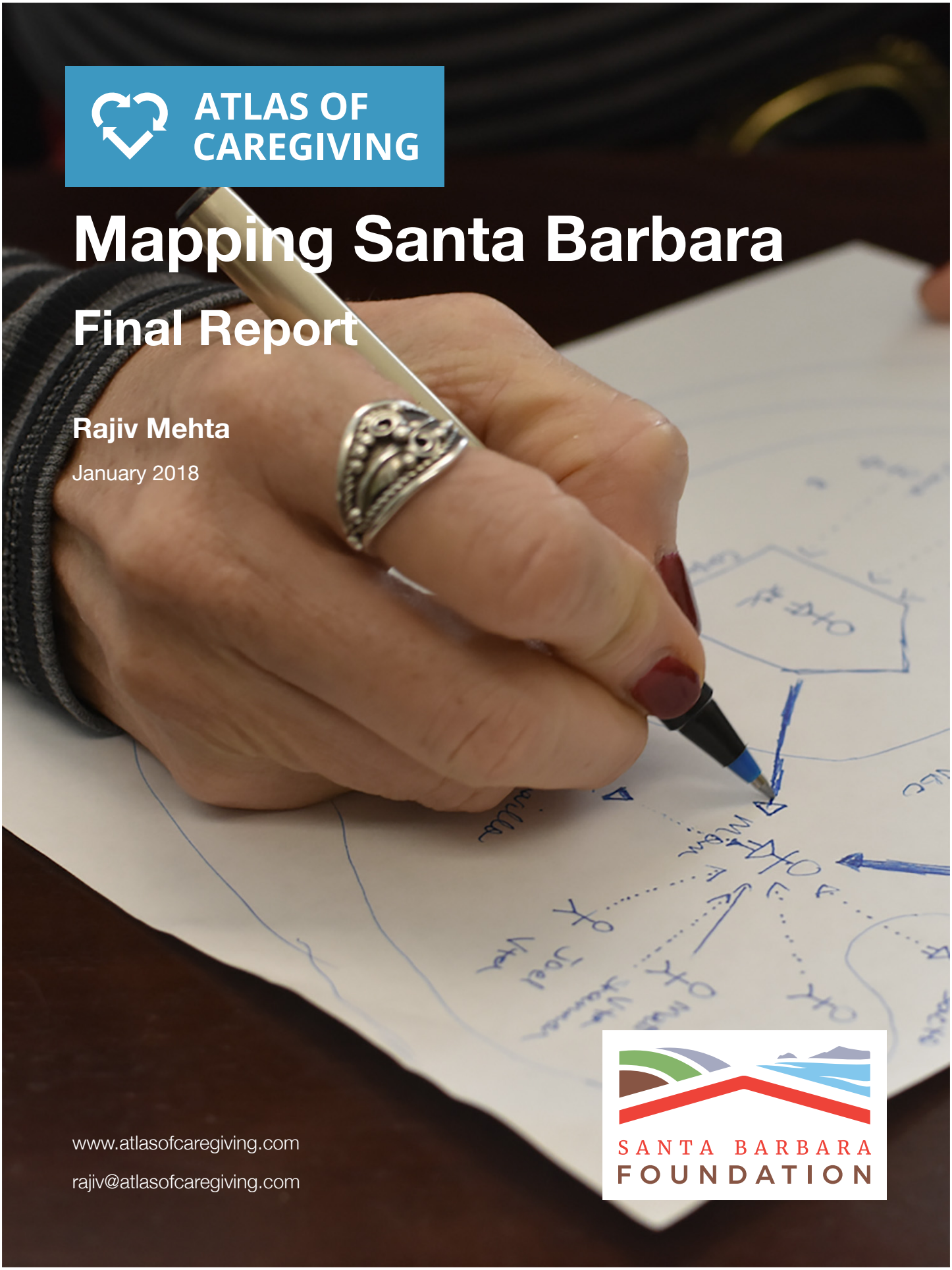

ATLAS OF CAREGIVING

Mapping Santa Barbara

Final Report

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January 2018

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SANTA BARBARA FOUNDATION

Foreword

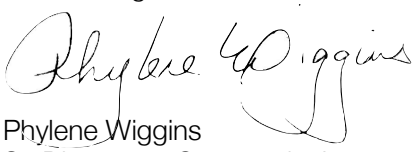
January 2018

The Santa Barbara Foundation was pleased to partner with the Atlas of Caregiving on the Mapping Santa Barbara project. The purpose of the project was to accelerate understanding about the lived experience of family caregivers that in turn would inform the foundation's Community Caregiving Initiative. When the project launched, we didn't know what we were in for and what an amazing opportunity it was! The findings were nothing short of transformative—both on a personal level and a community level. Probably the most important, we learned how to help family caregivers see and grasp their caregiving in the fullest sense of the word.

The first part of the project was to explore the potential impact of the Atlas CareMap tool. One of the partner organizations for this research was the Promotores de Salud, a group of lay health workers who conduct community outreach in the Latino community on topics related to health issues. As in most communities and ethnic groups, caregiver self-identification is very low in the Latino population. Caregiving is simply an assumption of what it means to be a family member—not a specific activity with real impacts. This lack of self-identification is a huge impediment to understanding and addressing the impacts of caregiving. When the Atlas CareMap tool was introduced to the promotores, suddenly caregiving was translated from "it's just what we do" to a picture of the real situation. Drawing their Atlas CareMaps, the promotores could see their caregiving—its activities, its frequency, and its context. They could see themselves as caregivers. In fact, so many of the promotores now recognize and acknowledge their caregiving that it has become an important means of understanding and supporting each other. This learning was quite amazing. Based on this and similar responses in other contexts, Atlas CareMaps are on the way to becoming embedded in community-based services and healthcare.

Another part of the project was an opportunity to use tools and technology to more deeply understand the caregiving experience. This work included a small group of six family caregivers who tracked their lived experiences using guidance from Rajiv, Dawn, and Susan in monthly meetings. As a family caregiver myself, I was part of the group of six. I was surprised at the depth at which the Atlas team was able to help us with reflecting and discovering meaning in personal data. I've been using a Fitbit for several years, but generally look at it daily and perhaps weekly to make sure I've exercised and gotten sleep. Before this project, I never used it to reflect more deeply on what was trending in other aspects of my life. This was an opportunity to go deeper. I could now see my daily data aggregated, and tie that information back to situations that were going on at particular times. It gave me greater insight into the nuances of my reactions. The empowerment that results from this level of personal knowledge is what is needed to help a family caregiver manage their often stressful circumstances. Once data is captured and reflected on, it becomes an opportunity for choice, and the choice is what is needed to drive transformation.

The self-generated data gathered and used for Mapping Santa Barbara is vibrant, personal, and alive. The tools used are simple, yet they can unlock new knowledge for change. If we can find ways to help others learn the value of this kind of information and reflection, we will find ourselves and our communities empowered in ways we never realized. I fully expect that the knowledge developed through this project will inform a variety of new efforts to move family caregiving from one of the most overlooked contributions in society to an acknowledged community issue that we can reflect on and address together.



Phylene Wiggins
Sr. Director of Community Investments and Director, Community Caregiving Initiative
Santa Barbara Foundation
Santa Barbara County, California

SANTA BARBARA FOUNDATION

The Santa Barbara Foundation, located on the south-central coast of California, was established in1928 by Max Fleischmann and a forward-thinking group of individuals who wanted to enrich the lives of people from Santa Maria to Carpinteria. For 90 years, the Santa Barbara Foundation has been at the center of civic activity, a vibrant expression of its engaged citizenry, a solver of problems, a partner in philanthropy, and a critical supporter of community organizations and efforts.

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Executive Summary

In late 2016, the Santa Barbara Foundation awarded an Accelerator Grant to Atlas of Caregiving for the "Mapping Santa Barbara" project. The decision was based on the community's positive response to Atlas' CareMap Workshops (held February 2016), on the success of the Robert Wood Johnson Foundation-funded Atlas of Caregiving Pilot[1] project, and on AARP's commitment to also fund Atlas efforts.

Local institutions Family Service Agency (FSA), Marian Regional Medical Center, and Promotores de Salud were key partners in Mapping Santa Barbara.

Mapping Santa Barbara had two project elements. One was to "Explore CareMap Adoption and Impact" through exposing many people to the Atlas CareMap concept and exploring how the partner institutions could incorporate Atlas CareMaps into their own efforts. (An Atlas CareMap, simply described, is a diagram of a family's care ecosystem, showing who is caring for whom and how.) Overall, more than 100 people participated in twelve Atlas-led CareMap Workshops, held in either English or Spanish. These Workshops taught participants how to hand-draw their own Atlas CareMaps, and how to learn and act upon what they had drawn. About 30 staff and volunteers from the local partner institutions also received training to lead such workshops themselves.

The response to the Workshops and the training was very positive. Many reported transformational changes in their lives resulting from what they discovered about their own caregiving situations. Many participants have gone on to teach the Atlas CareMap to family, friends, colleagues, and other other community members. FSA and Marian social workers have found CareMaps very useful in their work. Promotores describe a profound change in their impact on their community. The basic learnings are: that the Atlas CareMap is a powerful self-learning tool; that people find it easy to teach others and are motivated to do so; and that this individual empowerment leads to community-level change. As a result, many organizations across Santa Barbara County, private and public, have adopted Atlas CareMaps as fundamental to their efforts and/or are eagerly exploring how to do so.

Workshop participants and the local institutional partners have also informed the design and development of a digital Atlas CareMap tool (released to the public in January 2018).

The other project element, called "Mapping Yourself With Guidance", meant to extend the kind of research conducted in the Atlas of Caregiving Pilot, explored new methods for helping family caregivers investigate and assess their own caregiving activities and contexts. Experts provided guidance on tools and methods caregivers could use for this purpose, as well as on how to think about and glean meaning from the data collected, while the caregivers themselves collected data and reflected on their findings. Six caregivers participated in four, monthly sessions. They experimented with sensor devices to track movement and sleep; paper-based tools (the Atlas CareMap, and a newly developed visual activity log) to track activities, interactions and emotions; and a concept of "track-1-thing" to understand the impact of just one type of activity.

The response from participants about the overall Mapping Yourself With Guidance effort was uniformly and strongly positive — they gained new and deeper insights into their situations, seemed to enjoy trying new things, and found the discussions worthwhile. It was clear, from participants' comments and body language, throughout the four meetings, that they were very

[1] The final report of the Pilot study can be found here (https://atlasofcaregiving.com/pilot-study/). You can view case studies online, and download the report and visualizations.

pleased with the project and were learning a lot about themselves and their caregiving situations. The Atlas team also learned a lot about the value of the various tools and methods, and about caregivers' abilities to carry out such experiments and learn about themselves.

People in caregiving and health fields, across the US and the world, have heard about and been inspired by Mapping Santa Barbara. Team members have been invited to present the project and findings at leading conferences around the world. In addition, experts in the social sciences field have also been interested in the ground-breaking methods of this project.

The transformational impact both the Atlas CareMap-related and Mapping Yourself efforts have had on individuals, families and the community points to several opportunities to dramatically improve family caregiving in Santa Barbara County. There are obvious opportunities to extend and expand the Atlas CareMap and Mapping Yourself efforts. There is also an opportunity for more fundamental change, combining a focus on individual caregiver empowerment with the encouragement of peer-to-peer learning and support, to unleash community wisdom. There are also opportunities to explore some interesting questions raised in the project, about the extent of ethnocultural differences in caregiving, and potential disconnects between the public and health professionals.

The Santa Barbara Foundation was bold in providing Atlas of Caregiving an Accelerator Award for an innovative, but unproven, effort. The investment has paid huge dividends, in both immediate impact and in showing the way forward to a bright future.

Acknowledgements

Many people were involved in the design and execution of this project.

Key members of the Santa Barbara Team included:

- Santa Barbara Foundation
  Phylene Wiggins, Senior Director of Community Investments
- Family Service Agency
  Lisa Brabo, Executive Director
  Cynthia McNulty, Senior Services Program Manager
- Marian Regional Medical Center
  Kathleen Sullivan, Vice President Post Acute Care Services
  Tina McEvoy, Care Transition Program Coordinator
  Mary Amedeo, Family Care Navigator
- Promotores de Salud
  Georgene Lowe, Coordinator, SBCEO Health Linkages
  Josefa Rios, Health Advocate, SBCEO Health Linkages
  Maribel Landeros, Health Advocate, SBCEO Health Linkages

The Atlas of Caregiving team included Rajiv Mehta, Gabriel Acosta, and Susan Williams.

Several Atlas of Caregiving advisors were involved in the Mapping Yourself portion of the project: Dawn Nafus, Anthropologist, Senior Research Scientist, Intel (whose time was generously donated by Intel); Gary Wolf, Co-founder Quantified Self and Contributing Editor, Wired; and Jon Cousins, Founder, Signpo.st.

Giorgia Lupi, a Partner at the data-design firm Accurat, also contributed to Mapping Yourself.

Heikki Räisänen, CEO of Finland-based device company Emfit, lent sensors for Mapping Yourself.

AARP, through the leadership of Bob Stephen, Vice President Caregiving and Health Programs, funded complementary projects at the Santa Barbara Foundation and at Atlas of Caregiving. This funding indirectly supported the work of this project, and amplified its impact.

Project Background & Objectives

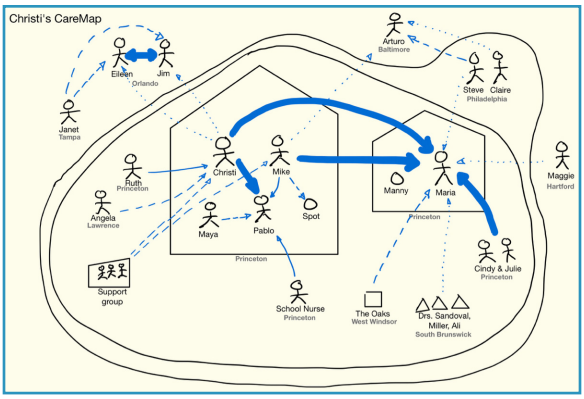
Background

Independent efforts at Atlas of Caregiving and at Santa Barbara Foundation came together in the Mapping Santa Barbara project.

The 2015-2016 *Atlas of Caregiving Pilot* project, funded by the Robert Wood Johnson Foundation, was in response to the findings of a 2014 expert roundtable, co-led by Rajiv Mehta, on *Catalyzing Technology to Support Family Caregiving*. In late 2015, an RWJF blog post mentioned the Atlas Pilot.

In 2014 the Santa Barbara Foundation began it's Community Caregiving Initiative (CCI), led by Phylene Wiggins, with a focus on supporting family caregiving in the county. As a result, Foundation staff were paying attention to leaders in the field, noticed the RWJF post, and contacted Atlas of Caregiving to learn more about the Pilot.

Phylene Wiggins was especially intrigued by a recent Atlas blog post, by Rajiv Mehta and and Jon Cousins, on Atlas CareMaps. Phylene and Rajiv discussed the idea of holding live, in-person workshops to teach CareMapping[2], which led to a quick experiment in February 2016. The Santa Barbara Foundation organized and marketed CareMap Workshops across the county; and Atlas of Caregiving developed and taught the workshops. Phylene, and Mary Sheridan, Executive Director of the Coast Caregiver Resource Center, part of Cottage Hospital, helped facilitate those workshops (as did a couple of other volunteers). Carol Levine, Director, Families and Health Care Project, United Hospital Fund, based in New York, came to observe. The workshops were a big success, with participants and observers feeling that the Atlas CareMap concept and the design of the workshop were very valuable. After the workshops, Rajiv, Phylene and Mary discussed the larger Atlas of Caregiving effort, that of conducting deep research on family caregiving and on developing practical tools (like the Atlas CareMap) to directly help families.



An example of a hand-drawn Atlas CareMap.

The first CareMap Workshop, February 2016. Held at the Santa Barbara Foundation.

Around the same time, the Santa Barbara Foundation board and staff were contemplating ways to drive innovation, to aim for more than incremental progress. This resulted in the creation

[2] Information found at (atlasofcaregiving.com/hand-drawn-caremaps/) explains hand-drawn Atlas CareMaps as taught in Workshops to-date. Information here (atlasofcaregiving.com/draw-your-caremap/) explains the Atlas CareMap web app, which is discussed later in this report.

of the "Accelerator Awards" program that solicited proposals for innovative projects that could result in dramatic progress. Phylene Wiggins made Atlas of Caregiving aware of the Accelerator Award.

Atlas reached out to three Santa Barbara institutions — Family Service Agency (FSA), Marian Regional Medical Center (Marian), and Promotores de Salud (Promotores) — to seek their collaboration in a proposal to leverage key findings from the Pilot project, including the Atlas CareMap and other tools for increasing caregiver self-knowledge.

Atlas's approach fit well with CCI goals: to increase caregiver self-identification; to increase caregiver capacity, knowledge and skills; and to generate more community awareness of family caregiving.

At the end of 2016, the Foundation's board decided to grant Atlas an Accelerator Award. The decision to do so was strongly influenced by AARP's decision to also support Atlas of Caregiving. The Foundation's award letter stated: "Also critical in our decision was [Atlas of Caregiving's] success in attracting the support and endorsement of AARP for the organization and its work."

Project Objectives

The Foundation award letter also noted: "We look forward to working with the Atlas of Caregiving during the coming year to create a strong, vibrant, diverse community and most of all, an environment where family caregivers are recognized and thrive."

We translated the Foundation's overall goals into two key principles informing project objectives and plans. One was doing things *together* (Santa Barbara institutions and Atlas). The other was an enthusiasm for *exploring* innovative, promising ideas, for learning-by-doing. At the kick-off meeting we spoke of "Co-inspire: To openly share, accept, and play with ideas toward the advancement of a mutual pursuit", and we acknowledged that we were doing things that were new, and so we would likely have to modify our plans as we discovered what worked well and what did not.

The project plan included two major elements to be carried out during 2017:

- Explore Atlas CareMap Adoption and Impact — Conduct many CareMap Workshops, in collaboration with FSA, Marian and Promotores. Observe responses to these Workshops, and the extent of organic adoption in the community. Explore how the organizations (FSA, Marian, and Promotores) could incorporate Atlas CareMaps into their efforts. And then use this learning to develop recommendations for county-wide adoption of Atlas CareMaps.
- Mapping Yourself With Guidance — This element was about exploring new concepts for understanding and empowering family caregivers, a continuation of the innovation in research-methods of the Atlas Pilot. The goal (or hope) was that this would accelerate the development of other "practical solutions" as useful and impactful as the Atlas CareMap. Other tools that could help caregivers track and learn from different aspects of their lives and caregiving activities. Initially we had expected to focus on a novel "wellbeing tracker", but eventually our exploration efforts led to a "visual activity log", "tracking-1-thing", and Atlas CareMap extensions.

A higher-level objective of the project was to use the learning from the two project elements to develop ideas for advancing CCI goals of creating a more caregiver-supportive community in Santa Barbara County.

Explore Atlas CareMap Adoption and Impact

CareMap Workshops led by Atlas staff

A key decision made at the project's kick-off meeting in February 2017 was that, given Santa Barbara County's large Latino population, it was important to conduct CareMap Workshops in Spanish, as well as in English. As a result, Atlas committed to supporting Spanish as much as possible, and recruited a very experienced, Spanish-fluent instructor (Gabriel Acosta) to join the Atlas team. All Atlas CareMap materials (marketing flyers, workshop presentations and handouts, web pages, etc.) were produced in both Spanish and English. This eventually led to both Spanish and English versions of the Training for CareMap Workshop Leads as well. In retrospect, given the powerful impact of Atlas CareMaps in the Latino community driven by Promotores (described in more detail later), this was a very important decision.

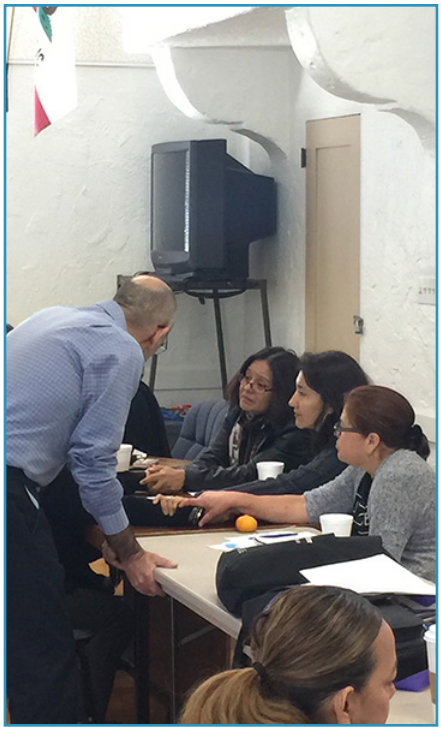
The CareMap Workshop, as presented in this project, is a two-hour program. It is designed to lead participants through drawing their own Atlas CareMaps, and to help them better understand their own care situation through both examining their own Atlas CareMap and from hearing about other people's situations. The program is organized into four, roughly 30-minute segments:

- Introduction to Atlas of Caregiving and Atlas CareMaps, to provide context
- Drawing own Atlas CareMap following step-by-step instructions, and ideas for learning from and acting upon one's CareMap
- Sharing of Atlas CareMap drawings and observations in small-group (3-5 participants) conversations
- Full-group conversation of findings and observations, and suggestions for including more information in Atlas CareMaps

The number of participants per Workshop ranged from as few as five, to as many as twenty. Some Workshops were held in English, and some in Spanish. The English-language workshops were led by two Atlas instructors, and sometimes with a third Atlas staff member helping to facilitate. The Spanish-language workshops were led by one Atlas instructor, sometimes with the assistance of several Promotoras.

Overall, more than 100 people participated in twelve CareMap Workshops. Six Workshops (three in English, three in Spanish) were held in early April in Santa Barbara, Lompoc and Santa Maria. Four Workshops (two in each language) were held in early June in the same cities. An additional two Workshops in English were held in September at the Santa Barbara Foundation office, especially for organizations interested in applying for future Community Caregiver Initiative grants.

As had been the experience with the initial CareMap Workshops (February 2016) that led to this project, there was always a high level of engagement and interest in all the CareMap Workshops. Emotions ranged widely. There was awkwardness at times, as people talked about personal



Betty (hidden) being comforted as she described being overwhelmed by her caregiving responsibilities.

situations that they rarely discussed with anyone, let alone strangers, but also a sense of relief at having done so.There was new awareness and a sense of gratitude, as people discovered they had more support than they had previously noticed. There was also pain and deep distress, as people discovered or confirmed, and spoke about, how alone and overwhelmed they were.

There were many memorable comments made during the conversation in the Workshops. These are a few:

- A social worker, who attended a CareMap Workshop in February 2016 and again in April 2017, talked about how her drawing had changed, and how it made her be more aware of the ever-changing nature of family care.
- A mother spoke of being pleased to discover how strong a support-system the family had created for a child with special needs, but alarmed to realize that the child would soon be going to college and so they needed to plan ahead to build a strong support system for very different circumstances.
- A doctor spoke of seeing his personal circumstances in a new light, of having deeper appreciation of what others in his family were doing.
- A social worker talked about becoming more aware of the downsides of having moved across the country from where she had grown up, and where the rest of her family still lived.
- One person, attending the CareMap Workshop knowing she *was* a caregiver for an aging parent, expressed surprise at "discovering" she was *also* a caregiver for a husband going through chemotherapy.

One qualitative conclusion we draw from these responses is that the recognition of oneself and others as caregivers is improved in these workshops, and this recognition itself has effects.

Post-Workshop surveys

At the end of each workshop, participants were invited to fill out a survey. Most did so. We collected 97 survey responses.

One portion of the survey asked people to rate how much they agreed with several statements, using a scale of "1-Don't Agree" to "5-Strongly Agree".

Two questions focused on the extent to which participants found the Workshop worthwhile. The responses were overwhelmingly positive.

Statement	1 (Don't Agree)	2	3	4	5 (Strongly Agree)
I am glad I attended the CareMap Workshop	0%	0%	0%	5%	95%
I would recommend CareMap Workshops to others	0%	0%	2%	9%	88%

Two questions asked about the value of studying one's own Atlas CareMap and the value of group discussion. Both were felt to be very valuable. Another question also focused on the perceived value of Atlas CareMaps by asking if it would be re-drawn.

Statement	1 (Don't Agree)	2	3	4	5 (Strongly Agree)
I learned something from drawing and studying my own Atlas CareMap	1%	0%	2%	13%	84%
I learned something valuable from the group discussion	0%	0%	2%	14%	84%
I think I will redraw my Atlas CareMap in the future	2%	2%	4%	17%	75%

Finally, two questions asked about the participant's interest in sharing Atlas CareMaps with others. The results show there is clearly less interest in sharing Atlas CareMaps with professionals, than with family and friends. The significance of this — is it a reluctance to be open with professionals? is it an indication of a lower expectation of value in sharing with professionals? is there an assumption that professionals are not interested in the caregiver's own observations and data? — is an important topic for future research.

Statement	1 (Don't Agree)	2	3	4	5 (Strongly Agree)
I plan on sharing my Atlas CareMap with family and friends	4%	1%	9%	25%	60%
I plan on sharing my Atlas CareMap with professionals	8%	4%	13%	26%	48%

These results are similar to survey results from other CareMap Workshops in 2017 (held outside this project).

The other portion of the survey asked people to respond to a few open-ended questions. Here are the questions, and some of the responses (lightly edited) grouped into themes:

Please share with us what you learned or discovered from your Atlas CareMap or the Workshop.

Need for more support and/or better use of resources

- "My caremap made me realize that while I was accessing all the resources I needed, I could have benefited from greater coordination."
- "As a single mother and caretaker I need more support for ME!"
- "Need to discuss with extended family better support for Dad's main caregiver (our sister)."
- "That I need to share with family for more support to myself and reach out for help to social groups."
- "How limited my ability to care for my mother is."
- "That there are a lot of people we can count on and others we can't. I discovered that I need a Plan B to take care of my father and brothers. I learned that I want to involve others and delegate responsibilities."

- "How big a job I have and little help. I do not ask for help or communicate problems to the family."

Recognition of existing support

- "I learned that I can delegate to others a little bit of my work. As well as I can recognize others for their efforts."
- "I realized that I'm not alone in taking care of my parents."
- "It's an emotional piece! It takes courage to admit that you have support. The process itself is very rewarding and insightful."

Increased awareness of current and future caregiving

- "If I am incapacitated, my parents will have a sad life adjustment."
- "That I was caring for more individuals than the one that was top of mind."
- "Apparently I have a good CareMap for my present situation but I do not know what might happen in the future. I need to mediate and take some measures to create a plan for the long term."

Usefulness as a professional tool

- "This tool will be useful to counseling family caregivers of dementia patients."
- "This will be a great way to help me support clients in my job. This seems to be an easy way to encourage people to think about who can help them."

What actions, if any, do you plan to take based on what you learned in the Workshop?

Seek, and offer, more help

- "Study the caremap to see what improvements to make and where else to insert help."
- "I need to talk with my family and ask for support."
- "Try to find more community resources which might help us."
- "Expand the network that cares for me."
- "I need to ask the family for help and delegate responsibilities."

Talk with family

- "Draw my CareMap again and share it with my family now that I'm going to Mexico. They are taking care of my dad. Especially share it with my sister who is the main caregiver."
- "To share my CareMap with all my family and all my friends."
- "Make myself more available to loved ones and family."
- "First of all to share my CareMap with all my family and second I want to learn everything I can about CareMaps so I can understand it 100%. Because every household should have a CareMap."
- "Communicate with the people included in my CareMap, let them know how important they are in my life and the person they are helping me provide care for."
- "I will talk with my family members to see how we can support each other better."

Prepare for the future

- "To have two CareMaps: one for the present and another one for the future."

Use with patients / clients

- "I plan on using this as a tool with my caregiver clients to give them a visual understanding of who is involved in their daily framework."
- "Evaluate strategies for incorporating this into a healthcare facility."
- "I would like to introduce this concept / tool to families struggling to identify support and also with families not struggling to highlight strengths in both situations."
- "Use it as a building block for an enriching counseling session with my clients."

No immediate action

- "No, it just made me feel secure that I will / am taken care of."

Recruitment difficulties

While over 100 people attended the twelve CareMap Workshops led by Atlas staff, there was room for many more. With a capacity of 15-20 participants per Workshop, more than 200 people could have been accommodated. We know that there are tens of thousands of family caregivers in Santa Barbara County, so why weren't there more attendees? Several possible explanations have been raised:

- Lack of caregiver self-identification — This is a problem expressed frequently about all caregiver-related services and programs. If caregivers don't think of themselves as "caregivers", they are unlikely to pay attention to communications directed towards caregivers.
- Reach of communications — The Workshops were advertised mainly via email and word-of-mouth by the partners (FSA, Marian, Promotores, and Santa Barbara Foundation). Would a much broader communications effort, with much more resources, achieve a larger response?
- Communicating value of Atlas CareMaps and CareMap Workshops — While Workshop participants found enormous value from their involvement (as noted above), how are potential participants to know this? Many participants have commented that the Workshop was far more valuable than they had expected, and that the original communications materials are now much more meaningful, with the benefit of hindsight. Perhaps it is possible to use the feedback collected in this first round to communicate the value more clearly in marketing materials. Or perhaps it just takes time for word-of-mouth to spread within the community such that people respond more strongly to the marketing materials.
- Caregivers have no time — A logistical challenge is that caregivers are often just too busy to be able to find the time to attend a two-hour Workshop (along with the time to drive to and from the Workshop). No matter how valuable a CareMap Workshop may be, if it is also nearly impossible for caregivers to attend then they're unlikely to do so.

Overall impressions

The CareMap Workshops were a tremendous success, as those who attended universally valued the experience. They learned a lot from both drawing their own Atlas CareMap, and from the opportunity to talk about it with others. The benefits accrued long past the Workshop itself, as people continued to reflect on their lives. It is also clear that what is learned in the Workshop is easily transferred, as afterwards many participants taught Atlas CareMaps to other family members, friends, and colleagues.

For many caregivers it is difficult to find the time to attend an in-person two-hour workshop (a general challenge for all caregiver-targeted classes). It should be possible to convey the instructional aspects of the CareMap Workshop through online, self-faced learning materials. And it should be possible to replicate the benefits of the group conversations (the sharing of Atlas CareMaps) through shorter in-person meetings, or even web-conferencing. Such innovations could enable many more caregivers to learn about and benefit from Atlas CareMaps, while the current Workshops, with their proven success, continue for those who can attend.

Training for CareMap Workshop Leads

Immediately following the April 2017 CareMap Workshops, we held meetings with staff from FSA, Marian, and Promotores to discuss observations and to plan for the next round of Workshops. There was very strong interest in learning how to lead Workshops, so that more families could be reached (rather than being limited to the number of Atlas-led Workshops planned for the project). So, Atlas committed to develop a "train-the-trainer" class, for those interested in leading their own CareMap Workshops, as well as those who wanted a deeper understanding of Atlas CareMaps for supporting patients/clients.

In developing this class, Gabriel Acosta and Rajiv Mehta realized this needed to be much more than writing down a script to accompany the slides used in the CareMap Workshop. They discovered how much of their experience and tacit knowledge had gone into the design of the workshops, and how much teaching and people-management skills go into conducting each workshop. In the end, they developed a three-hour "Training for CareMap Workshop Leads" class.

The material covered included:

- Discussion of the philosophies of caregiver empowerment, of self-learning, and of instructional design that the structure and materials of the CareMap Workshop are based on.
- Detailed walk-through of all the slides and materials used in the CareMap Workshop.
- Discussion of how a CareMap Workshop instructor might respond to variations in participants' family situations and reactions to the workshop materials.
- Discussion of potential practical challenges in leading CareMap Workshops (e.g. teaching a group with widely varying learning abilities) and/or using CareMaps in one-on-one settings (e.g. social workers already have too little time to cover all the material they are required to do).

Two sessions of Training for CareMap Workshop Leads were held in June 2017. One session, held in English, included nine social workers from Family Service Agency, Lompoc Medical Center, and Marian Regional Medical Center. Another session, held in Spanish, included eighteen Promotoras. Twenty five of them had attended CareMap Workshops in April; two of the Promotoras had learned CareMaps from their colleagues.

The two month separation between the original CareMap Workshop and the Training session was intentional. This meant that all participants had time to learn from and act upon their own Atlas CareMaps, and time to share the concept with family, friends, and clients. As a result, participants came with a substantial amount of self-knowledge and experience in using Atlas CareMaps with others, enabling them to learn more deeply from the material presented in the Training session.

We began the training session by asking participants to speak about their Atlas CareMap experiences. Many were eager to do so. In the Promotores session, such reflections went on for over an hour, as the previous two months had been life changing for some. Later we invited them to speak of their experiences on-camera to share with others. Three of these interviews can be found online: Betty (https://youtu.be/YqvfrllSq4g), Mayra (https://youtu.be/K3PZ62Shr8M), and Josefa (https://youtu.be/E73ZpHg7ink).

The energy in both sessions was very positive. Many spoke up to say that they very much appreciated learning the philosophies underlying the design of the Atlas CareMap as well as of the CareMap Workshop. This gave them a deeper appreciation of the material as well as why and how their own Atlas CareMaps had had such an impact on their perceptions of their own personal

circumstances. Many also said that they now felt confident about leading CareMap Workshops themselves.

We invited the newly trained Workshops Leads to join Atlas-led CareMap Workshops that had been scheduled over the following few days — to lead the workshops if they felt comfortable, to help by sitting amongst the students and answering individual questions, or to just observe. Several Promotoras did so. The next day, two of the Promotoras led a portion of a Workshop, and the following day, at another Workshop, another Promotora led the whole Workshop (in both cases, with occasional assistance from Atlas staff). In both of those Workshops, several other Promotoras helped facilitate.

Anna leading a CareMap Workshop, two days after Training for Workshop Leads.

Atlas CareMap Usage by Local Partners and Impact

Family Service Agency — Cynthia McNulty, Senior Services Program Manager at FSA, reports that social workers trained on CareMaps have used them with approximately 40% of their clients. They bring up the Atlas CareMap with clients whenever they feel that clients would benefit from taking a deep look at their care ecosystem. One such situation is when a client feels they have no one to help — by drawing their Atlas CareMap, they might discover people who could be asked for assistance, and the client can use the Atlas CareMap to better explain their needs and advocate for assistance. Another situation is when the social worker feels that the client could make better use of their network — by using the Atlas CareMap to talk about how different people may be able to help, the client is made aware of new possibilities and is empowered to start conversations. Cynthia believes there is potential to do much more with Atlas CareMaps, but they just don't have the time to lead their own CareMap Workshops or teach clients more deeply. She would like to be able to train more social workers, and to have a convenient way for social workers to discuss best-practices and share tips about using Atlas CareMaps.

Marian Regional Medical Center — Mary Amedeo, Family Care Navigator at Marian, reports that she and Tina McEvoy, Care Transition Program Coordinator, led four CareMap Workshops in 2017, and have plans to do more in 2018. She says that the Atlas CareMap has made a big difference with the Latino families she visits. During the initial intake session, after all the other information giving and receiving has been completed, she works with the client to draw a Atlas CareMap. She reports this has been very effective in helping the client (as well as herself) better understand the situation. Sometimes the client realizes the value of the help they do have from other family members. Sometimes it becomes clearer that despite the presence of other family members, the client is doing almost all the work. Sometimes the validation of the hard work that the caregiver is doing is very comforting and empowering. Mary shows them how existing services could help fill some of gaps in the Atlas CareMap, and clients have been very pleased to learn that such help is available. By contrast, with English speaking caregivers, there is not enough time to present the Atlas CareMap. This is due to the first session (in English) being more exhausting, as there is more information about available services to convey. Mary notes that Marian Regional Medical Center is "at the beginning" of using Atlas CareMaps, that many more people at the Center

could benefit from being trained, that many more people in the community would benefit from learning about CareMaps for themselves, and that there is a lot of potential for the rest of the Dignity Health system to use Atlas CareMaps.

Promotores de Salud — Georgene Lowe, Coordinator of the SBCEO Health Linkages program (which includes Promotores de Salud), reports that the Promotoras have fully embraced the Atlas CareMap. They have held many classes for the community, and led a CareMap Workshop at the national conference for such organizations. They have plans to conduct twelve Workshops in 2018, one per quarter in each of the three regions (South, Central, and North part of the county). Unlike other Promotores projects, in which the group functions mainly as a liaison and communications channel from health institutions to the Latino community, the Atlas CareMap is a tool that the Promotoras have been able to adopt, use, and lead themselves. It has allowed them to leverage their own knowledge and experience to lead the community.

This author can't do justice to how passionately, powerfully, and emotionally the Promotoras themselves describe the impact of Atlas CareMaps on themselves, their families, and the community they serve. *All* of the Promotoras Atlas has spoken with have told us that the insights gained from the Atlas CareMap have made a huge personal difference, and that they have taught and use Atlas CareMaps with many family members. They have also taught it extensively to friends and co-workers, as well as in their role as Promotoras. A Promotora named Eva said she's impacted over 30 families, and checks in with them often to discuss how their Atlas CareMap has changed. The Promotoras also speak about how the Atlas CareMap has had a huge impact in the group's own dynamics. They are much more connected to each other than ever before, more of a family. They're more aware of the importance of caring for oneself, and now support each other in doing so. Speaking of one's map, asking how something will impact one's map, is now a normal part of their conversation. They feel much happier about the impact they're having on their community, proud to bring this tool to the community. Josefa Rios, who leads the South County Promotoras, summarizes their perspective by saying, "we needed this tool to come into our lives!"

It's worth noting that all three organizations have felt comfortable modifying Atlas CareMap teaching materials to suit circumstances. For example, the Promotores had small groups draw a Atlas CareMap together on a flip-chart, rather than having each individual draw their own Atlas CareMap, for a Workshop they held at their national conference. When Mary Amedeo and Tina McEvoy taught the Atlas CareMap to a group of caregivers who had met over several consecutive weeks, as part of a caregiver education program, they were able to shorten the normal two-hour workshop to 90 minutes. Learnings from such variations, such little experiments, can help improve Atlas CareMap training methods and materials.

Building a "community of practice"

One of the desired objectives of the project was that there would be cross-organizational learning, that FSA, Marian and Promotores staff would share with each other their experiences and jointly discover good practices. Very little of this happened in practice, as there is not much naturally occurring cross-organizational conversation, and it was very difficult to coordinate schedules to get everyone together. This was not unique to the Mapping Santa Barbara project; a common refrain amongst these staff was how little time they have, and how there are already too many meetings.

Still, everyone expresses a desire for a community-of-practice around Atlas CareMaps, and in the future more efforts should be made to try to find a way for such collaborative knowledge sharing to occur.

Outreach within Santa Barbara County

Although the Mapping Santa Barbara project's formal partners were only Family Service Agency, Marian Regional Medical Center, Promotores de Salud, and the Santa Barbara Foundation, many other local organizations became involved and/or have plans to leverage the work in the future. Those listed here are ones that Atlas of Caregiving had direct conversations with; many others attended CareMap Workshops and/or learned about Atlas CareMaps from other people.

Central Coast Commission for Senior Citizens — This is the Area Agency on Aging for San Luis Obispo and Santa Barbara Counties, led by Executive Director joyce ellen lippman. They have decided to require all future grant seekers (starting in July 2018) to include the use of Atlas CareMaps in their interactions with families, as part of the initial assessment and for ongoing involvement. This is the first time the organization has imposed such a requirement. joyce ellen had attended one of the initial CareMap Workshops (February 2016), and had come away impressed with the potential value of Atlas CareMaps. After seeing the value confirmed during the current project, Atlas was invited to speak to the organization's advisory board. As a result, the board enthusiastically approved making Atlas CareMaps a requirement. (There is still a process to go through, including public hearings, but joyce ellen is confident this will happen.) She praises the Atlas CareMap as "a gift to caregivers" — something that is valuable not only to professional service providers, but also very much to family caregivers themselves. She also praises the Atlas CareMap's simplicity. joyce ellen plans to present Atlas CareMaps at a national conference for Area Agencies on Aging, and hopes to have it adopted nationwide.

Santa Barbara Foundation / Community Caregiving Initiative — It is worth noting that the Foundation is also requiring CCI grantees to include the CareMap in their project proposals. Two CareMap Workshops were held in September specifically for potential grant seekers to learn about Atlas CareMaps.

Lompoc Valley Medical Center — One of the early (February 2016) CareMap Workshops had been held in Lompoc, and social workers from LVMC attended CareMap Workshops during the current project. Since then, LVMC has promoted Atlas CareMaps to it's community (https://lompocvmc.com/blog/675-are-you-a-family-caregiver) as part of the CaringTogetherLompoc Campaign.

Santa Barbara County Department of Social Services — Several members of the Adult Programs leadership team have met with Atlas to learn about Atlas CareMaps. They are enthusiastic about using CareMaps across many departments — training many staff and using Atlas CareMaps with families — but so far have not been able to do so for lack of staff and funding (the department has recently endured cutbacks in both).

Sansum Clinic / Ridley-Tree Cancer Center — Several people from Sansum Clinic have attended CareMap Workshops in 2016-2017. The center is planning a research project to investigate incorporating Atlas CareMaps into the patient experience and provider processes.

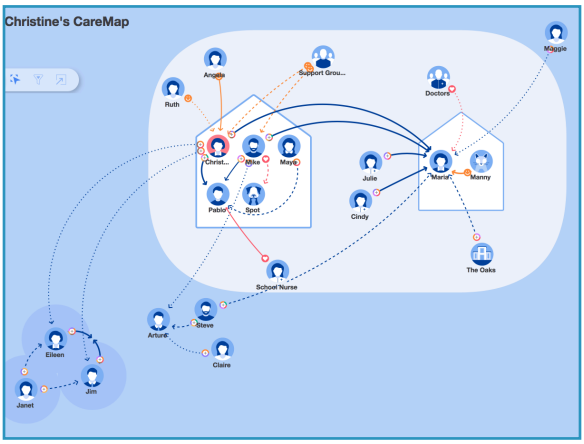
Cottage Health System — Senior research and population health staff members have met with Atlas to discuss use of Atlas CareMaps, and other tools (like those explored in Mapping Yourself With Guidance), in population-health and community-engagement projects and research. The

conversations are continuing. The possibility of doing a large multi-site (with other provider institutions across the country) study is being explored.

Development of Atlas CareMap web app

Throughout 2017, Atlas of Caregiving has been working on the design and development of a Atlas CareMap web app. This was made available to the public in January 2018 at AtlasCareMap.org.

Observations by the Atlas team of the many Atlas CareMaps drawn in the CareMap Workshops informed design decisions for the web app. In addition, team members from FSA, Marian, and the Santa Barbara Foundation gave feedback during the development process.



A CareMap created using AtlasCareMap.org.

Everything one can do with a hand-drawn Atlas CareMap, can now be done online, and much more. The Atlas CareMap web app was designed such that if a person has already learned to draw one by hand (as is taught in the CareMap Workshops) that knowledge applies to the digital version as well. Not only the concepts, but some of the gestures, will be familiar. The web app provides much more functionality.

For caregivers, the key benefits of the digital CareMap are:

- **Add more details** — Specify the types of and frequency of support provided.
- **View an Atlas CareMap in different ways** — Highlight different aspects of a care ecosystem. (For example: just those providing "medical care" or "social/emotional support", or those involved on a daily basis.)
- **See changes over time** — Save snapshots of an Atlas CareMap at different points in time.
- **Add Potential Actors** — What would the ecosystem be like if …?
- **In the user's preferred language** — Instructions are available in English and Spanish. User-entered information can be in whatever language the user prefers.
- **Print CareMaps** — Get a pdf of an Atlas CareMap that can be printed or emailed. The pdf includes the Atlas CareMap as well as details about all the Actors and Links.

In addition, the Atlas CareMap web app generates never-before-available data on real-world care ecosystems. The analysis of this data, from thousands of Atlas CareMaps created using the web app, will enable new understandings of our social systems and communities. Initially such analyses will be of a straightforward statistical nature: How many people are on Atlas CareMaps? How many caregivers and how many care recipients? How many provide medical support? How many provide social/emotional support? etc. Over time, more sophisticated analyses may be possible: How strong (or weak) is a family's care ecosystem? How do ecosystems in urban settings differ from rural? How do "small" or "large" ecosystems effect health outcomes? etc.

Note: A computer or tablet (but not a smartphone) with an up-to-date OS and modern web browser (Chrome, Safari, Firefox and Edge) is necessary for AtlasCareMap.org. Some functions may not work properly with older software.

Mapping Yourself With Guidance

This part of the overall Mapping Santa Barbara project was meant to extend the kind of research conducted in the Atlas of Caregiving Pilot, exploring new methods for studying family caregiving. The focus was on guiding family caregivers to investigate and assess their own caregiving activities and contexts. Experts provided guidance on tools and methods caregivers could use for this purpose, as well as on how to think about and glean meaning from the data collected, while the caregivers themselves collected data and reflected on their findings.

We began with a public event to introduce the concepts to the community, and then worked with a small group of caregivers over several months.

Discovering the Quantified Self event at Impact Hub

Gary Wolf, Jon Cousins, Rajiv Mehta and Richard Kreis at Impact Hub.

Discovering the Quantified Self

To introduce the idea of "self-tracking" — of a person using applications, devices, and self-observation to learn about oneself and one's circumstances, and using this information to impact change — to the Santa Barbara community, Atlas organized a "Discovering the Quantified Self" event. It was held at the Impact Hub in downtown Santa Barbara in April 2017. Roughly 75 people attended. A volunteer captured the event on video (https://youtu.be/HCOKNAu563Q).

Phylene Wiggins spoke of the Santa Barbara Foundation's overall Community Caregiving Initiative efforts, and introduced the Mapping Santa Barbara project.

Phylene Wiggins at Impact Hub.

Gary Wolf, co-founder of Quantified Self (a worldwide community of pioneering self-trackers and makers of tools for self-tracking) spoke of the power of self-discovery through personal science, and how experts could contribute to, encourage and support such personal learning.

Jon Cousins, an expert on mood tracking, described his own experiences tracking mood daily for several years, of his latest efforts to develop a tool for mood tracking, and what he had learned from his most recent data.

Richard Kreis, a caregiver as well as a person with his own significant chronic health issues, spoke of his family's

situation, and what they had learned from keeping a detailed log of their activities. They had wanted to learn "Where does the time go?", and Richard shared their surprising findings.

Rajiv Mehta described a time he had been concerned about how poorly he had been sleeping, and how he had tracked sleep over several months only to discover from the data that he did *not* have a sleep problem. (He'd only been noticing the few bad nights, while overlooking the far more common good nights.) He noted the value of such "failed experiments".

After a very active Q&A session, which had to be cut short for lack of time, Rajiv described the Mapping Yourself With Guidance project, with a call for participants. To close, Rajiv shared examples from the *Dear Data* project and book (http://www.dear-data.com), by Giorgia Lupi and Stefanie Posavec, to show how anything in life can be tracked and diagrammed.

Mapping Yourself With Guidance

The framework for Mapping Yourself With Guidance was a small group of family caregivers, plus two experts, meeting monthly for four two-hour sessions, from July to October.

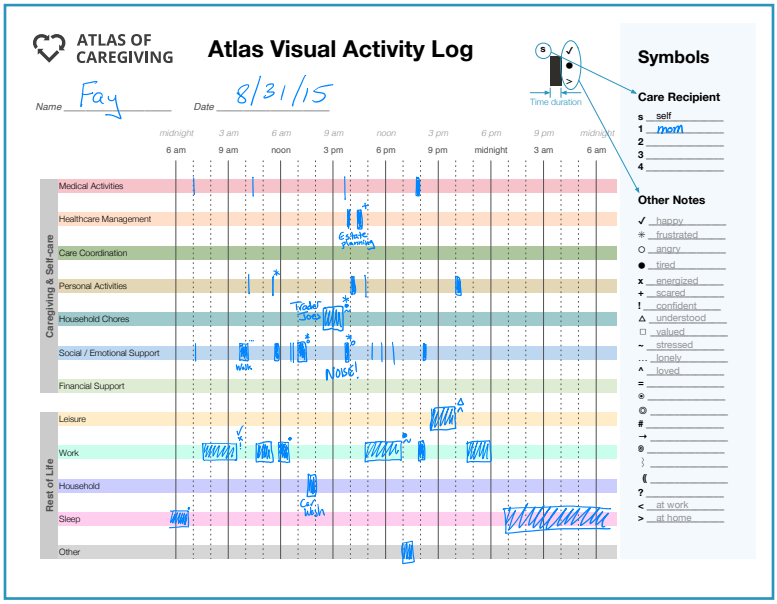
Rajiv Mehta and Dawn Nafus were the two self-tracking experts who led this effort. Susan Williams assisted during the sessions. Gary Wolf, Jon Cousins, and Giorgia Lupi contributed to the design the program.

We had a goal of recruiting 6-8 caregivers. Given the experimental nature of the project — we know of no-one who had conducted such a project — we wanted to keep the group small so as to be better able to manage the unexpected. Recruiting resulted in eight caregivers registered; though in the end only six actually participated. Of these, one person attended all four sessions; three people attended three sessions; one person attended one session in person, but contributed to group discussions by sending in notes by email; and one person only attended the initial session. From what we know, all absences were due to caregiving emergencies, or a combination of last-minute work demands + travel time to Santa Barbara (so they couldn't get to the session on time). Rajiv and Dawn had planned the project with the idea that all participants would attend all sessions. The first project "learning" was to redesign the program, and our communications, to allow participants to participate as much as possible despite the calendar-chaos that is part of being a caregiver.

At each session, participants were introduced to new self-tracking tools and methods. In addition, for sessions two, three and four, the group discussed the experiences and data from self-tracking efforts preceding that session. Rajiv and Dawn were aware that we were likely going to be overwhelming participants with learning a wide variety of new tools in a short period of time, but we were also confident that they would likely learn something from even a less-than-ideal learning experience, and that we would learn a lot about the value of the tools and the potential for helping caregivers with self-tracking.

At the first session, participants learned two tools. First they drew their own Atlas CareMap, and then were shown how they could use their finished Atlas CareMap as a base upon which to track interactions with the other people in their ecosystem, and the emotions raised by such interactions. (Note that such use of a Atlas CareMap is beyond anything taught in the CareMap Workshops discussed above.) Next they were introduced to a brand new tool, a "visual activity log" (see image on next page). Participants could use this to keep track of all activities over 24-hours, noting the activity, it's length, it's category, and some attributes (who it was for, or what emotion it raised). An example filled-out log is shown here. Though new, this concept was based on several previous

diagrams of caregiver's activities that had great success as part of the Atlas of Caregiving Pilot project, and earlier projects stretching back to 2010.



Prototype caregiving activity tracking tool explored during Mapping Yourself With Guidance.

At the second session, participants were given Fitbit Charge 2 activity trackers (fitbit.com/charge2). These wrist-worn devices track movement ("steps"), sleep, and heart rate. The participants were encouraged to wear them as much as they could. They were also introduced to the idea of "track-1-thing" — that sometimes something of value can be learned through tracking just one specific type of activity, with only a few simple variables noted as details. For example, one could track moments of frustrations, noting the time of the occurrence, the cause of the frustration, and how frustrated the person felt (say on a 1-3 scale). As another example, one could track drinking, noting the time, what was drunk (tea, beer, etc.) and how much. We provided several such examples. The Track-1-thing concept is based on many years of experience within the Quantified Self community (by Rajiv, Dawn, Gary and Jon), and Giorgia Lupi's experience with *Dear Data*.

At the third session, participants were given Emfit QS sleep trackers (emfitqs.com). This ribbon-like device, placed underneath a mattress, captures sleep data (tossing and turning, breathing, heart rate, etc.) with high precision. Participants were told that they could use this device for themselves, to compare with their Fitbit-generated sleep data. Or they could use it for collecting sleeping data of their care recipients, to see how their patterns compared and (perhaps) how one impacted the other.

At the fourth session, we took a close look at some of the collected data on Data Sense (makesenseofdata.com), using data shared by the participants. Data Sense is an unreleased data analysis tool developed by Intel, meant to allow non-technical people to analyze their own data.

Participant response

The response from participants about the overall Mapping Yourself With Guidance effort was uniformly and strongly positive — they gained new and deeper insights into their situations, seemed to enjoy trying new things, and found the discussions worthwhile. It was clear, from participants' comments and body language, throughout the four meetings, that they were very pleased with the project and were learning a lot about themselves and their caregiving situations.

Two participants summarized their thoughts via email (edited):

> "I found my participation to be very valuable in that it validated so much of what I do and the time that it takes to do it all. In addition, it reflected upon the circle of support that I have which was encouraging. Using a CareMap itself was a great snapshot of reality! Tracking my sleep was also

very interesting as I am not getting as much sleep as I believed I was getting. This caused me to focus on more sleep. Also, it was nice to hear the perspective of other caregivers."

"I enjoyed being part of Mapping Yourself. The reason why was the time spent with others and level of interest Rajiv and Dawn displayed in all the little nuances of caregiving. Because of their deep engagement with the caregiving experiences, I became aware of stuff I never thought about — like the diversity of emotions that are experienced. It's not like I didn't know I had feelings, but I had never taken the time to look at them so explicitly as when doing the tracking project. It really opened my eyes to the RANGE of emotions going on inside. I also gained a new appreciation for having patience. The fact that everything takes so long and actually seeing this play out means I can now simply acknowledge it and move on — hopefully with a reduced sense of frustration. I guess what I'm trying to say in all this is that the project increased my self-awareness and with it, my capacity for making better choices to manage myself."

Reflections on the self-tracking methods explored

Atlas CareMap — Everyone found value in the Atlas CareMap. However, everyone also found it difficult to use the result for tracking of interactions and emotions (as explained in the next paragraph).

Visual activity log — Everyone found this hard to do, partly because of the time challenge of making many entries throughout the day every time something happens (as with keeping any sort of real-time log), and partly because of the mental energy required to note associated meta-data (it is especially difficult to reflect on one's emotions when one is experiencing strong emotions). At the same time, it was also clear that participants learned so much about their caregiving situations from having tried to use the tool — they had a lot to say during the discussion of this tool, and everyone took extra copies of the blank worksheet.

We believe both of these tools — the visual activity log and using the Atlas CareMap for tracking — show great promise. As a newer tool, the visual activity log could use another round of design iteration to make it as easy as possible, while recognizing that an activity of this kind will always require some level of effort from the person logging.

Track-1-thing — Participants used this with varying success. One person learned a lot from tracking all phone calls having to do with caregiving. We believe there is great potential to develop this into a more formalized approach.

Fitbit — This consumer device was easy to use, and participants found the data very interesting. In the future, using multiple Fitbits (for the caregiver, for the care recipient, and perhaps others in the family) might be valuable.

Emfit QS — Technical difficulties in setting up this device for most of the participants meant that unfortunately little was learned with the device.

What we learned more broadly

All participants were already deeply engaged in their caregiving efforts, so the fact that they felt they learned a lot about their situations is very meaningful. It supports the project's premise that caregivers can benefit from assistance and tools to better understand and manage their lives. This also reinforces previous Atlas of Caregiving findings that the results of survey-based analyses of

caregiving are fundamentally limited by caregivers' limited awareness of their own activities, emotions, and challenges.

Participants were eager to try the new tools, but also found them quite difficult to use. This is not surprising — they were faced with many new ideas in a short period of time, while already being overwhelmed. For such tools to be widely useful in common practice, we must take the time to introduce them in smaller steps, and provide ongoing support to help people become more and more proficient. (To state the obvious, caregiving is hard and complex, and we should not be expecting cheap shortcuts to making caregivers' lives easier.)

Many in the technology and healthcare industries seem to assume that the technological fanciness of a data collection is strongly correlated with value, that the less a human being is involved in data collection the more "accurate" and useful the results. The experience of Mapping Yourself suggests otherwise. Participants learned the most from the non-technological tools (Atlas CareMap, visual activity log, and track-1-thing). This was despite, or perhaps because of, the demands these tools made on time and mental energy. Even with the Fitbit, where everyone liked seeing their data in the Fitbit application, much of their learning came from actively reflecting on what the data said about their lives. One participant became more aware of how walking with their care recipient impacted both of their exercise levels.

We also came across examples of how easy it can be to get misleading interpretations of "objective" data. As one example, one person's activity levels seemed to have declined dramatically (as measured by Fitbit). As it turned out, the person had been exercising so strenuously, building up for a major hike, that they had shed all unnecessary clothing and jewelry (including the Fitbit). The best "meaning making" occurs with the active participation of the person to whom the data refers.

We also learned not to mistake a person's lack of technological sophistication with a lack of critical thinking skills. One participant noted they were not a "gadget person", and in fact had a lot of difficulty getting the Fitbit properly set up. It would be easy to assume that they would be the last person to develop options about proper data cleaning techniques, but that's exactly what they did when we walked through the data together, and they saw something that didn't appear quite right.

Meeting in-person makes a difference. We know from previous research that people are much more inclined to go through the process of interpreting data when there is a defined time and place to do so. In our workshops, participants did indeed discuss their data in ways that were not obvious, and said something meaningful about their caregiving experiences. While clearly at some level what they described were things people already knew, and could have reflected on in private, having an occasion to say it out loud, discuss it with others, and have others ask questions, provides a space for people to take a step back and reflect on what has been going on. If participants do want to make practical changes, or even just re-evaluate the emotional or social aspects of caregiving, this process did enable, or facilitate, critical distance to do so. Talking about data together is different from a support group, in that the focus isn't on the heavy stuff, and how hard it all is, and more on the day to day. It brings to the foreground the daily practices, and people have visibility into what the concrete experience of caregiving is like for other people. Emotionally difficult matters do come up, but in these sessions they are contextualized in the flow of all the other things. For those who found support groups valuable, this was a useful adjunct to support groups—a way of talking about your situation with others who are likely to really understand without always focusing on emotion. For some who did not like to attend support groups because of the emotion focus, this was a useful substitute.

Although we never used such language, much of the Mapping Yourself project could be thought of as “lessons in the scientific method and data collection and analysis protocols”. Participants weren’t only learning specific self-tracking tools, they were learning how they could investigate their own lives. They are now better positioned to pay attention in more deliberate ways, and to think about introducing other data products into their lives. We believe there is great potential for helping family caregivers through teaching them “personal science”.

Public Communications

Within Santa Barbara

As noted above, there was a lot of public outreach for the CareMap Workshops and the Quantified Self event, and there were conversations with a variety of county institutions.

Beyond Santa Barbara

People across the world have heard about the project, its activities and impact, through the efforts of Atlas of Caregiving and Santa Barbara Foundation staff, and through word-of-mouth.

Both Rajiv Mehta and Phylene Wiggins presented at the *Medicine X* conference, Stanford University, September 2017. The panel was titled "Designing for Family Caregivers: Creating the Map as We Go" (video at https://youtu.be/DLyVqhWcCIM).

Rajiv Mehta and Phylene Wiggins speaking at Stanford's Medicine X.

Rajiv spoke about the project at several other conferences:

- *Updates on Dementia Conference*, organized by the Alzheimer's Assocation of Northern California and Northern Nevada, South San Francisco, May 2017
- *QS17, Quantified Self Conference*, Amsterdam, the Netherlands, June 2017
- *Early Prevention and Intervention of Dementia*, organized by the Shanghai Health Development Research Center, Shanghai, China, November 2017
- *Changing Minds: Innovations in Dementia Care and Dementia Friendly Communities*, organized by Salzburg Global Seminars, Salzburg, Austria, November 2017
- *Family Health over Lifespan*, organized by Hanze University of Applied Sciences, Groningen, the Netherlands, February 2018

Phylene also spoke about the project at *Family Caregiving 2018: An Executive Summit*, organized by AARP, Washington, DC, December 2017.

In addition, the project was featured many times on the Atlas of Caregiving blog (atlasofcaregiving.com/about/blog/) and social media.

The success of the project has led to many communities across the US and the world exploring how they can also leverage Atlas CareMaps for their health-and-wellness and community-empowerment efforts.

Phylene Wiggins at AARP Family Caregiving Summit.

Dawn Nafus also discussed the significance of Mapping Yourself With Guidance for social scientists in these social scientific research venues:

- Keynote presentation, "It's Experiments All The Way Down," *Experimenting with Social Data Workshop*, University of Copenhagen, Denmark, October 2017.
- "The Undone Science Before the Algorithms." Currently under peer review for *Current Anthropology*.

Social scientists are currently struggling with assessing the research value of personal data like the kind that participants collected in Mapping Yourself With Guidance. Dawn made the argument that the real social scientific significance of data can only become known in events like Mapping Yourself, where the participants themselves can also discuss the context and their own interpretations. While the purpose of Mapping Yourself was to directly benefit caregivers, it has helped Dawn reconsider an important social scientific dilemma. She believes her fellow researchers would do well to learn from it as a better way to use supposedly "objective" data with greater social awareness and empathy.

Avenues for Leveraging Opportunities

Based on the overall success of both the Atlas CareMap and Guiding Yourself elements of the project, we believe there is tremendous potential to positively impact family caregiving in Santa Barbara County through improving and accelerating adoption of these concepts. In addition, observations of cultural differences and potential disconnects between the public and care professionals are worthy of deeper study.

We make six, complementary recommendations for next steps. These are summarized here:

Build upon the successful elements of the project

1. **Accelerate Atlas CareMap adoption** Through more in-person CareMap Workshops, new online learning tools, and new materials to enable inclusion of Atlas CareMap training within other caregiver-oriented programs.
2. **Create a Atlas CareMap community-of-practice** Encourage and enable cross-learning amongst healthcare and social services professionals.
3. **Explore Mapping Yourself adoption and impact** Improve upon what was done in 2017, and include many more people.

Act on the more fundamental insights gained in the project

4. **Unleash community wisdom through individual empowerment** A holistic, community-focused effort to empower individuals to better understand their own circumstances, and to encourage peer-to-peer learning and support, would have a huge impact on the community.

Investigate key questions raised by the project

5. **Research ethnocultural differences** Better understand how best to obtain value from Atlas CareMaps and Mapping Yourself in different communities.
6. **Research possible public-professional disconnects** Understand the relative lack of interest in people sharing their Atlas CareMaps with professionals, and discover ways to reduce such reticence.

Accelerate Atlas CareMap adoption

Given the ease, acceptance and impact of Atlas CareMaps, a wider adoption would allow for increased caregiver self-identification and empowerment. Data, both qualitative and quantitative (through use of the Atlas CareMap web app) would provide a new lens on the extent and needs of caregiving in the community. Widespread usage of Atlas CareMaps by both the public and professionals (healthcare and social services) could be accomplished by: holding more CareMap Workshops; more Training for Workshop Leads; developing and deploying online equivalents of the CareMap Workshop (for scaling and convenience); and developing materials to enable inclusion of Atlas CareMap training within other caregiver-oriented programs.

Create an Atlas CareMap community-of-practice

As noted in the report, an unrealized project objective was cross-organizational learning. There is a belief that if people from different organizations and across different professions share their Atlas CareMap experiences and learnings, that this would accelerate the effective incorporation of Atlas CareMaps into the healthcare and social services systems. There is also a belief that if all professionals and institutions serving a particular family had the same, rich understanding of that family's situation through the Atlas CareMap, that the result would be more efficient services and better results for the family.

There is an opportunity to create such a community-of-practice, using online systems for both synchronous and asynchronous communications, and complementing this with occasional in-person events.

Explore Mapping Yourself adoption and impact

Build on the success of the 2017 experiment, by improving the program and testing it on a larger scale.

Program improvements could include: improved tools (devices like the Emfit QS, apps like the Atlas CareMap, and manual methods like the Activity Log and track-1-thing); more interaction both in-person and on-line; and more assessment of changes in the confidence, quality-of-life, and health of participants and their care recipients.

A larger scale means more, and a wider range of, participants as well as a program that runs over a longer period of time (say 6-12 months).

Unleash community wisdom through individual empowerment

The Santa Barbara community could seize a hard-won opportunity — an opportunity made possible by the foresight and collaborative efforts of the Community Caregiving Initiative and the transformative power of well-designed self-learning tools (like the Atlas CareMap and others used in Mapping Yourself) — to strengthen the community now and be better prepared for the future.

The biggest learning from the Mapping Santa Barbara project is not that the Atlas CareMap is transformative, and not that participants found value in Mapping Yourself, but rather the more fundamental points that (1) it is possible for family caregivers to gain much better understanding and control over their situations through well-designed tools (and good teaching), and (2) that such self-empowerment leads to organic, community-driven change.

With local leadership and appropriate investment, the existence of extensive family caregiving in the County can become a positive resource rather than a challenge. Today caregivers are often isolated and overwhelmed, and there is concern about how the society will deal with the ever increasing burden borne by family caregivers. But the future could be different. If the impact of Atlas CareMaps within the Promotoras can be replicated and expanded, if the increased self-knowledge and self-confidence of Mapping Yourself participants can be replicated and expanded, Santa Barbara would benefit from innovation driven by the community's own expertise and energy. The spirit could change, from "How can we possibly cope?", to "We (together) will manage, and even thrive!"

To effect such a radical change, there must be commitment to a multi-year effort involving a wide spectrum of the community (not just health and social services, but also local entrepreneurs and artists, schools and church groups, businesses and libraries). It would also require the patience to build community-support from the start, and to accept that the path forward will not be straight or pre-defined (there'll be lots of experimentation, and changes in plans, along the way).

This must be a locally-led effort, but there are two major ways that Atlas of Caregiving can help. One, as demonstrated during Mapping Santa Barbara, is our expertise in tools and methods for caregiving self-empowerment, and for continuing research to deepen understanding of family caregiving. The other, only lightly touched in the current project, is in driving cultural-change, in providing expert consulting/coaching on the overall community-engagement effort.

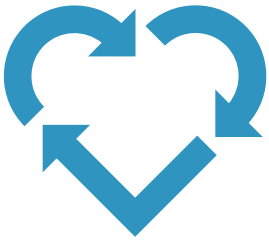
Research ethnocultural differences

Given the diversity of Santa Barbara County's population, as well as differences observed in this project's impact across different groups, it is important to get a better understanding of how best to obtain value from Atlas CareMaps and Mapping Yourself in different communities.

Some questions raised by the project include: Why were the experiences of Promotores so different from FSA and Marian? Why have Marian's Mary Amedeo's experiences using Atlas CareMaps with Latino and English-speaking caregivers been so different? Are these due to ethnocultural differences, or other factors (e.g. wealth, or professional-vs-volunteer)? How might the response to Mapping Yourself vary with a larger variety of participants?

Research possible public-professional disconnects

CareMap Workshop participants expressed less interest in sharing their Atlas CareMaps with professionals than with family and friends. If we are expecting professionals to make full use of Atlas CareMaps, we must understand this relative lack of interest and discover ways to reduce such reticence.



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