headway

a survivors' guide
to survivorship

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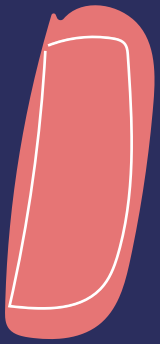
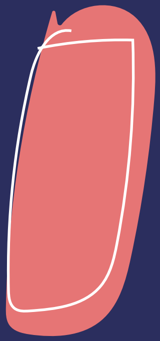
Preface





One in three people in the US will get cancer. It's a massive population that right now totals 15 million people. And as we live longer, that population continues to grow.[1]

But the population of survivors is exploding too. The number of people who have survived cancer is at least as large those who currently have it. Treatment is growing in effectiveness at truly astonishing rates in recent years. But the recency of that rise in survival has translated to a growing population whose multiplying challenges are only beginning to be observed, much less understood – new disabilities, serious side effects, isolation, anxiety, and loss or risk of losing their careers.

Cancer survivors frequently find their healthcare providers, workplaces, friends, and family all too quick to move on after their cancer is 'cured', if not even before. But survivors face new sets of obstacles that weren't part of their treatment experiences, and without much of the support that was.

That's why we're making **Headway**: a survivor's guide to support in survivorship, shaped in real time with other survivors. We're connecting survivors to each other, and to experts who want to help, so that they're better equipped and empowered together to get what they need to thrive.

Foreward

Taken together, the number of cancer survivors in the US is more than the combined populations of Baltimore, Denver, San Diego, Seattle, Phoenix, Atlanta and Miami. And the population of survivors is still expected to grow by more than 30% in the next eight years alone.[2]

On one hand, this increase in the number of survivors is evidence of a trend: diagnosis and treatment are getting better, and that's very good news.[3] Yet as long-term survivorship increases, the healthcare field is seeing evidence[4] that survival might not be the unmitigated positive experience we might hope it will be. For instance, two in 10 working-age survivors say that physical, mental, or emotional problems have limited in part or entirely their ability to do their work, and 40% of survivors say they've found their near and long-term career prospects decline.[5]

Our thesis began with a broad question, formed by months of previous research one of us conducted as an intern at Memorial Sloan Kettering Cancer Center (MSKCC) in the summer of 2017:

what's going wrong for cancer survivors, and how can we help?

Our early assumptions, based on findings from the research we conducted last summer at MSKCC, were that the central challenges lay in:

1. difficulty transitioning survivors from periodic monitoring after treatment to primary care physicians (PCPs),
2. indications from survivors that they experienced daunting emotional and physical side effects, stemming from their treatment, in the post-treatment transition period,
3. as well as MSKCC's perception that awareness lagged of the support services they offered, potentially owing to information overload patients might experience during treatment.

We chose early on to focus on those survivors in transition after active treatment. We wanted to understand what we could of the cause, experience and impact of their side effects; if there were addressable segments of the survivor population (cohorting by cancer site or another demographic differentiator) that were particularly at-risk and under-supported; and to establish a baseline of what resources already existed, what kind of uptake was occurring, and why or why not.

Research Methodology

Our first goal was to discover what kind of cohort of survivors we could recruit in for semi-structured qualitative interviews.

Our early literature reviews of cancer survivorship illuminated negative trends in the outcomes for minority and immigrant communities; young adult survivors of childhood cancer; women; as well as survivors of rarer cancers with persistently higher comparative mortality and/or morbidity (e.g. gastric cancer survivors). We theorized multiple cohorts of interest, and with no established connections, we began simultaneously searches for connections to representatives of all groups in order to move forward as efficiently as possible.

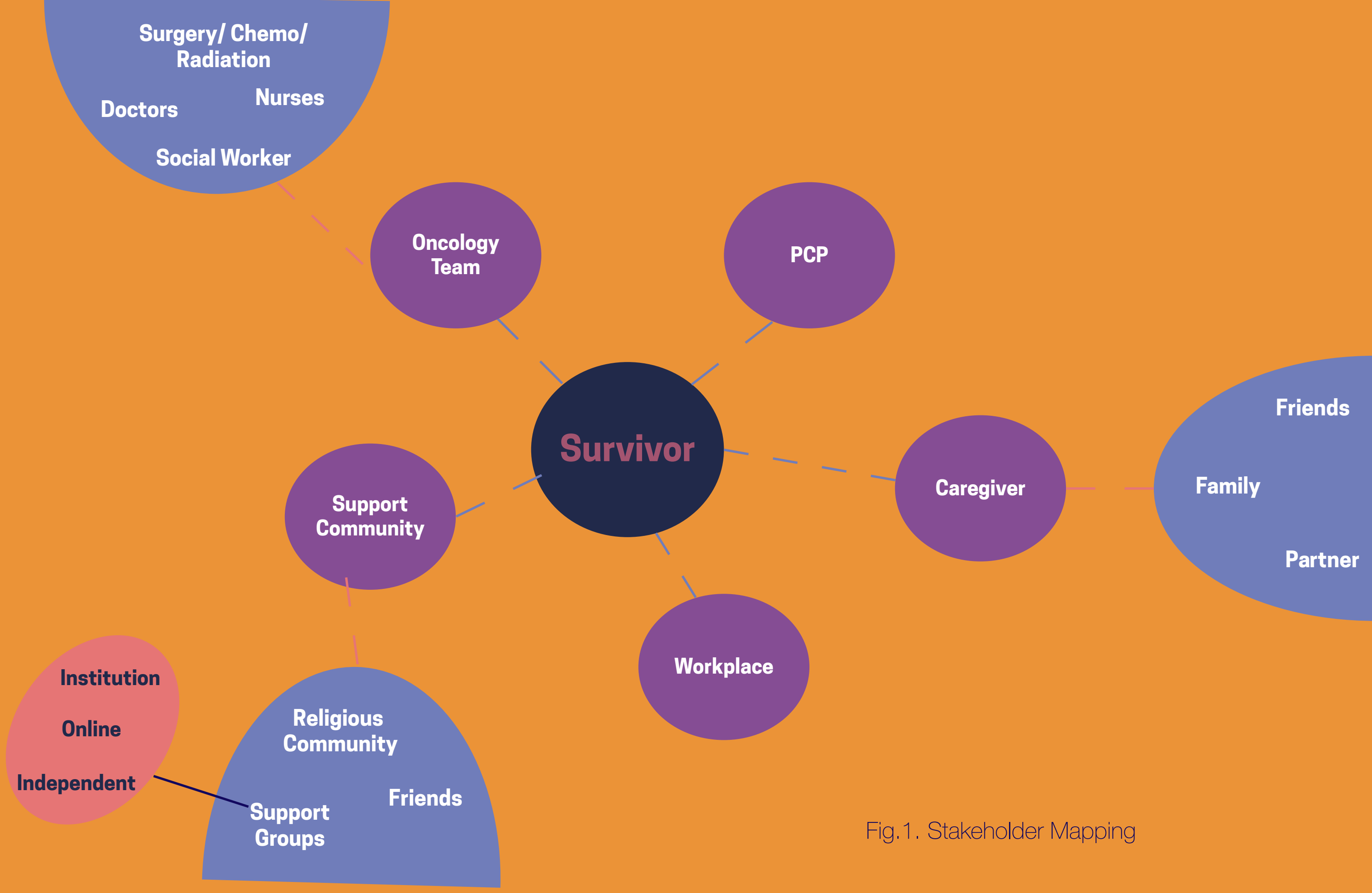


Fig.1. Stakeholder Mapping

Our literature review eventually encompassed 42 peer-reviewed journal articles, as well as various other professional, but non-peer reviewed reports and resources intended for practitioners, patients, survivors and caregivers. This time created our knowledge base, as well as a handle on relevant language and topics ranging from clinical to community settings, from orienting by cancer sites to the involvement and impact of caregivers, from emerging models of team-based care to specialist-specific concerns, and outcomes including mortality and morbidity, economic instability, incidence of mental illness and likelihood of receiving treatment, and so on.

Conducted partly to make good use of a period in which early project momentum was slow as we sought and built relationships and partnerships with stakeholders and communities, the literature review ultimately prepared us very well for the conversations we've had since. Although the capacity to engage in jargon can be helpful when quickly creating trust and communicating competency with deeply embedded stakeholders like researchers, hospital administrators, and other healthcare practitioners, we also found patients to frequently have done a great deal of self-education throughout their own treatment, often speaking in acronyms and shorthand references that we had to learn. This may have proven particularly helpful when faced with the skepticism that the idea of two designers might provoke as we asked interviewees to patiently revisit with us some of the basics so as to collaboratively establish a fresh baseline understanding .

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Meanwhile we reached out to contacts at MSKCC, as well as 2 other major centers of excellence for cancer treatment in the NYC area. We attended public symposia and relevant seminars and workshops that social workers and researchers at these institutions conducted, and followed up with those leaders after for one-on-one interviews. We conducted outreach to community cancer support organizations operating at local, national and international levels, including to those primarily serving people still in treatment. We also reached out through personal networks.

In all, we wrote more than 30 pages of quick introductory emails in our project's early phase.

To present, the final tally of semi-structured interviews we conducted includes 10 'experts' (doctors, nurses, physicians' assistants, social workers, patient navigators, researchers, therapists, human resources professionals etc.), 3 focus group sessions with cancer survivors (each varying between 10 and 14 participants), 2 caregivers, and 17 individual survivors.

Additionally, our thesis research includes ongoing online tests that have netted more than 30 respondents to date.

We sought and received permission in all interviews to take notes and share responses publicly where needed, with assurances that we would anonymize all information and would not show their images.

Findings

To understand the survivors' experience, survivors told us it's important to understand the story of what immediately precedes it.

So, with a one in three chance, imagine that your doctor tells you, **"You have cancer."**

Imagine fearing the loss of your job during your chemo. Imagine wondering if firing you was legal, but knowing they could get away with it either way.

Imagine your brain doesn't work like before, when you can't tell if it'll go back to normal.

Imagine wondering where some of your close friends went, why members of your family treated you as if you were radioactive. Or contagious.

Imagine being told to keep your illness a secret.

Imagine the uncertainty, the complexity, the confusion of being in this vast system of treatments that didn't exist a few years ago. Imagine at first being encouraged because they were new, and then being worried because no one seemed sure what the long-term effects would be. Imagine being worried when your side effects surprise or even confuse your doctors. Imagine being doubted, dismissed. Feeling like a liability to everyone you love, being unable to recognize your own life as you know it.

Now.

Imagine hearing that the cancer is gone.

And one year later hearing yourself saying these words:

“Survival was worse than chemo.”

Many people express skepticism over this thought. Many people, but not a single survivor we’ve talked to.

We *expect* to hear that things are hard **during** treatment. We understand it, even if we haven’t gone through it yet ourselves. It seems reasonable. But if one was to get a cancer diagnosis, we wondered, what could be *better* than surviving it? Why would things get worse?

“(n.b. All quotes, unless otherwise attributed, are from survivors that we interviewed.)”

ENTERING the Hidden World of Survivorship

Cancer seems on its face to be about diseased cells. But for people who live through it, the experience impacts virtually every part of their lives.

“It’s not just, ‘Oh, I had cancer, woe is me…’ It’s about more than that. It’s about life.”

“What we call by this six letter word, it’s 100’s of different diseases treated 1,000’s of different ways that affects people at different parts of their lives. Cancer survivorship is incredibly complex and diverse.”

01 Survivors: younger, and overwhelmed

We found that many survivors today are working-age and eager to restart the lives and careers that were derailed by their diagnosis and treatment. When they can't, they're vulnerable economically, financially, mentally and even physically. Aside from needing to recover from the economic and psychological trauma cancer often brings, people seek to reestablish purpose and direction beyond the next check-up appointment.[6]

We met survivors who'd during treatment juggled support from hospitals, workplaces, friends, family and even community organizations – holding their lives together during life-saving treatment. And some survivors get incredible, holistic help. But some manage it just barely and feel alone and abandoned in the end.

But no matter how good survivors are at this juggling, or how amazing their hospitals or communities have become at caring for them during treatment, a lot of that support still frequently goes away when treatment ends. Maybe that would be fine if cancer-related harm disappeared with the tumor. But we're seeing increasingly that it doesn't. It continues to evolve over time like a deep-seated, untreated wound.

The last experience that many survivors have of support during treatment is of the pain of losing it, and the hardship of rarely finding a real substitute. It's like getting pushed off a cliff that was built high by a kind of support that only exists as long as you have a tumor. To make things more bewildering for survivors, when in treatment, we found that most reported feeling incapable of entertaining ideas beyond what they need moment to moment to survive. Services and support might be going untouched while survivors can't use them, and vanish when they can. Why is that happening?

We found three common components of survivors' experiences that function as central sources of support, and that likewise have outsized affect on the experience of survivorship. We'll take you through what we found for each, starting with hospitals.

02 Hospitals: a place for tumors

You get into a cancer center for having cancer. And survivors leave when their cancer is managed. Seems straightforward. People expect to feel excited to not have to go back.

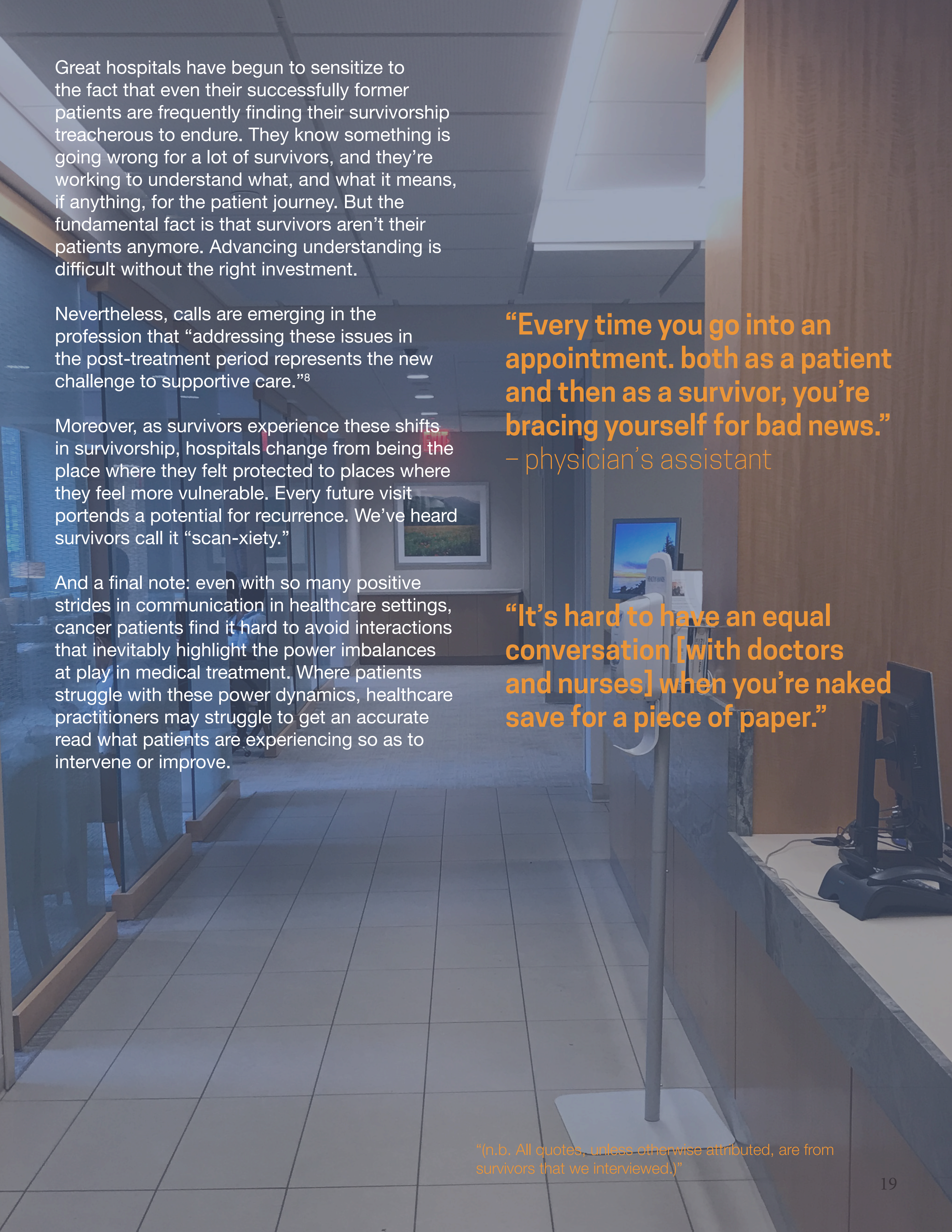
But for a survivor, this is often the first calamity of survivorship. Because many survivors actually wish they could stay in some form. Hospitals have gotten so much better at helping with the stress, side effects and broader impacts of cancer and cancer treatments. Some cancer centers are even offering more and better supportive services than patients feel they have the capacity to take advantage of. For many, it's hard to seize on such expansive support until they no longer have to think about their treatment. But there isn't yet another place a survivor can go after treatment for continued access to the range of services they were offered while at a great hospital. And that's the time they need it, and are ready to seize it.

> **"If I were running one of these institutions, I'd run it like companies opt employees in for 401k's. They should sign you up for everything up front, because you'll need it, even if you don't understand it at the time."**
> – caregiver

And let's note, having the monitoring eye of a treatment team means, to a survivor, protection from their cancer. Put crudely, cancer arrived when no one was watching, and it goes away once people are. Does not having that attention mean it comes back? The prospect haunts survivors.

A hospital's first priority is the people coming in with a new diagnosis, and no cancer center we've found has the resources to also meet the needs of those who've successfully finished treatments. After all, cancer diagnoses are rising faster than the supply of trained staff. Cancer centers are on the hunt for new ways of addressing this emerging shortfall, but it's challenging.

In the meantime, many clinics have taken aim at more effectively reconnecting survivors with their pre-treatment primary care physicians (PCPs) as the solution.[7] Patients, however, might carry into survivorship an array of issues and experiences that cause them to feel unenthusiastic about PCPs as a solution to their challenges – not least that some of those problems have putatively little to do with what is normally within a PCP's scope.



Great hospitals have begun to sensitize to the fact that even their successfully former patients are frequently finding their survivorship treacherous to endure. They know something is going wrong for a lot of survivors, and they're working to understand what, and what it means, if anything, for the patient journey. But the fundamental fact is that survivors aren't their patients anymore. Advancing understanding is difficult without the right investment.

Nevertheless, calls are emerging in the profession that "addressing these issues in the post-treatment period represents the new challenge to supportive care."[8]

Moreover, as survivors experience these shifts in survivorship, hospitals change from being the place where they felt protected to places where they feel more vulnerable. Every future visit portends a potential for recurrence. We've heard survivors call it "scan-xiety."

And a final note: even with so many positive strides in communication in healthcare settings, cancer patients find it hard to avoid interactions that inevitably highlight the power imbalances at play in medical treatment. Where patients struggle with these power dynamics, healthcare practitioners may struggle to get an accurate read what patients are experiencing so as to intervene or improve.

"Every time you go into an appointment. both as a patient and then as a survivor, you're bracing yourself for bad news."
– physician's assistant

"It's hard to have an equal conversation [with doctors and nurses] when you're naked save for a piece of paper."

"(n.b. All quotes, unless otherwise attributed, are from survivors that we interviewed.)"

03 Workplaces: a minefield

> **“There’s no tolerance right now for different ways of working.”**
>
> – V.P. of H.R.

Many survivors are working-age and eager to restart the lives and careers that were derailed by their diagnosis and treatment. When they can’t, they’re made more vulnerable economically, financially, mentally and even physically. But research shows that for more than two in ten working-age survivors, physical, mental or emotional problems either prevent them from working at all or limit the type or amount of work they can do. Moreover, “40% [of survivors] report their experience of working and of future career prospects as having deteriorated.”[9, 10]

We researched workplaces, exploring the experiences of survivors, colleagues, HR professionals and employment lawyers in interviews, and we learned about policy frameworks at business, local, state, and federal levels. We found that, short of a big change in state and federal laws, workplace protections remain inconsistent, unpredictable, inflexible and often flimsy, even when HR wants to help. Indeed, of private and public sector jobs, the private sector fares far worse, even while employing the overwhelming majority of Americans, failing to consistently support employees with cancer or having survived.[11]

One H.R. professional we spoke to had recently gone out of her way to help an employee who was ill. She made some exceptions to policy to have things work for the employees, and she suffered legal complications as a result. “I tried to help somebody out, and I have to go to court this week because of that,” she said. “What do you think I’m going to tell the H.R. team members I manage next time they’re tempted to go the extra mile to help someone on staff?” We want to emphasize: this professional very much *wanted* do to more, but found reality to be entirely against it.

> **“It’s all about precedent in HR.”**
>
> – V.P. of H.R.

The protections and accommodations are often thin or nebulous enough that survivors are disincentivized to even speak of their multiplied challenges. But of course, survivors need their careers, and as they experience sometimes serious side effects, they need accommodations to succeed in their careers at times.

So, many survivors suffer where they find it too risky to ask for such accommodation. And you don't often receive something that you can't ask for.

And as survivors try to get by without accommodation, we heard multiple stories of those who were fired for failing to hit an impossible standard that should have been workable. It's a pernicious cycle fed by an inability to openly negotiate the strictures and quirks of the American employment landscape.

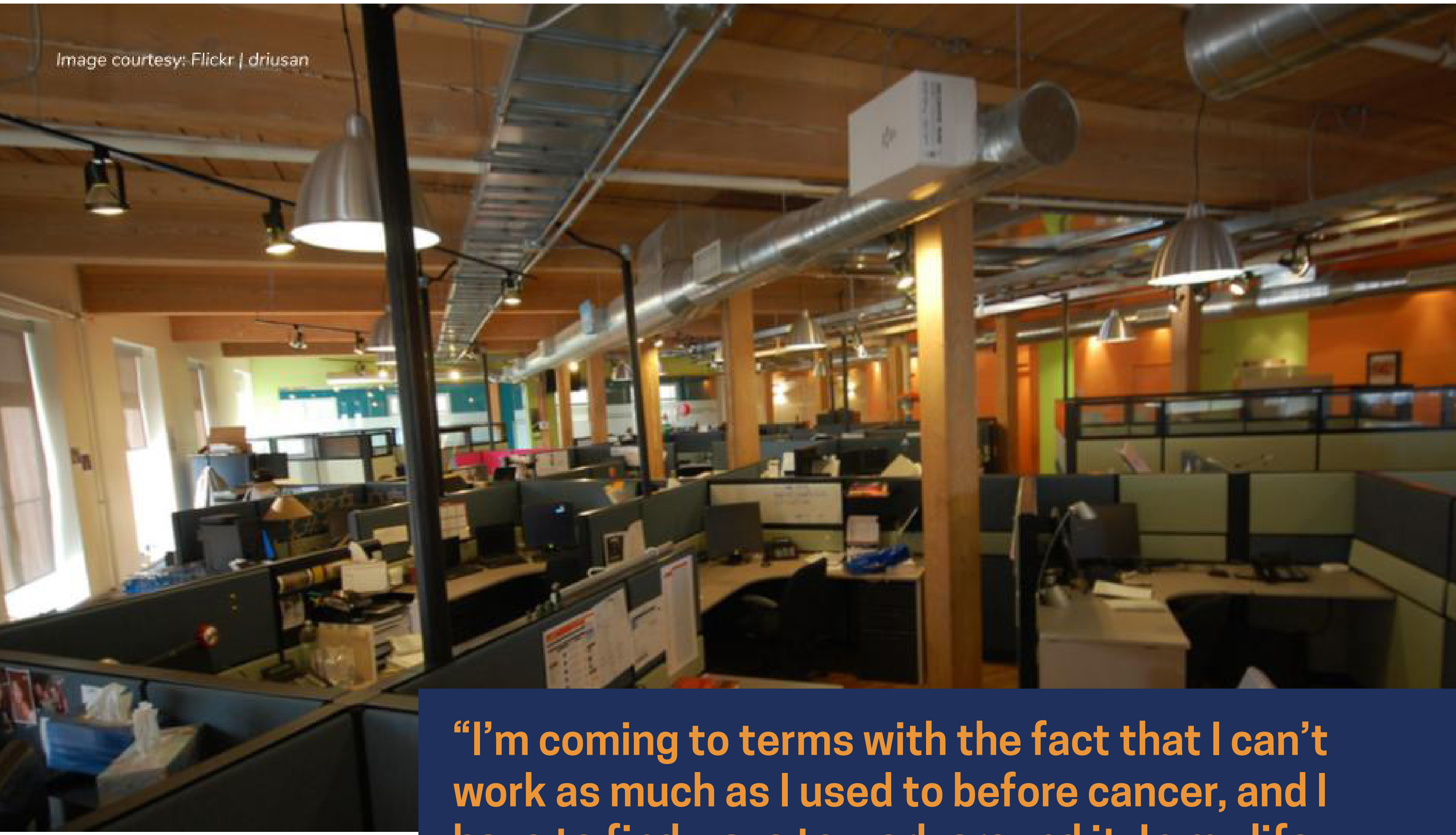


Image courtesy: Flickr | driusan

"I'm coming to terms with the fact that I can't work as much as I used to before cancer, and I have to find ways to work around it. In my life, work is the hardest part. How do I manage both work and my health? My colleagues don't feel that I'm as engaged as they want me to be."

"(n.b. All quotes, unless otherwise attributed, are from survivors that we interviewed.)"

04 Family, Friends, Communities: the good, the disappeared, the faded

Next, from parents, spouses and siblings to colleagues, sports buddies and communities of faith, we wondered if close relationships with family and friends fared better than hospitals and workplaces as sources of needed support after treatment.

We worked with family, friends, social workers and survivors to understand what successful support and pain points looked like there.

We were surprised to find that what survivors described as support that had a positive impact on them seems easy and simple to provide. The bar for effective support is generally as low as a text or call from time to time, just to let them know you're thinking of them. Maybe the chance to rant or laugh or find distraction for a while without penalty or expectation.

This seemed to us like a phenomenally low-hanging fruit. How often is it happening, and how easy is it to foster where absent?

For anyone interested in 'health-related quality of life,'[12] this is an important question to ask. Research shows this kind of social connectedness and support to be a profound determinant of health outcomes – even of mortality – for anyone, not just the ill. [13]

Yet survivors are often getting and keeping this support less than when they were well, not more. Every survivor we talked to could tell us of once-close friends and family members who were no longer a part of their lives after treatment; they 'disappeared' during their cancer treatment. Every subsequent person informed becomes more and more, to many survivors, a risk in an exceedingly vulnerable moment: how will this person react? Will survivors be made responsible for their reaction?

"Prayers, phone calls, texts, someone cooking, family members showing up with me to my chemo sessions..."

"Imagine sitting there by yourself for months at a time, constantly being let down."
– physycian's assistant

"When you tell somebody [about your cancer], you become a little bit responsible. Because they can't do nothing. I lost some friends who knew and didn't do anything."

Almost to a person, the survivors we talked with, individually and in groups, demurred firmly when asked to explore why that may have happened. The 'disappeared' had often been close relationships at the time of diagnosis, but survivors told us that they were later considered 'not real' friends, given the distance that emerged during treatment when those friends or family failed to 'show up' for them. And even if they were loathe to explore root causes in detail, each could give very detailed accounts of the 'wrong' things close relations may have said or done during treatment, to their emotional distress. They were frequently simple things that might in another context have proven dismissible. But almost nothing, in cancer, ends up simple.

Their reluctance to speak of their 'disappeared' with us was joined by an inability to think of contexts under which they might be moved to re-engage these relationships once lost. In fact, when we tried to design activities that might provide low-risk processes to begin facilitate productive re-engagement with some of those in an attempt to bolster social support in survivorship, survivors adamantly objected to the idea of reengaging them, let alone initiating.

"Understanding has been difficult for my dad. He's often said horrible things without realizing it (e.g. My 13-month hospitalization was a "vacation"). Sometimes, he points out that he didn't want to have "these conversations" until I was older. I know he's hurting, too, but it's put major barriers in our relationship."

"I think he's doing his cancer wrong! If I had cancer, I'd do it different!"

– caregiver (spouse)

"(n.b. All quotes, unless otherwise attributed, are from survivors that we interviewed.)"

Among those relationships that didn't disappear during treatment, many often still fade after treatment and into survivorship. Although we can't speak conclusively or authoritatively on this point, we offer that our research might indicate a kind of emotional exhaustion in survivors' social support communities. That point where treatment ends and patients hear they're cured? With relief, family and friends take that as a sign that survivors won't need further support.

And since survivors would rather get their lives back on track than risk being 'the needy one' forever, they struggle with how to correct the misperception. And they lose support while they do so. Survivors feel increasingly isolated, struggling with careers, loss of their healthcare team, and other traumatic elements. Losing their social support can be all the more crippling.

[n.b.: It was challenging to thoroughly explore with a survivor their relationships with people who have hurt them and then ask for the contact info to follow up. As such, we were limited in recruiting participants who were in these 'disappeared' or 'faded' categories.]

> **"So many times, the extended family is at the end of their rope [during and by the end of treatment], that the minute you're 'cured', they move on."**

> **"These psycho-social issues can be debilitating for people."**
> – social worker

"(n.b. All quotes, unless otherwise attributed, are from survivors that we interviewed.)"

05

Interwoven with Stigma

Interwoven with these experiences is a persistent social stigma around cancer. We note, as others increasingly do, that this stigma isn't as bad as it once was, yet other research shows that it's still a powerful factor, particularly in many immigrant and minority communities where it may still profoundly inflect outcomes both for those who have or have had cancer, as well as those who will. Cancer mortality is still comparatively elevated in such communities, perhaps because the continued stigma depresses health-seeking behavior, lowering screening, and leading to poorer prognoses.

So let's get specific about "stigma," because it can be a wide-ranging term encompassing the experiences survivors have of how people act towards them without ever quite articulating why. If we were to imagine, based on our in depth interviews, what survivors heard behind those interactions, it might sound like this: Instead of getting treated as if you had cancer, people act a lot more as if you are cancer. As if you were contagious. As if the anxiety and uncertainty involved is too great to be around someone who did.

You ~~had~~ are **Cancer.**

Which is, ironically, not dissimilar to how it makes survivors feel too.

What stands out here is how similar these concerns are to those we heard survivors express about themselves. The anxiety and uncertainty that plagues and sometimes paralyzes survivors seems shared by others. But of course, survivors don't have the same ability to simply put distance themselves and the source of that anxiety as workplaces, friends and family do. They can't. The source is in their own bodies. It's a profoundly intimate disadvantage.

Time can help, but doesn't always. Many survivors are told that after five years cancer-free that their chance of a recurrence is the same as the general population. But that framework actually increases anxiety: their odds were average the first time too, and they got cancer nonetheless. Even odds mean they could get it again.

> **"Stigma is having to deal with family at a moment they're not prepared for."**

> **"I feel the ball is dropped when it comes to your support network preparing you for life after cancer. They don't tell you how much anxiety you will be facing and how their is no 'back to normal' for you anymore. Their is only a new normal that you must find and that is difficult to do."**

"(n.b. All quotes, unless otherwise attributed, are from survivors that we interviewed.)"

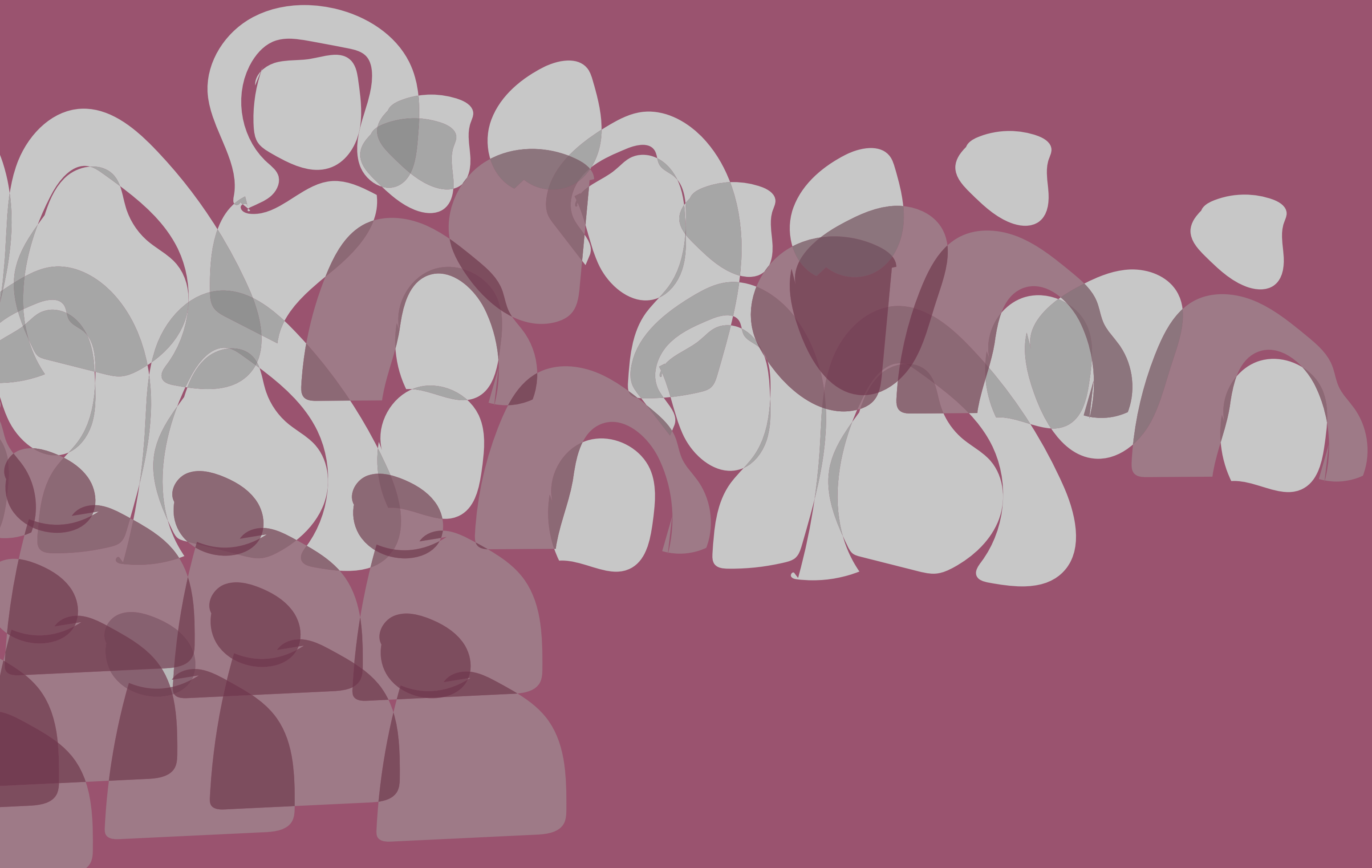
To recap...

That’s hospitals, workplaces, friends and family.

We found ourselves looking closely at each because, as we considered the systems at play when centering on survivors’ lives, they were consistently cited by survivors as significant elements of the cancer journey, even into survivorship. Indeed, survivors with whom we spoke couldn’t describe challenges in survivorship without including them.

In short, those three sub-systems form a survivor’s ‘natural ecosystem’ in motion. We find that as survivors enter lifelong survivorship, they’re losing critical expert knowledge and monitoring, the confidence and guidance to effectively advocate in complex career conditions, and the invaluable social support to back their advances in the face of these challenges.

If this is where they feel losses, where do they make advances?



Survivors' FTW

We did find, however, a source of support that doesn't withdraw or fade when survivors mention and struggle to manage their cancer: other survivors.

Survivors provide de-risked, well-informed, consistent support.

What's so unique about survivors compared to hospitals, workplaces, family and friends?

> "Survivors will have very different cancers and experiences, but you just connect with them in a way you don't with other people."

> "It's best to talk to a survivor. I had friends, but they just didn't get it."

"(n.b. All quotes, unless otherwise attributed, are from survivors that we interviewed.)"

Survivors are a big, trustworthy tribe. Survivors ‘get it’, a phrase that the majority of survivors we worked with used at one point or another specifically to refer to other survivors in general. That precondition builds a lot of trust at the outset for people having a tougher time with trusting relationships where their cancer is concerned. The range of experience and challenges endemic to cancer, even in survivorship, is readily acknowledged and rarely rejected, minimized or narrowed with survivors. We found survivors to be consistently, surprisingly ready to meet another survivor wherever they were, even when specific experiences might differ widely, even when needs and challenges varied, even when cancer type and treatment history and other contextual information varied from one’s own.

“There’s that cathartic feeling of talking about it. It’s a sad feeling, but there’s that connectedness. ’You’re not gonna freak me out by talking about some crazy shit.’”

“I like that you’re keeping it real. Whatever you’re feeling is totally valid! I wish you had more help.”
- survivor to another survivor

Survivors bring knowledge and support that build self-efficacy. When together, survivors are often encouraging, informed, understanding, believing and nudge others towards productive action and outlooks without diminishing the challenges at present and along the way. Survivors are cancer autodidacts virtually unmatched among lay-people for breadth. Survivors trend resourceful - perhaps because survival seemed to demand it.

In short, it’s not so much that survivors fill one of the survivorship gaps. Rather, they show up as resources in addressing nearly every gap, either as ‘solutions’ themselves (think: sympathetic ears and understanding responses to rants that create relief) or as guides towards workable solutions, ready to offer ideas, experiences and suggestions to source what’s needed wherever possible.

“I feel you. *hug*”
- survivor to survivor

Helping is itself profoundly helpful. Survivors are feel compelled to be Good Samaritans in survivorship. They help each other, because they know broadly and consistently what survivorship is like, and how much of it is misunderstood. And helping others in their shared struggles helps survivors manage with their own ongoing anxiety as well. When providing social support, both the giver and the recipient experience the benefits of better social connectedness.

We find here a compelling case that survivors can be uniquely available to offer guidance towards resources and encouragement to self-advocate. The two most vital resources that evaporate or fracture are access to people who can promptly address concerns in survivorship as they emerge, and access to people who can provide the social support that builds self-efficacy, leading to improvement in overall health-related quality of life.

Timely knowledge specific to survivors’ needs, and a community inclined to sustain social support.

“It’s selfish of me not to talk to more people, wasting all the lessons I’d learned.”

“(n.b. All quotes, unless otherwise attributed, are from survivors that we interviewed.)”

Support Groups: More of What Helps

So, if survivors are good, are more survivors...more good?

To answer that question, we worked with survivors who'd found support groups, survivors who'd formed support groups, and we partnered with Shareing and Careing– a breast cancer support non-profit formed by survivors in Queens, NY 24 years ago.

We were consistently amazed at and grateful for their openness and generosity to share their stories, experiences, and their work with us, allowing us in many cases to come back again and again over time to clarify and confirm our understanding, and to build and test prototypes to find interventions that worked across their range of experiences – and to learn if those measures were appropriate, possible or desirable.

> "The support group felt like a community. It helped me feel part of things again."

"(n.b. All quotes, unless otherwise attributed, are from survivors that we interviewed.)"

We found a few significant things happening in support groups.

1. Everyone, and everything, has a place.

Support groups are validating communities where, when survivors speak of their experiences, all heads nod. Survivors groups welcome those stories – and believe them. This validates experiences and builds self-advocacy in the face of the fear of disclosure that dominates other areas of their lives.

"I understand where you are coming from. It is a natural feeling we all have."

- survivor to survivor

2.Cancer isn't only one thing, so neither are we.

That's why it's so helpful that survivors readily exchange enabling knowledge and support on a big range of challenges. And when assembling programming, a good support group will first survey what survivors' challenges are, because challenges can change and surprise over time. Some support groups respond by trying to bring in experts related to emergent challenges.

"There's that cathartic feeling of talking about it. It's a sad feeling, but there's that connectedness. 'You're not gonna freak me out by talking about some crazy shit.'"

3. Ad hoc mutual monitoring helps manage anxiety.

Survivors are able to use the community they find in support groups to stand up their own ad hoc, mutual monitoring. It's comforting, and effective, and helps build back what was lost when they finished treatment.

"You feel better when you have people looking at you."

*** We note, however, that even at this hyper-responsive community level, things don't always work. We found a few common bottlenecks:**

Needs vs. Numbers: Although such organizations try to shift resources around survivor needs, holding a meeting that only one survivor attends can be discouraging for the survivor, even when the meeting is specific to their need. Topics often require a 'coincidence of need' among a group of sufficient size to be properly met in social support contexts without causing harm.

Resources: Even great organizations can't do everything survivors might need. Particularly when they aim to serve both patients and survivors. And targeting only one is infeasible: patients can become survivors, and survivors sometimes become patients again.

Discovery: Community-level organizations often have to use a portion of their limited resources conducting non-cancer-related events just to help raise awareness among potential cancer patients and the survivors who might need their support. Getting the word out and finding the ideal audience is hard.

Access: Although many survivors are interested in connecting with other survivors for social support groups, travel and timing considerations are not infrequently cited as barriers, sometimes because of the inflexibility of lower wage jobs in particular or when households are single-parent.

Soft Entrances into Social: We also observed that some survivors are eager to connect with community groups that offer support groups, but only to work directly with the individuals and volunteers available for 1-on-1 meetings. Some of these survivors just aren't ready for or interested in wider group settings. Some go on to become group attendees in time, whereas others never move to group meetings. Not everyone desires a group larger than two to achieve sufficient social support. Community organizations appear to have no objection to this, other than that it is resource-intensive to support survivors one-by-one.

*** Survivors are offering needed acceptance, information, and affirmation – all as flexibly and responsively as possible. That's pretty good (to understate things a bit).**

A System with Survivors in the Center

In sum, we believe that the system survivors need in their lives to thrive in survivorship would look like this:

Social support, characterized by

- survivor-to-survivor centrism,
- safety to share stories essential to self-advocacy and self-efficacy,
- and mutual validation that builds on actual experiences.

Responsive guidance that's

- timely, trusted, and adaptive to the wide array of interrelated experiences in cancer's after-effects,
- acknowledges the experiences of survivors as essential to understanding needed support,
- and gives direction and empowers progress.

Otherwise of note:

Is it the Information or the Timing?

Newer, much-lauded frameworks of “the right information at the right time” are doomed to disappoint if it turns out that, as our research suggests, the right time for certain best-in-class services may be after patients have already been transitioned away from clinics. Real commitments to delivering patient-centered care may require healthcare providers to begin to think more flexibly about the timelines over which that care is delivered.

The Meaning of “Survivor”

An excerpt from “Cancer Survivorship: Why Labels Matter” in The Journal of Clinical Oncology[14]

“The term ‘someone who has had cancer’ engenders a view of the disease as something a person either has in the present or had in the past. Although some people may experience cancer in such terms, for others this label is likely to have similarly constraining effects, making invisible the ongoing presence of cancer in the lives of many of those who had the disease. […] The complexity of cancer treatment contrasts with that of a majority of chronic illnesses. The initial diagnosis of cancer is acute and yields a speedy response, in contrast to the typical response to a diagnosis of chronic illness, which generally emerges over time. Although this experience of acute and chronic episodes occurs in attenuated form in a number of diseases, cancer is unusual insofar as those successfully treated may be deemed cancer free—although not, for the most part, cured. Moreover, few other chronic diseases (apart from HIV/AIDS) evoke such strong fears about mortality.

“Until we have a better framework for conceptualizing diseases such as cancer, these definitional issues are unlikely to be resolved. Indeed, they are likely to only become more salient in light of our aging population, with the numbers of cancer survivors estimated to reach 18.1 million in the United States alone in 2020. However, in the meantime, it is important to recognize that words not only describe, but also construct, the phenomena under question.”

What “Accessible” is for Survivors

In our research and prototypes, we found reason to consider ‘accessibility’ through an analagous framework to that presented by Mullainathan and Shafir in their book “Scarcity: Why Having Too Little Means So Much.”

Accounting for survivors’ states of mind and recent experiences when designing services and support might bring us to consider how not designing adequately for the variety of their challenges leads to a fragmentation of resources that disincentivizes making the effort to take them up, and depresses the self-efficacy more generally that those resources meant to bolster.

Solutions should design for trust, connection, elasticity and the longer-term emergence of questions and challenges in survivorship.

> “Treatment was a bit of a blur. You were following some kind of path. An appointment. A milestone. You’re kind of living by these dates and treatments to help orient you.”

> “One thing that could be better is one central location for resources. It’s hard to find things.”

> “I consider nutrition to be the bare minimum. If there’s nothing for that, I don’t expect there to be anything for mental health.”

“(n.b. All quotes, unless otherwise attributed, are from survivors that we interviewed.)”

The ‘Jury Duty’ Effect

We heard from one interviewee about a day during the treatment phase that they’d been called up for Jury Duty and chose not to delay. In the telling, the days spent having been selected were a relief. They went to court every morning, took a lunch break at the appointed time, went back to finish the day, and went home feeling a kind of accomplishment that seemed otherwise evasive during treatment.

Early speculation in conversation with others in our DSI thesis group touched on whether in this space a kind of Snow Day experience was at play – the relief of a day off, an exceptional and distracting space in an otherwise demanding routine.

However, as we probed in subsequent interviews and prototypes, we began to believe that the Jury Duty Effect wasn’t as much about escaping life so much as reengaging purposeful activity that centered on the survivor’s ability to make their contribution instead of a ‘passive’ consumer of resources.

A survivor’s life in treatment often revolves around simply showing up and fighting to endure treatment. But something like the Jury Duty story shows less that they need a holiday (although we’re sure that many need that as well), but rather that they need a chance to engage in purposeful, productive activities that restore a sense of agency and self-efficacy outside the overwhelmingly passive experience of being defined as cancer patients.

If it has a clear positive effect on others, all the better.

> **“It felt like I could actually create something good in the world.”**

“(n.b. All quotes, unless otherwise attributed, are from survivors that we interviewed.)”

What Leaders Recommend, but Survivors Don't

Interestingly, we found that there were high-profile, sometimes well-funded support organizations with national or even international reach that offer group sessions which survivors tended not to recommend nearly as frequently as we found that health professionals themselves (in both physical and mental health) did.

Some survivors found that these meetings felt expert-led, programmatic or impersonal. They didn't feel enabled to respond conversationally to presentations. They felt the meetings were optimized for absorption of information, but not optimized for connection and information exchange. It was presentational, but not conversational.

> **"It's like going to a doctor's office. 'This is the way it's done, and we do not deviate from it.'"**

It was, in short, like being back with a hospital specialist: having myriad needs that they feel nervous about shoehorning into a narrow context.

While survivors frequently lack and eagerly seek out access to specialist insight and guidance, they dislike doing so in non-survivor-centric, which is to say ways where they doubt they'll come away feeling heard. Understanding this, we recalled stories we heard of survivors during treatment feeling frustrated with similarly impersonal, sometimes-rushed interactions with treatment staff such as doctors that led them to adopt "let's just get out of here and figure it out for ourselves at home" outlooks. They would sense when access offered wasn't meaningful, invested and responsive. As such, it wasn't, to them, access at all.

> **"Why can you only put in one cancer? I wanna talk about both my cancers and other symptoms and complications."**

This is important to note, because otherwise these seminar-style offerings that are already available might seem to be tidy solutions to survivors' problems instead of rather introductory elements of what should extend into longer-term experiences.

"(n.b. All quotes, unless otherwise attributed, are from survivors that we interviewed.)"

Is Online Any Good?

Not every online solution solves more problems than it creates, of course. This became particularly salient for us as we explored use of the Facebook API for sign-ins, account creation and use of friends lists – around the same time that the Cambridge Analytica scandal broke.

So we're tried to take a step back when considering the potential to deliver an 'online solution' at all.

So, why go online? Well, we find that survivors are often going there anyways, starting during treatment. We live in the WebMD era of consumerist healthcare. Our research suggest that some survivors looked to learn as much as they could online to better support their own care decisions. They tried to bring educated questions and approach their options collaboratively with their treatment team.

For others, online resources are their last redoubt after disappointing appointments – the place one figures things out after a dissatisfying appointment is done. This is particularly true for patients who aren't fortunate enough to find attentive, patient-centered care teams in treatment.

One caregiver told us, "[My spouse] wanted it to be like, 'Give me the real facts.' And [doctors] don't wanna do that. It can be like talking to a politician. Sometimes it's just like, 'Let's get the hell out of here, and we'll figure out the questions later."

Into survivorship, online communities on platforms like Facebook become essential resources to many survivors. But those outlets have overlap that can make survivors feel they're sacrificing one social resource for another. We spoke with survivors who found themselves having to choose when their normative participation in Facebook knocks up against the potential for a stream of cancer posts to overwhelm newsfeeds that they might otherwise need for more trivial social media use.

Moreover, as we mentioned before, many survivors don't want their lives further interrupted or their narratives spun increasingly out of their control by knowledge of their diagnosis spreading via social media. This is particularly true for those getting counsel to avoid disclosure. However, social media provides for many survivors an easy, effective tool to activate one's social support network around needs relating to cancer. Cutting off this means of accessing support can increase isolation.

Finally, we also found evidence both in our research as well as peer-reviewed publications that anonymity is not always required for social support in stigmatized health-related online conversations, and that a wide range of impactful support often comes to people able to use those online fora to connect with others who share and understand their challenges.[15]

"My dad told me, 'Don't post anything.'"
– caregiver

"Every day in my Facebook feed I'm seeing about cancer, and it can be hard…"

"What made [going through treatment] easier is doing the research. You're fighting!"

"(n.b. All quotes, unless otherwise attributed, are from survivors that we interviewed.)"

Prototyping

Starting in late November, we undertook design of a series of prototypes to begin to test findings and move towards potential solutions.

F#&% Cancer Parties

Concept

The Fuck Cancer Party prototype was presented to a focus group session of survivors in a storyboard layout (the same session as storyboards for the 'Career Wellness Program' and 'Survivor Storylabs').

We envisioned the parties being thrown by or for a survivor on the occasion of the end of treatment. The kits could be modular, with activities, games, decorations and 'party favors' organized so that survivors and caregivers could identify the thematic elements that corresponded to the survivor's cancer experience, both to sensitize the attendees as well as to help catalyze less fraught discussion around topics important to successful survivorship. Additionally, we believed that Fuck Cancer Parties could be useful in galvanizing support around survivors so that social support wouldn't so frequently see a precipitous drop in quantity and quality as they begin to 'get back to' their lives.

We got the idea from a similar event put on by a caregiver we interviewed whose purpose was getting friends and family to understand that their partner "wasn't radioactive." Both the caregiver and the survivor felt that the event helped normalize the relationships somewhat after the trauma and tension of treatment.

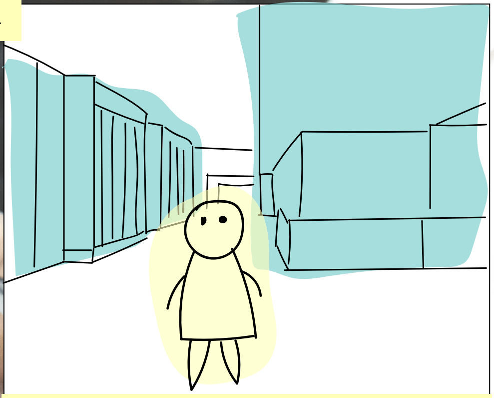
Learning

Most survivors were tepid towards this concept. We heard things like, "I just wanted to get away after treatment, not have a party with everyone," or "It might have been nice if someone else had thrown one for me," or even as simple as "I didn't need a party." We understood that it could have been that we didn't properly communicate the concept, or also likely, the survivors we asked just weren't interested in this.

There may still, based on other stories we heard, be an opportunity for other members of a survivor's social support network to throw a party from which a survivor would benefit. But we understood two critical oversights we'd made: 1) virtually no one wants to throw their own party, and 2) the immediate benefits we were imagining might more accurately accrue to those around the survivor as information, exposure, and normalization of the survivor's cancer experience, while subjecting the survivor to a kind of ogling at a weird, cancer-themed party ostensibly celebrating them.

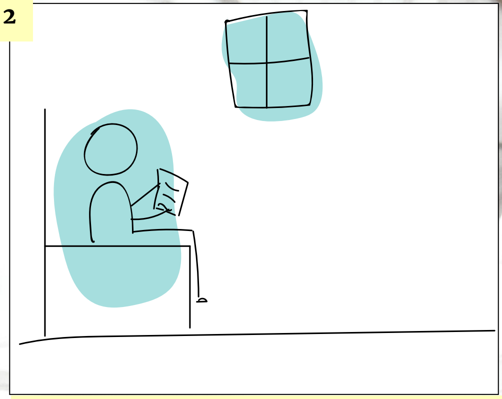
Notably, a number of social workers each thought the idea could still be valuable, mostly in the potential to productively address shifts in life-stage, or honor and acknowledge the new experiences. One even told us they were thinking of writing something up for publication about the idea of the lack of life-transition ceremonies for survivors transitioning after treatment.

1



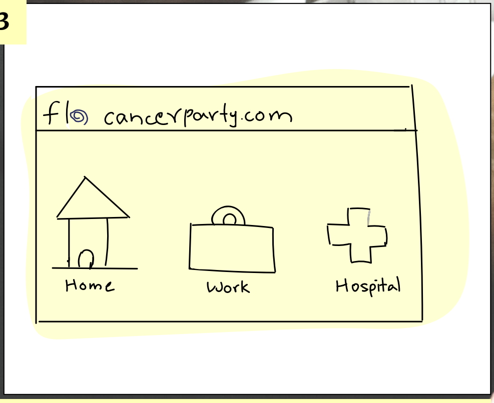
After treatment...

2



Caregiver plans a ‘F#&% Cancer’ party for the survivor

3



Caregivers choose the kind of party kit they appropriate to the environment they are setting in. The party kits can also be used by survivors to throw a party

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Available in editions appropriate for both active treatment and survivorship, and to friends & family, workplaces looking to support colleagues,or broader community such as houses of worship

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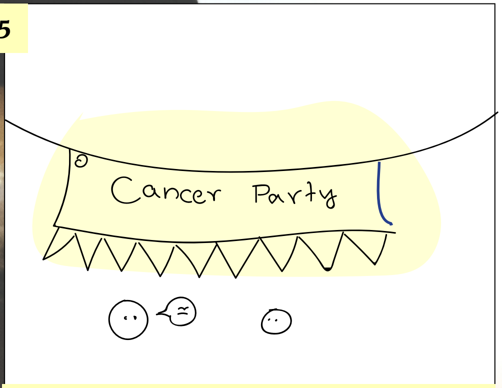

Cancer parties can be used for probing in meaningful and guided conversations with survivors and their community of family and friends

Thoughts/ Suggestions or Feedback

Career Wellness Program

Concept

The Career Wellness programs were meant to address challenges we heard around re-starting careers that were interrupted by treatment. We understood from survivors we interviewed and the important work of organizations like Cancer & Careers that, at a minimum, the resulting employment gap and, for some, the associated explanation could make it more difficult to get a job.

Moreover, as we probed the ‘Jury Duty’ Effect (described elsewhere in this paper), we noted that survivors (and patients) were describing benefits through purpose and creating locus of control, not just a mere distraction. Indeed, many survivors reacted negatively to the idea of ‘distractions’ during treatment, feeling that a sense of focus was valuable.

For these reasons, we proposed to many survivors a Career Wellness Program that could be made available during treatment, developed specifically to set them up for more successful survivorship as related to their career development. As such, it could involve learning new skills such as coding, attending workshops on tips, tricks and techniques to manage their productivity while they recovered from or acclimated to some of their disabling side effects, as well as interview and resume coaching.

Learning

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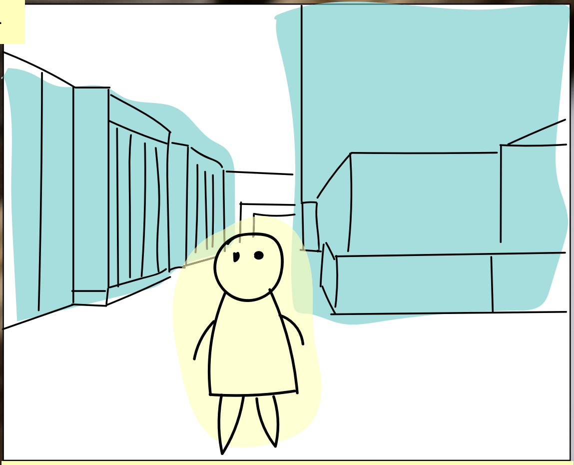
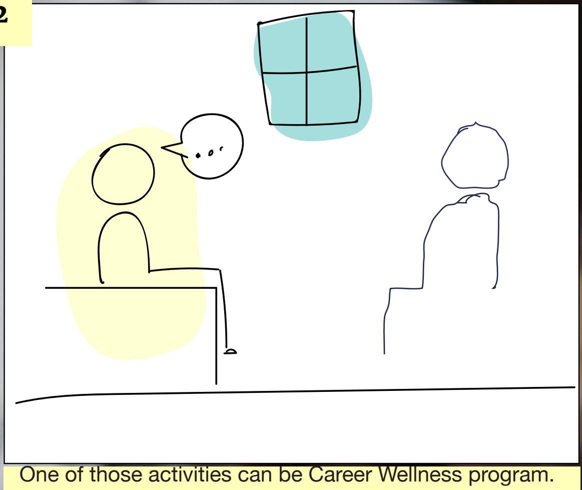


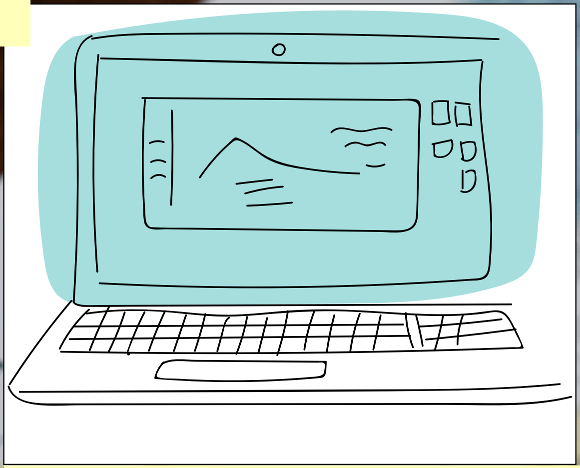
During treatment, when there is no work, taking time off for other activities while at the hospital/ home

2



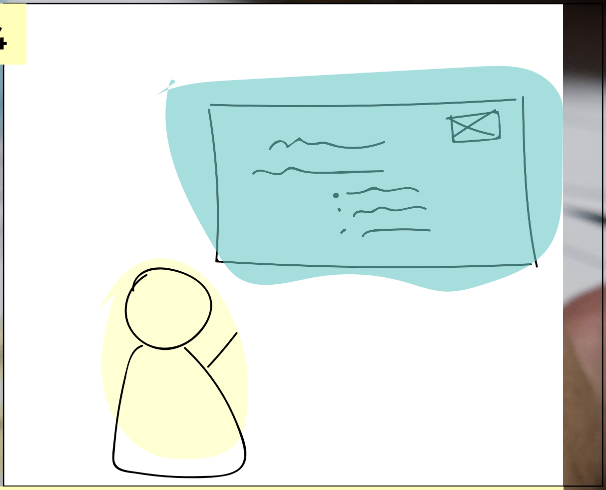
One of those activities can be Career Wellness program. Consists of role playing, scenario planning, workshops and interview techniques

3



Online education access, Language Ed, Coding courses, Certificate Courses

4



Seminars on Career topics, Productivity Aids, Practical tools and techniques

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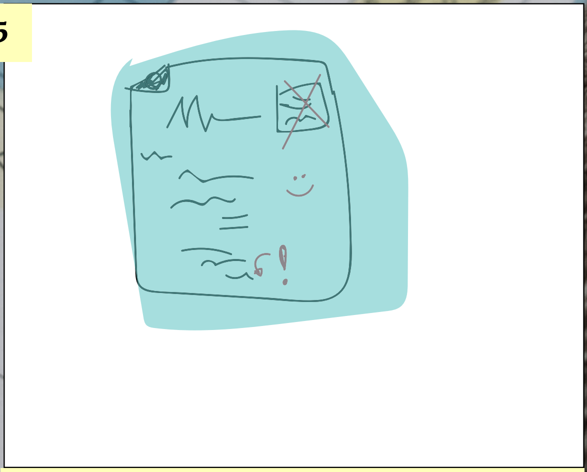

Resume' Help

Thoughts/ Suggestions or Feedback

Survivor Storylabs

Concept

We conceived of Survivor Storylabs as being a media lab built expressly for survivors during treatment to facilitate storytelling around their cancer experience to preserve it, to process it, to share it, or to build familiarity with it that would could well-serve the survivor as they would be soon out of treatment and often in need of self-advocacy and attendent comfort with their story.

There would be a variety of media production tools available for use, including video, audio, fine arts and writing, as well as supportive, facilitative activities to help people get started in framing their experiences narratively.

Learning

Beyond the above reasons to decline the invitations to prototype in treatment areas, the Storylabs seemed frequently to come off as being about recording stories for those likely to pass away from their cancer – a kind of in memoriam in progress. In fact, the well-known StoryCorps organization itself had undertaken a similar program in partnership with MSKCC and others to do exactly that.

This, of course, would have dramatically shifted not only our locus of intervention, but our target population.

Feedback showed that these activities, particularly during treatment, sometimes felt to survivors like they carried a pallor of impeding mortality.

A bright note, however: in testing the concept, a survivor told us of how they'd felt increasingly guilty hearing their caregiver partner over and over again on the phone having to provide friends and family with successive updates after each appointment, treatment and test. To save the caregiver time, sanity, and stress, the survivor began to write the updates himself in a regular blog. He told us that the process of recording his experiences in the blog at first was about capturing details for updates, but they soon began also to include his thoughts and feelings about what was happening, and finally a realization that he actually found the blogging helpful and therapeutic – a space to process and validate what was happening to him, as it was happening, and work out what it meant to him.

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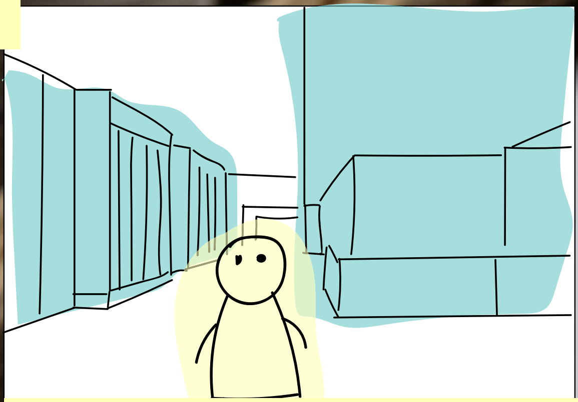

During treatment, when there is no work, taking time off for other activities while at the hospital/ home

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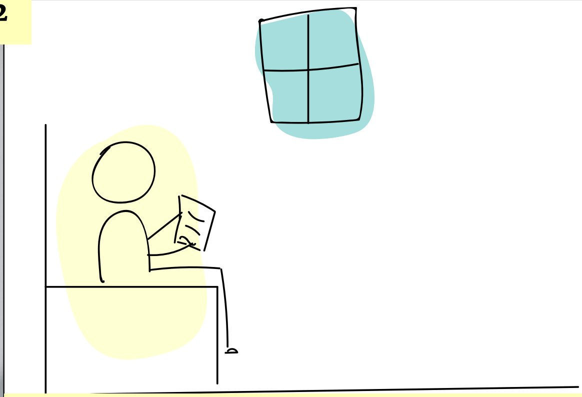
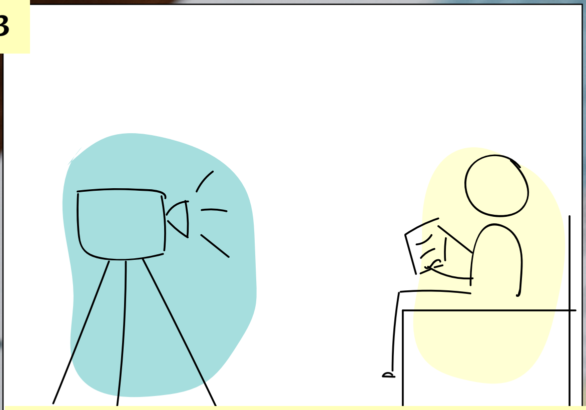


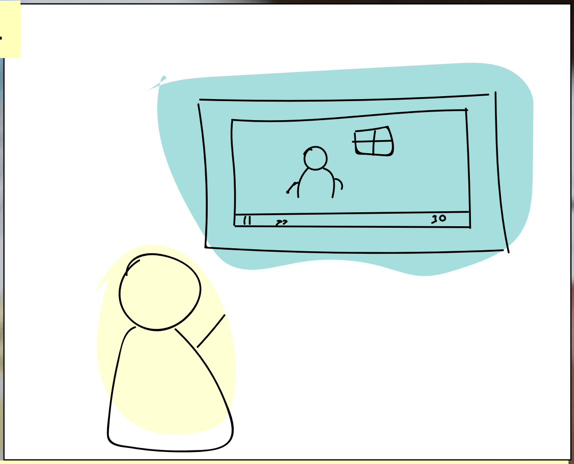
Looking at the light touch curriculum.The curriculum is structured to facilitate reflection on and expression of patients’ unanswered questions, concerns, stressors and expectations.

3



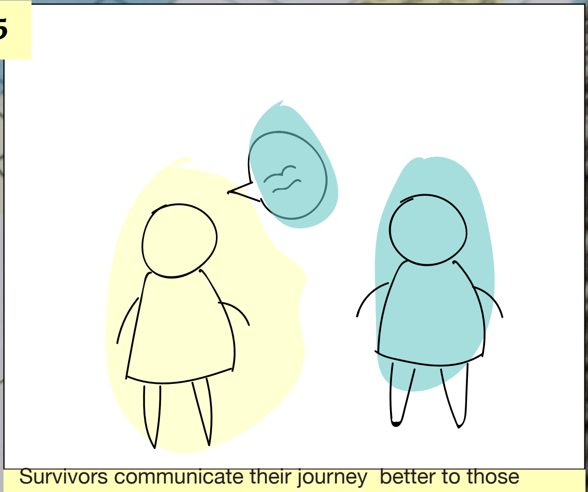
Patient takes the opportunity to creatively document their treatment journeys
guided by the .curriculum from shortly after diagnosis to the end of treatment

4



Survivors reflect on their treatment journeys.

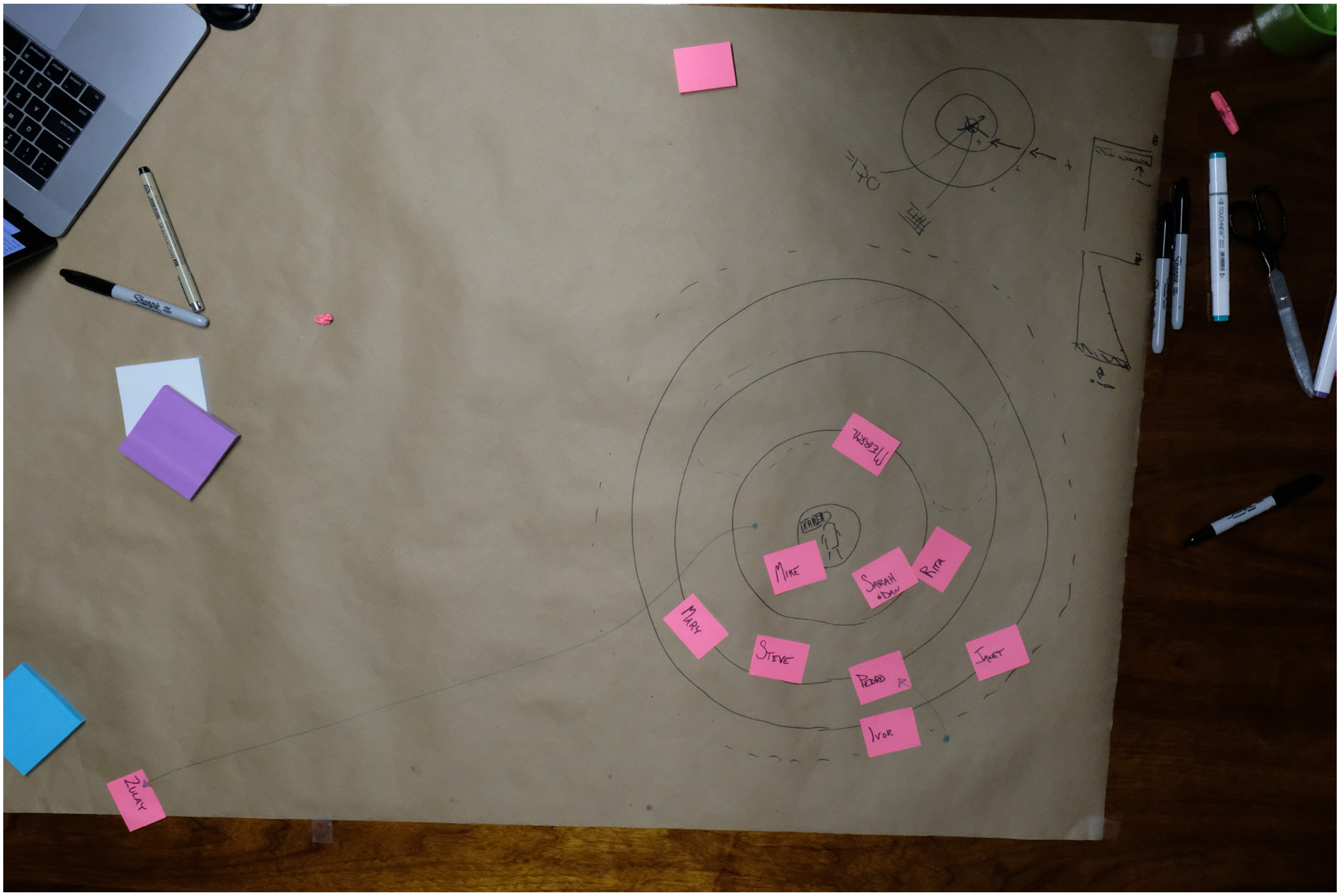
5



Survivors communicate their journey better to those around them, as well as,
tell their stories in survivorship.

Thoughts/ Suggestions or Feedback

Social Support Proximity Maps



Concept

Following on our first few prototypes, we became curious to define more precisely what successful support looked like for survivors as they reflected on their experiences with social support, from diagnosis up to the present.

The Map prototypes were an activity wherein we drew a series of concentric circles in one-on-one interviews with survivors and sketched a figure to represent them in the center. We titled it “A Map of People Important to You: by Amount, Value, or Frequency of Support,” and invited the survivors to begin to name people they remember as having been significant in any during their time of treatment and survivorship, with proximity to their center translating to relative nearness. Survivors needed little prompting to being naming names.

As names began to accumulate, we asked about people who were not on the map but might have been before treatment, and people who were on the map, but whose position had changed in some way over time. Here we began to naturally hear of people who’d been trusted friends or family before who were no longer close, who were held at a distance, or with whom the survivors wanted nothing at all to do. One survivor physically moved the card with the name of one of those people off the map and to the far, far end of a very long conference table.

We then took time to ask questions about what the reasons and stories were. Frequently people who’d become closer were described in specific, and admiring, terms. Meanwhile, people whose position had shifted negatively, however, were vaguely described as having faded or disappeared or met with a shoulder shrug and no other response.

Learning

This activity is where we discovered that survivors found great value even in very simple, seemingly undemanding forms of support: as little as the occasional call or text (although of course others went so far as to move in as a caregiver or perhaps make it appoint to cook meals or accompany the survivor to appointments). Survivors could, of course, point out those who'd shouldered a bigger burden to support, but they were consistently understanding and appreciative towards those who did less but still something.

But those who were the 'faded' or 'disappeared' – the state of confusion we had as to why they hadn't managed to meet even that very low bar for support seemed to be the same state that also brought deep pain to the survivor. We never got enough information on these particularly painful relationships to form a theory of causation, or even a story of how it happened. We sensed we were having negative effects on survivors by asking them to speak about it, and at least one became quite emotional.

(One such interview was conducted with a social worker present, and the social worker expressed some concern that if those questions had continued, it might have risked re-traumatizing the survivor.)

An Interview Activity

Concept

We created the survivor interview activity for a couple of reasons. We were curious if we could help reinforce connections between survivors and people who would have ranked near the middle of the above Proximity Maps – that is to say friends or family who are considered supportive, but might be more likely to ‘fade’ from the survivor’s life after treatment, a moment when the survivor still very much needed continued social support. Additionally, the activity could deliver artifacts of relationships we were interested to understand but had found difficulty capturing in research.

The activity entailed a kind of StoryCorps-esque interaction wherein the survivor would choose someone in their life to be their interviewer, ideally someone who the survivor trusted but who might not have been so near the survivor’s treatment experience to already have familiarity with what it was really like for the survivor.

We began by delivering a small welcome/project packet to a survivor that included an introduction to the idea in warm, enthusiastic language. The survivor would be instructed to fill in the questionnaire prompts included in the packet (questions we developed based on our research and interviews, leaving blanks in the questions where details go), making the questionnaire more specific and relevant to their own experiences. They would give this questionnaire to their chosen interviewer, along with the interviewer guide we also developed and included. The interviewer section included their own introduction to what they’d been asked to do, a brief orientation to typical struggles in survivorship, tips on interviewing with links to resources, and a few points on ‘active listening’ techniques.

In the guide, we suggested that the participants record the audio of the ‘interview’ and share it with us. We also noted that it was entirely acceptable to keep the audio for themselves, or decline to record at all. Our hope was that we might get primary source material on these potentially important, supportive relationships to better understand the nature and quality of those interactions as those intimate conversations advance.

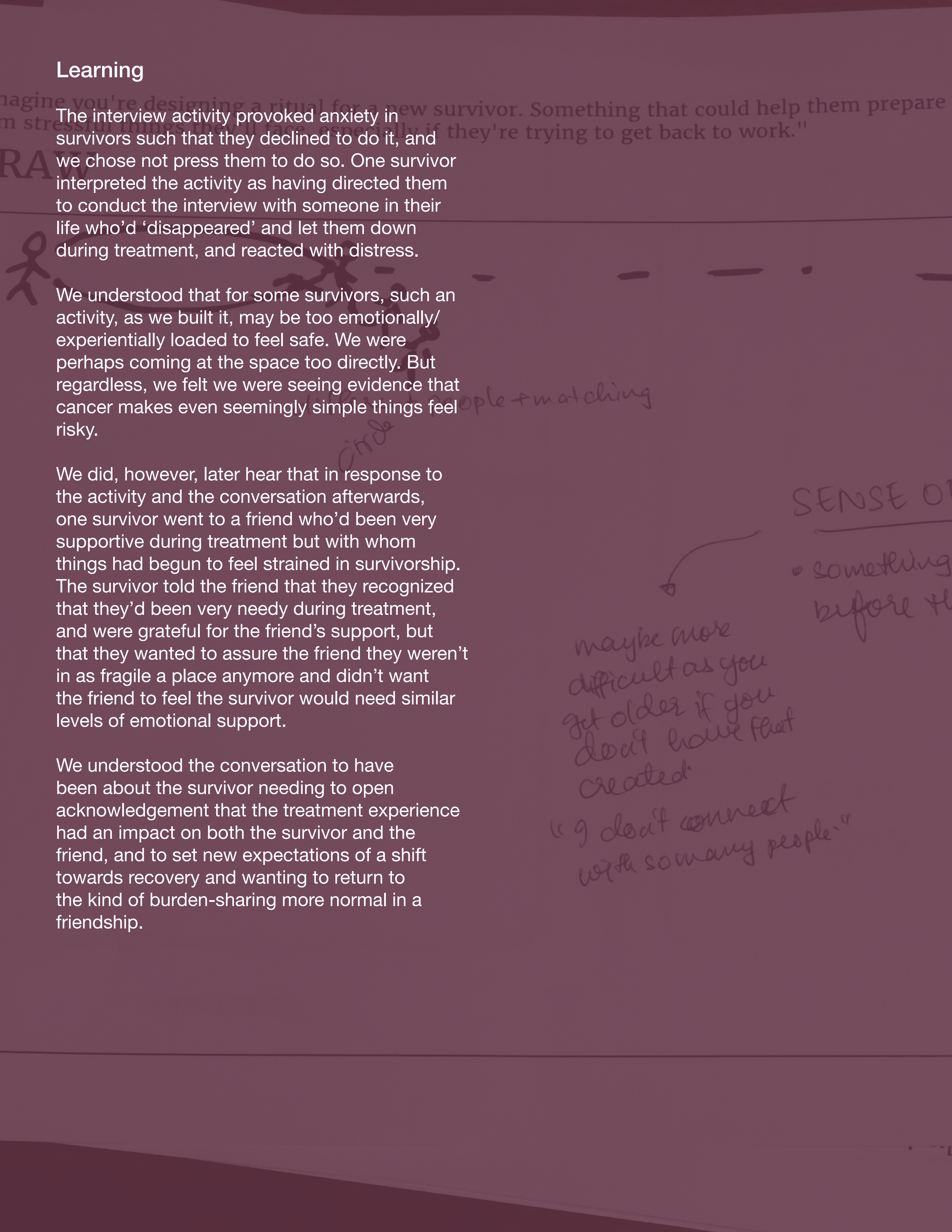
Learning

The interview activity provoked anxiety in survivors such that they declined to do it, and we chose not press them to do so. One survivor interpreted the activity as having directed them to conduct the interview with someone in their life who'd 'disappeared' and let them down during treatment, and reacted with distress.

We understood that for some survivors, such an activity, as we built it, may be too emotionally/ experientially loaded to feel safe. We were perhaps coming at the space too directly. But regardless, we felt we were seeing evidence that cancer makes even seemingly simple things feel risky.

We did, however, later hear that in response to the activity and the conversation afterwards, one survivor went to a friend who'd been very supportive during treatment but with whom things had begun to feel strained in survivorship. The survivor told the friend that they recognized that they'd been very needy during treatment, and were grateful for the friend's support, but that they wanted to assure the friend they weren't in as fragile a place anymore and didn't want the friend to feel the survivor would need similar levels of emotional support.

We understood the conversation to have been about the survivor needing to open acknowledgement that the treatment experience had an impact on both the survivor and the friend, and to set new expectations of a shift towards recovery and wanting to return to the kind of burden-sharing more normal in a friendship.



Platform IRL

Concept

We wanted to test a number of nascent ideas and assumptions about what headway (which didn't have a name at the time) could be, and how survivors would interact with it. Would prompts based on prior interviews and research be enough to coax survivors into storytelling experiences? How much would survivors share? Would they share with strangers? Would they respond to positive, negative and/or neutral posts? How would the age or life-stage of the original poster versus the respondent factor? Would those interactions feel like social connections to survivors? What kind of effect would these events or non-events have?

We created low-fidelity paper versions of a post/newsfeeds environment. We pre-populated the worksheets with real statements from other survivors: some from our interviews, some from posts we found on other message boards on the sites of existing support organizations. We added options for each blank post box where a survivor could note the level of visibility they wanted the post to have: Survivor-to-Survivor, Survivor + Experts, or Anyone. We gave a brief description of the activity, asking them to imagine the rough contours of a platform built for survivors, a little in the way Facebook is built more or less for anyone. They were then invited to make their own posts, either based on things they were experiencing at that time or on impactful things that occurred earlier in their survivorship journey. They were then invited to read the sample posts which had usernames and ages attached, and write a response in the post box below it if they wanted.

Learning

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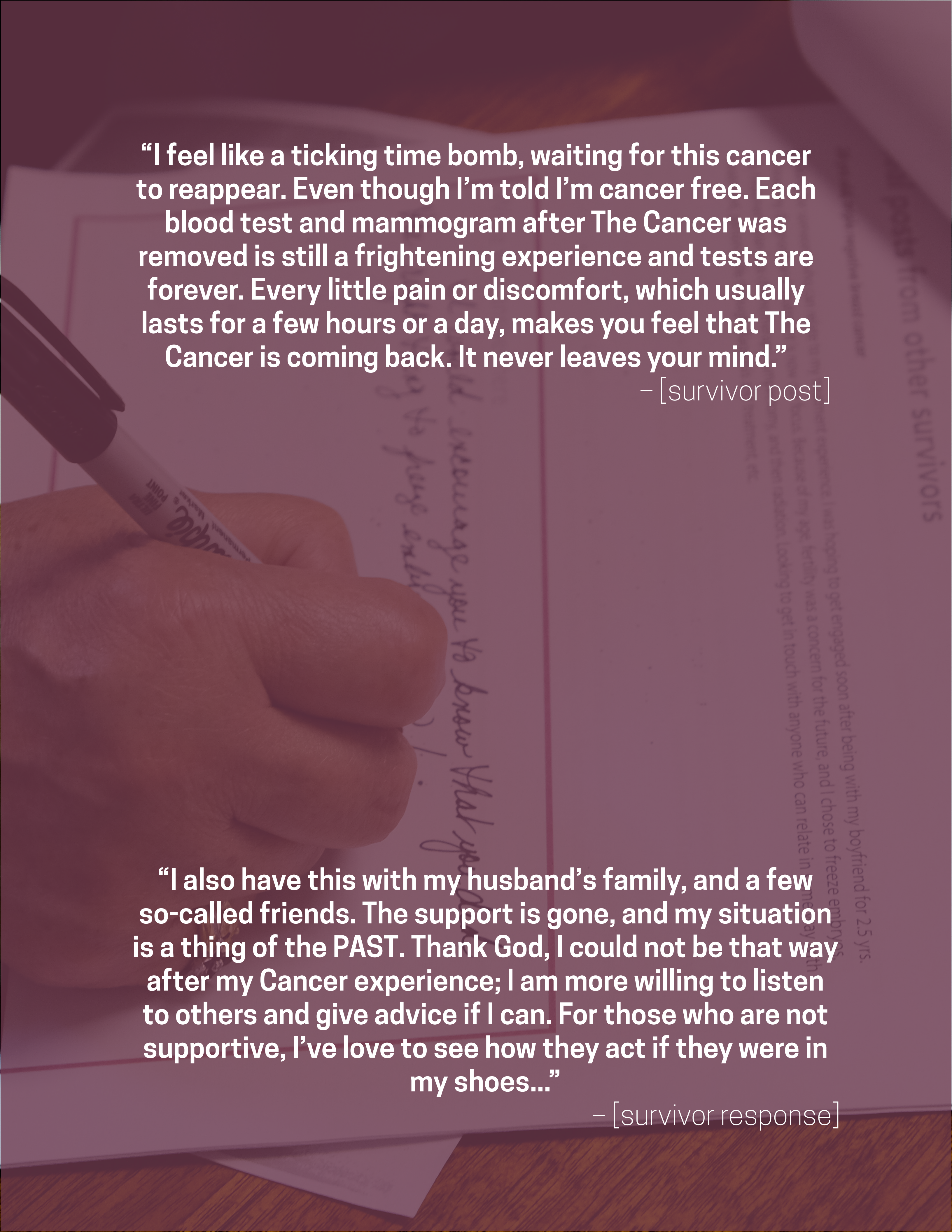


"I feel like a ticking time bomb, waiting for this cancer to reappear. Even though I'm told I'm cancer free. Each blood test and mammogram after The Cancer was removed is still a frightening experience and tests are forever. Every little pain or discomfort, which usually lasts for a few hours or a day, makes you feel that The Cancer is coming back. It never leaves your mind."

– [survivor post]

"I also have this with my husband's family, and a few so-called friends. The support is gone, and my situation is a thing of the PAST. Thank God, I could not be that way after my Cancer experience; I am more willing to listen to others and give advice if I can. For those who are not supportive, I've love to see how they act if they were in my shoes..."

– [survivor response]

Platform Online

Concept

Our next step was to move this paper-based interaction online. We did this by setting up a paid Typeform survey, loading in custom art and logic jumps, among other features. Our goal was to make it feel less like a survey and more like an interactive experience with the tone of voice, conversationality, and story + impact combo we observed in the paper prototyping stage. We wanted to see if the little bits of conversational interface would serve as a connective tissue that would lead to more people completing more sections instead of skipping ahead or bailing out.

We also rotated in some of the posts that we received from survivors who participated in the paper prototypes. We were curious if they too would get engagement just as the originals we'd provided. Would survivors continue to respond to other survivors posts? Would they engage with the variety of post types (rant, question, story, etc)? And given that the Typeform would offer even less identifying information about the author of the post, how much information about others do they need in order to be willing to engage?

In total, the Typeform had almost 30 steps to completion.

Learning

After designing the Typeform, we quickly sent it out to a few survivors we'd interviewed solo – one of whom we'd talked to twice, and the other two once each. Each of them completed the survey within 24 hours. When we sent it to them, we told them to feel free to send on to any others who they thought might be interested. Within about a day, we had another 17 responses, on top of the first three. Then we sent the link to SHAREing & CAREing, who sent it out to their email list. Within days of that, we had another 10 responses, totaling 30 responses.

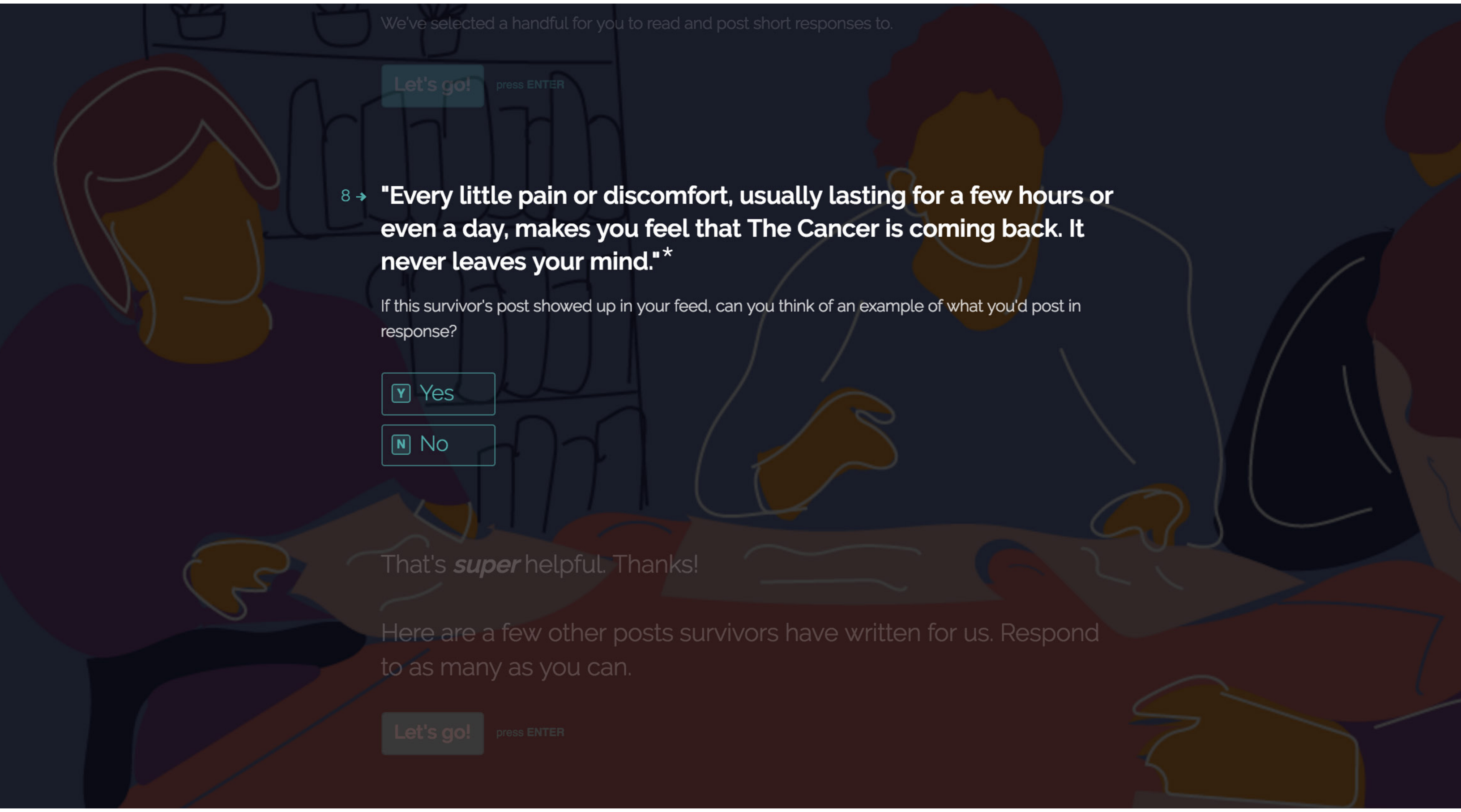
The average completion time was 20 minutes. The majority of responses were via smartphone, followed by computer, followed by tablet. 26 out of 30 expressed a desire to continue to stay engaged in future development, and half of respondents rated the experience 5 out of 5 stars, with another quarter rating it 4 stars. Almost every respondent gave their name, email and phone number.

One survivor told us in an in-person follow up interview, "When I got the link, I'd just planned on hopping on to see what it looked like and answer one question. But you did such a good job, I ended up doing the whole thing! It just felt so good! Every part, it felt encouraging and like it knew me!"

We also heard, "This whole thing is a blessing to be able to vent without judgement and get some great advice."

And, "I think that it's helpful to be able to respond in this way. There needs to be ongoing support for YEARS."

Taking in the response we received in this and the paper prototypes, we pivoted our design for headway.



We've selected a handful for you to read and post short responses to.

Let's go! press ENTER

8 → **"Every little pain or discomfort, usually lasting for a few hours or even a day, makes you feel that The Cancer is coming back. It never leaves your mind."***

If this survivor's post showed up in your feed, can you think of an example of what you'd post in response?

That's ***super*** helpful. Thanks!

Here are a few other posts survivors have written for us. Respond to as many as you can.

Let's go! press ENTER

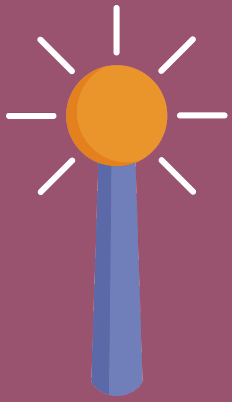
Introducing: Headway

We designed ***headway*** to create sources of knowledge, social support and self-efficacy through connections with other survivors so that they're better equipped to advocate for their needs and pursue their goals.

headway is a survivors' guide to survivorship, created with a community of survivors and supportive experts.

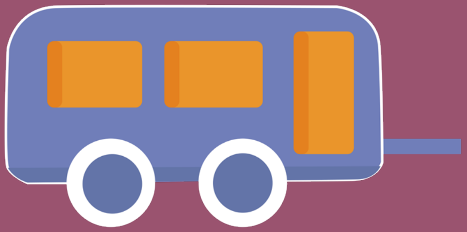
We can't make surviving cancer easy, but we think we can make accessing needed support in survivorship a little less

Headway includes three core functions that help survivors:



Beacons (declare timely concerns and questions to the community, and support those of others)

Guides (survivors and specialists create and share ‘guides’ that Headway facilitates through prompts that surface experiences)

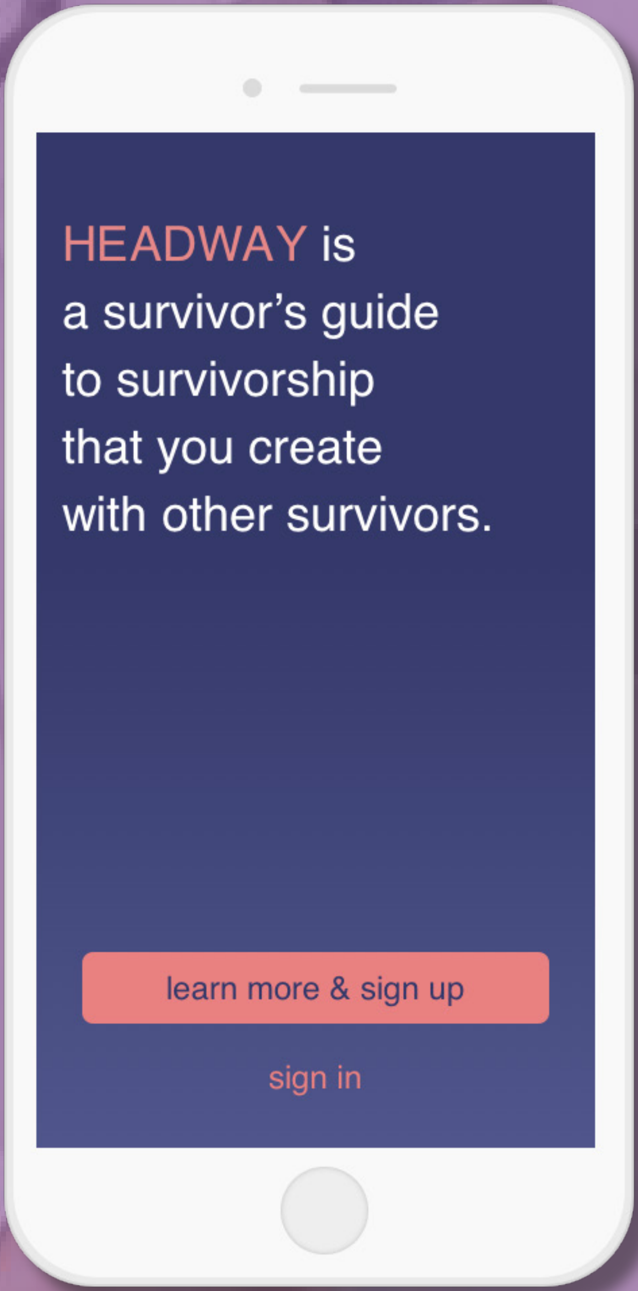


Caravans (connect survivors with offline support groups, or help them form their own groups when the right one isn’t available to them)

Discovery

Let's say you're the survivor. You hear about headway through your nurse or social worker as you finish treatment, a patient navigator from a support organization, an HR representative in your workplace, or even another survivor. All of these people have told us they'd love to recommend headway.

So you download the app and get a quick tour of the features.



HEADWAY is
a survivor's guide
to survivorship
that you create
with other survivors.

Beacons

Survivorship can be unpredictable, with challenges that are, at times, urgent.

The first thing you find in headway help with this: Beacons.

In moments you're sad or frustrated and need space to rant, or you're feeling stuck and need some perspective from people you can trust, you can pick a quick category and set a notice for support.

The alert you post shows up to headway's community, who can respond with insight and affirmation seated in their own firsthand understanding.

Our tests showed survivors responding consistently with support that all agree was encouraging and helpful. It's a light-touch, high-impact interaction survivors want.

Rant

My cancer is ultra rare/ultra orphan. A very large sense of loneliness and isolation once treatment was over. I spent a lot of time at home alone because I wasn't going to treatment 4 times a week in a 28 day cycle. I wasn't having doc visits and blood draws done weekly. I went from chemo and three surgeries to recovery at home and scans/doc appt every three months with monthly blood draws. Adjusting to being in the thick of it to being isolated was VERY challenging.

Need

Understanding has been difficult for my dad. He's often said horrible things without realizing it (e.g. My 13-month hospitalization was a "vacation"). Sometimes, he points out that he didn't want to have "these conversations" (health related) until I was older. I know he's hurting, too, but it's put major barriers in our relationship.

Fear

My cough is back and that was my first cancer symptom back when it all started. My doctor says it's not back... that they radiated the hell out of my lungs and nothing can grow there again but I'm so scared. I can't live like this, I'm terrified every moment. The fear is paralyzing I'm so scared I don't know what to do.

Guides

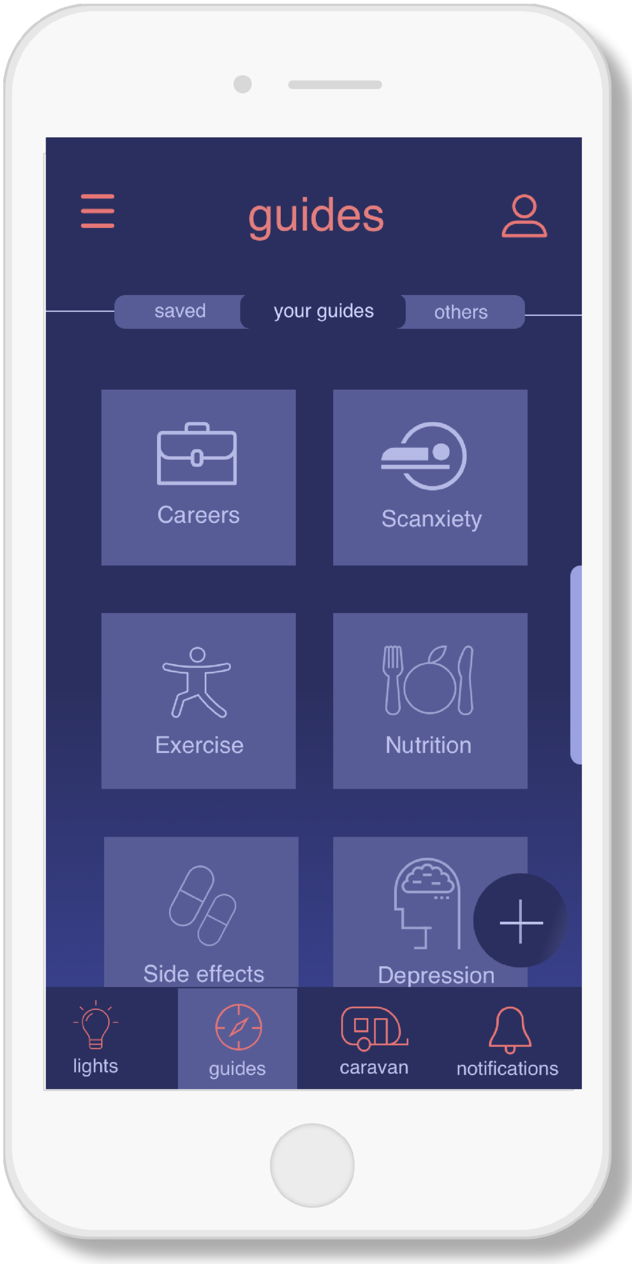
Survivors can of course note their cancer(s), treatment(s), side effects, topics of interest, demographic info and other key elements of their journey that are specific to them, but that's not what takes center stage in Headway.

Now, you come to Guides.

As a survivor, your needs and challenges can be long term and complex and can feel hard to really communicate out of the context of your experiences.

headway, facilitates that communication for survivors by giving them an easy starting point for their story. With prompts based on real posts by other survivors, you can begin to build a 'guide' to your life survivorship. And you can use that guide to connect with support and create support for others.

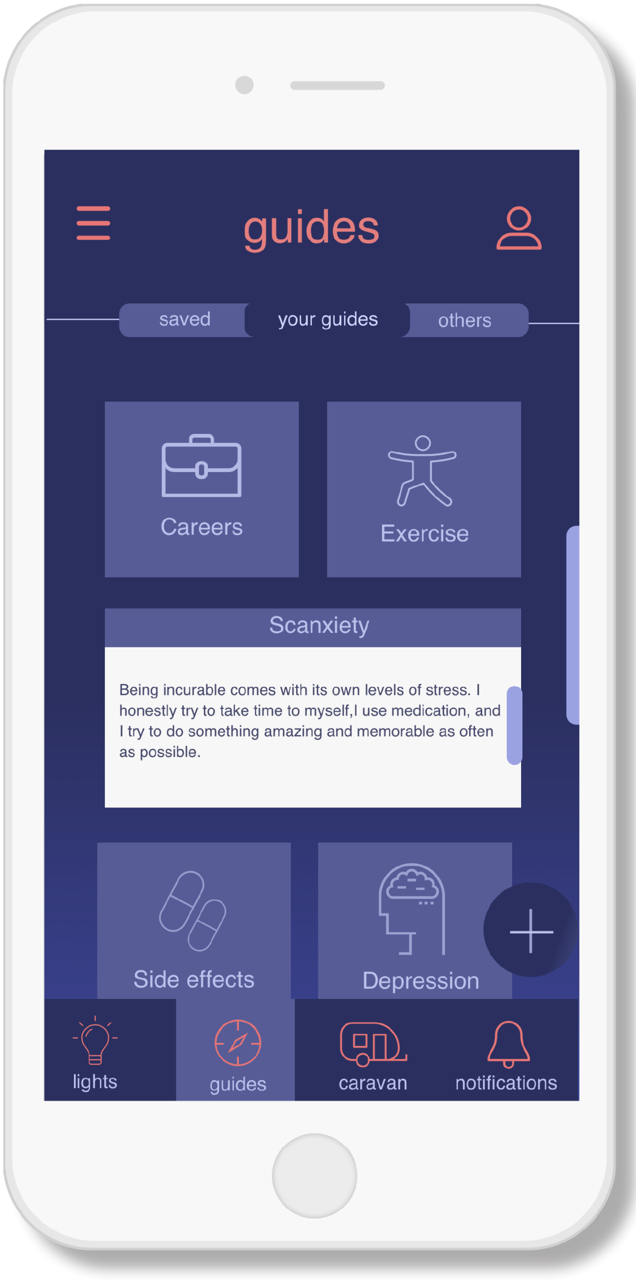
headway facilitates structure and meaning in sharing these stories by providing an array of prompts to which survivors can freely respond as they correspond to their experiences, building a guide to their survivorship.



Guides

When you find a prompt that speaks to a challenge you share, you can explore the answers other **headway** survivors gave in their guides, and save the responses that help. Plus, **headway** includes a wide range of experts who volunteer time to address those same concerns, guided by the context survivors find important to real understanding. Headway experts are survivor-led, spending a few hours each month on the things that matter most to the most survivors.

Survivors help each other not only to connect with support and advice, but to explore and build out the stories each has to aid others. And each survivor and expert's responses become a part of their own guide to the challenges, experiences and advice specific to survivorship.



Being incurable comes with its own levels of stress. I honestly try to take time to myself,I use medication, and I try to do something amazing and memorable as often as possible.

Caravans

Finally, you arrive at Caravans, the third way survivors move forward together with headway.

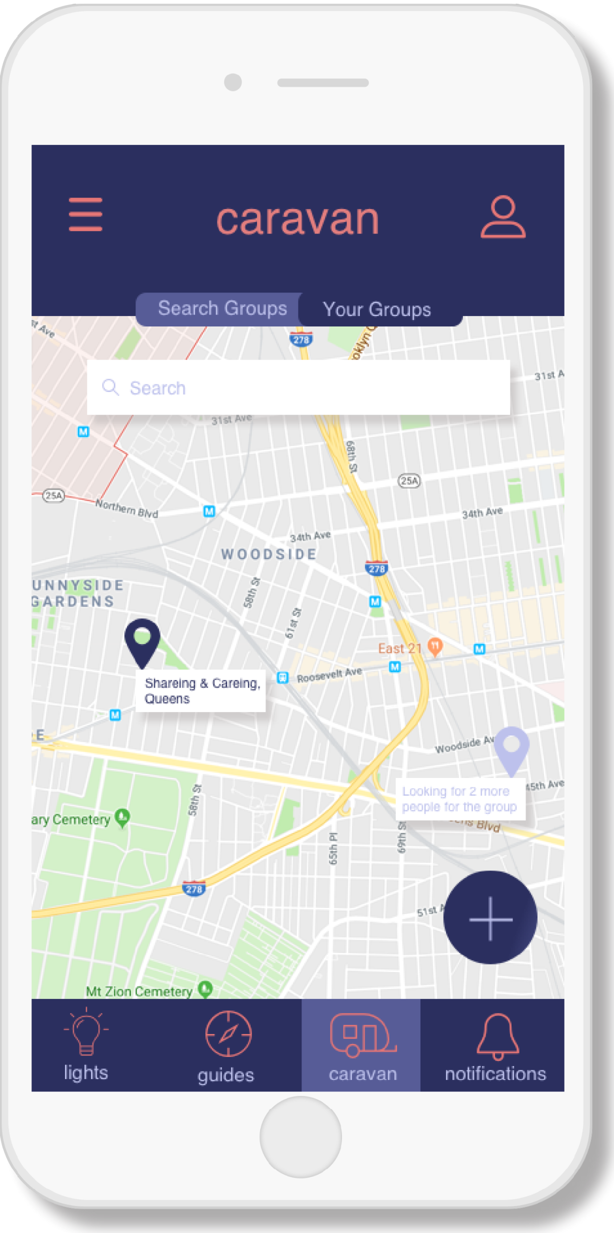
You don’t want a life in survivorship that only works online. So you use the Caravan search to find a support group near you.

We seek to assemble, in partnership with cancer centers and community organizations, a database, searchable by topic and geographic location, of existing support groups and community organizations where survivors can continue to ‘make headway’ offline and ‘in real life’.

You can check the locations, group types and times. But if you don’t find one that works for you, you can quickly set a new group location. Create the new group so that other survivors looking can find and join in on. When the minimum number that you set is met, survivors are notified and connected to each other!

You can find and create new sources of local support without fear of showing up to an empty room.

With Headway’s Caravans can find and create new sources of local support to move forward with, without fear of showing up to an empty room.



Why Experts are headway participants?

Alongside the myriad benefits that connecting and sharing with other survivors brings, our research and user tests demonstrate a demand for the opportunities to get guidance from and ask questions of a range of specialists relevant to the specific needs and concerns of survivors, as needs arise. Survivors say they would benefit from a low-touch interaction on the order of general guidance.

Subjects that survivors have asked be available include physical therapy and exercise, fertility and sexual health, communication with family and friends, financial planning and billing, nutrition, human resources and employment law, counseling and psychiatry, and other items indicating the holistic breadth of cancer's impacts. We already have interest from a number of these subject matter experts to participate, and we are seeking others to expand our offering, in close consultation with the three to four dozen survivors currently participating in our tests.

Survivors, therapists and social workers in the community confirm that the range here is what is specific to survivors' needs, rather than a single subject for expert attention. Following the end of treatment, one of survivors' most persistent challenges is the piecemeal nature of their care and access to resources. By making the network diverse, yet easy to explore, it can be highly responsive to one of the most daunting barriers they face: the unexpectedly variegated and unpredictable nature of their obstacles to seeking success in lives and careers. The impact of such opportunities seems particularly pronounced as they report their paralyzing anxiety is dissipated by quick consultations with trustworthy advisors in survivor-centric contexts.

What makes headway different:

- more purposeful than journaling alone by making sure your stories add up to something that helps you, and others like you.
- It’s less ephemeral than using social media, making sure your important experiences don’t just get pushed down a news feed.
- Where you look at Instagram to get lost, you look at headway to feel more found.
- It’s more alive than a ‘how-to’, more interactive than an FAQ.

PILOTING headway:

Our Headway prototypes (above, Platform Online & Platform IRL) were developed to see if survivors would write their own posts, respond to the posts of others, and identify interests, challenges and needs as we expected.

Making ourselves the ‘invisible backend’ of the network, we were able to facilitate some of the basic functions of the platform and elicit feedback on the experiences. This process corrected our early assumptions that we were working towards a kind of Facebook-meets-Reddit-meets-Meetup. We captured comments from users at both stages of prototyping, as well as followed up again in person with the original group of survivors from the paper prototype, a few of whom had gone on to join to the online cohort as well.

These are some of the responses we recorded:

- “It covers a lot of areas that are really core. It covers the spectrum of the experience.”
- “This is the core of what everybody needs.”
- “You really got to the root of it.”
- “Support is really hard, and you brought out that connection and encouragement.”
- “It’s the therapy. When I joined this support group, I thought to myself, ‘Maybe I’ll be here for a year.’ And now it’s been 13 years. Being with other survivors is therapy for us.”
- “It lets you ‘slide’ the way you would in a conversation.”
- “It’s more conversational than other things. This isn’t just one statement that risks sending you into a depression if it’s the wrong thing.”
- “Breaking the topics down like this is good.”
- “It’s all positive, through the whole thing, unlike the other things I find online.”
- “I love the Beacons idea. I want ‘light’ like that.”
- “It would even help to just be told ‘you need to talk to your oncologist.’”
- “I think it’ll work. I go to [the cancer clinic] and all I see is magazines…”
- “When I was finishing treatment, I was excited, but I was scared. I was leaving my safe haven. So you need this then.”
- On things that organize survivors (and support) primarily by cancer type: “Some people are doing that already, and it’s not working. I know someone in the group who had a totally different cancer than the others, and she totally fits in.”
- “You have taken three people who normally wouldn’t use something like this who now say that they would.”
- “You guys gave them the opposite of cancer. You put them in a mysterious situation, but it was a healing one. All they really want is, ‘Let’s be lost together.’”

The Expert Incentive

So what does headway do for some of the other groups we've mentioned who are important to survivorship?

Healthcare systems:

- **headway** provides healthcare systems concerned about the success of their survivors a 'market intelligence' on survivor experiences, challenges and untapped opportunities to thrive, while facilitating the input of key staff at low-impact intervals to create outsized positive impact on the questions that are key to survivors' health-related quality of life.

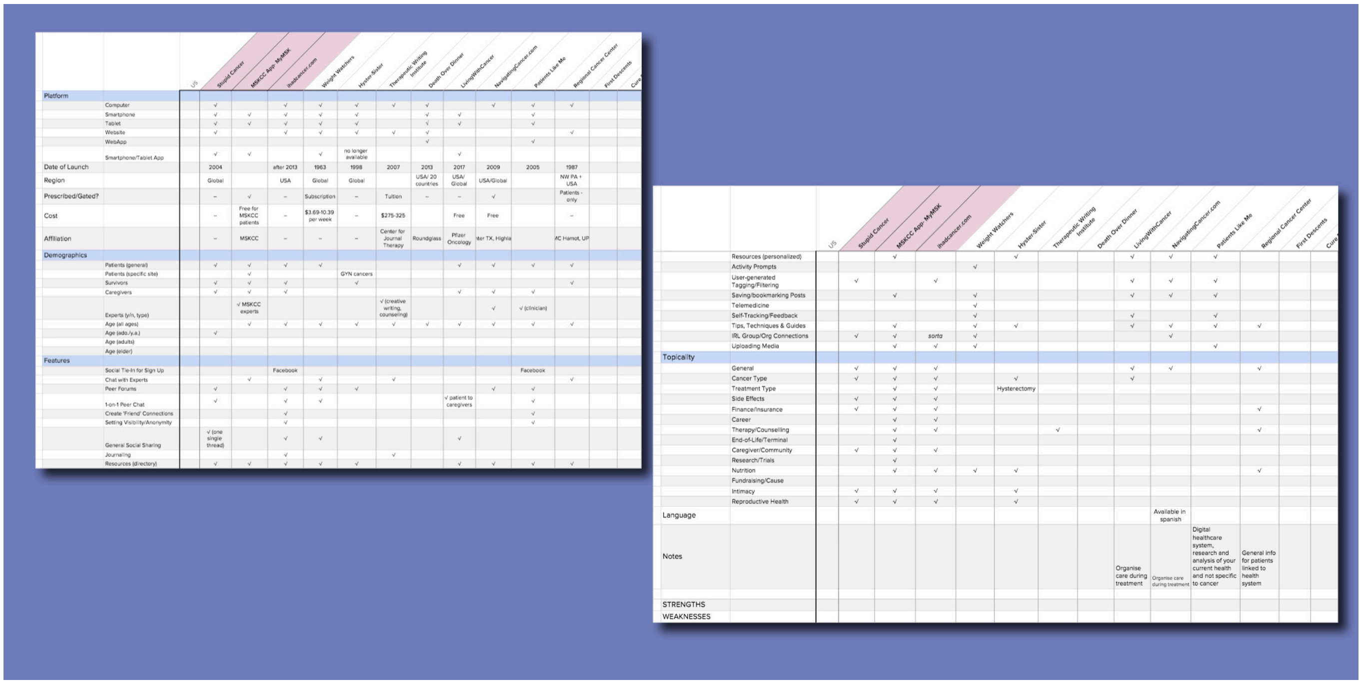
Employers:

- **headway** is a free resource employers can offer to employees. Many in HR wish they could offer more in the way of support. headway is a start to creating the guidance survivors need to navigate workplaces when disclosure feels risky. And we've found that the broader HR community is interested in making the guidance found on something like headway more useful to struggling survivors.

Community Support Orgs:

- By using **headway**, organizations like our partners at SHAREing & CAREing get help more easily finding and being found by the survivors who need their support, and insights on survivors' needs and demands to help them apply their limited resources to high-impact areas. Without an abundance of time and personnel, every efficiency or extra bit of insight at those local levels creates capacity for additional support to survivors and patients who need it.

COMPETITIVE ANALYSIS

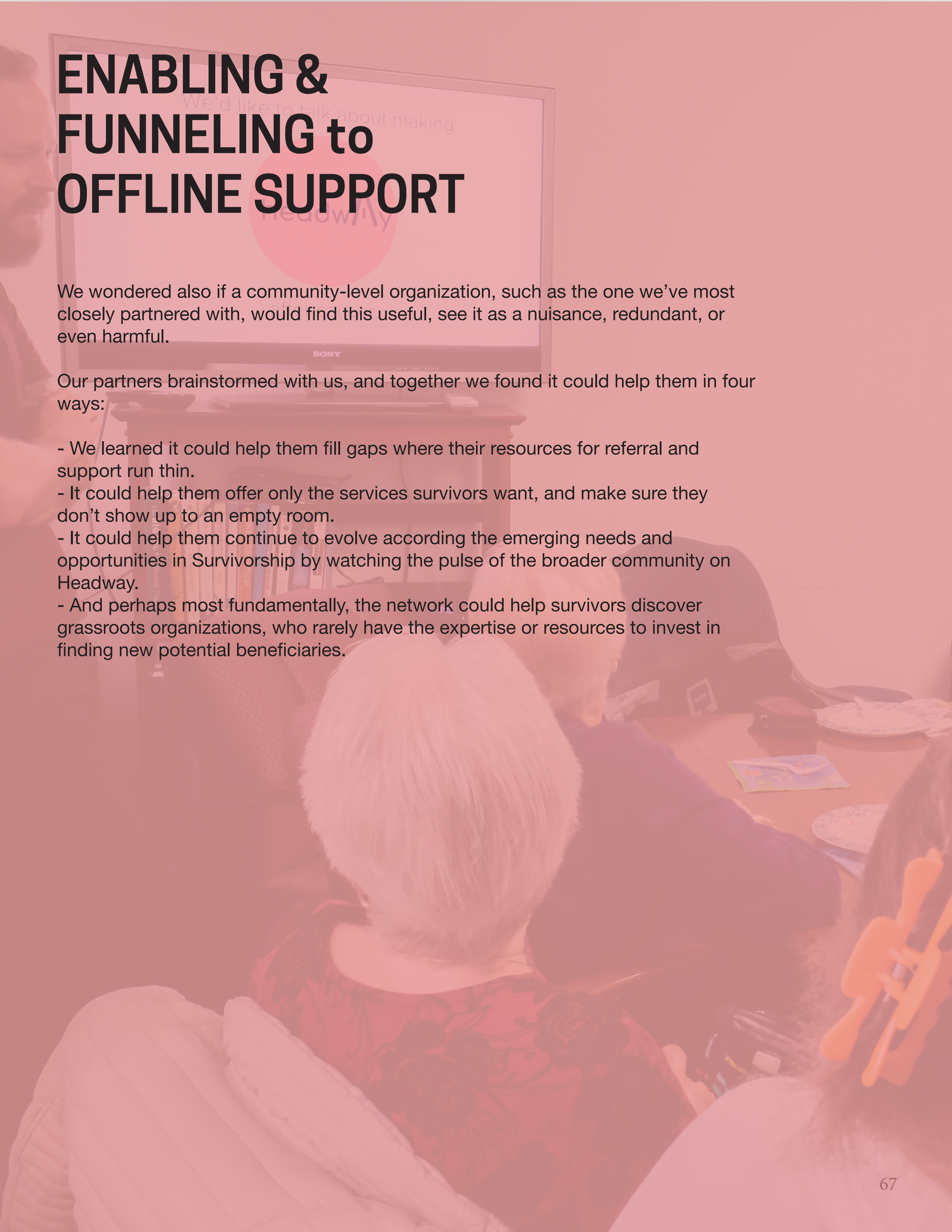


		US	Stupid Cancer	MSKCC App- MyMSK	ihadcancer.com	Weight Watchers	Hyster-Sister	Therapeutic Writing Institute	Death Over Dinner	LivingWithCancer	NavigatingCancer.com	Patients Like Me	Regional Cancer Center	First Descents	Cure
Platform															
	Computer		√		√	√	√	√	√		√	√	√		
	Smartphone		√	√	√	√	√		√	√		√			
	Tablet		√	√	√	√	√		√	√		√			
	Website		√		√	√	√	√	√				√		
	WebApp								√			√			
	Smartphone/Tablet App		√	√		√	no longer available			√					
Date of Launch			2004		after 2013	1963	1998	2007	2013	2017	2009	2005	1987		
Region			Global		USA	Global	Global		USA/ 20 countries	USA/ Global	USA/Global		NW PA + USA		
Prescribed/Gated?			–	√	–	Subscription	–	Tuition	–	–	√		Patients - only		
Cost			–	Free for MSKCC patients	–	$3.69-10.39 per week	–	$275-325		Free	Free		–		
Affiliation			–	MSKCC	–	–	–	Center for Journal Therapy	Roundglass	Pfizer Oncology	ter TX, Highla		C Hamot, UP		
Demographics															
	Patients (general)		√	√	√	√				√	√	√	√		
	Patients (specific site)			√			GYN cancers								
	Survivors		√	√	√		√						√		
	Caregivers		√	√	√					√	√	√			
	Experts (y/n, type)			√ MSKCC experts				√ (creative writing, counseling)			√	√ (clinician)			
	Age (all ages)			√	√	√	√	√	√	√	√	√	√		
	Age (ado./y.a.)		√												
	Age (adults)														
	Age (elder)														
Features															
	Social Tie-In for Sign Up				Facebook							Facebook			
	Chat with Experts			√		√		√					√		
	Peer Forums		√		√	√	√				√	√			
	1-on-1 Peer Chat		√		√	√				√ patient to caregivers		√			
	Create 'Friend' Connections				√							√			
	Setting Visibility/Anonymity				√							√			
	General Social Sharing		√ (one single thread)		√	√				√					
	Journaling				√			√							
	Resources (directory)		√	√	√	√	√			√	√	√	√		
	Resources (personalized)			√			√			√	√	√			
	Activity Prompts					√									
	User-generated Tagging/Filtering		√		√					√	√	√			
	Saving/bookmarking Posts			√		√				√	√	√			
	Telemedicine					√									
	Self-Tracking/Feedback					√				√		√			
	Tips, Techniques & Guides			√		√	√			√	√	√	√		
	IRL Group/Org Connections		√	√	*sorta*	√					√				
	Uploading Media			√	√	√						√			
Topicality															
	General		√	√	√					√	√		√		
	Cancer Type		√	√	√		√			√					
	Treatment Type			√	√		Hysterectomy								
	Side Effects		√	√	√										
	Finance/Insurance		√	√	√								√		
	Career			√	√										
	Therapy/Counselling			√	√			√					√		
	End-of-Life/Terminal			√											
	Caregiver/Community		√	√	√										
	Research/Trials			√											
	Nutrition			√	√	√	√						√		
	Fundraising/Cause														
	Intimacy		√	√	√		√								
	Reproductive Health		√	√	√		√								
Language											Available in spanish				
Notes										Organise care during treatment	Organise care during treatment	Digital healthcare system, research and analysis of your current health and not specific to cancer	General info for patients linked to health system		
STRENGTHS															
WEAKNESSES															

We've also conducted a competitive analysis of over a dozen other existing services, finding that most aren't doing anything like Headway, and that those closest to our offering had something of a goldilocks problem, from the viewpoint of our research findings: too much of one thing, or too little of another, and missing some key elements that keep them from serving survivors more effectively.

However, we don't seek to make something in competition with others. We took as a very positive sign that some are 'in the neighborhood' of our solution, sharing our survivor-centric principles, and we reached out to those who were coming nearest. We're now in conversations with a number of them to share our research and findings, as well as our design for Headway!

We are exploring partnerships around the potential to build the features we're designing into their existing apps to better serve those in survivorship.



ENABLING & FUNNELING to OFFLINE SUPPORT

We wondered also if a community-level organization, such as the one we've most closely partnered with, would find this useful, see it as a nuisance, redundant, or even harmful.

Our partners brainstormed with us, and together we found it could help them in four ways:

- We learned it could help them fill gaps where their resources for referral and support run thin.
- It could help them offer only the services survivors want, and make sure they don't show up to an empty room.
- It could help them continue to evolve according the emerging needs and opportunities in Survivorship by watching the pulse of the broader community on Headway.
- And perhaps most fundamentally, the network could help survivors discover grassroots organizations, who rarely have the expertise or resources to invest in finding new potential beneficiaries.

Encouragement Kiosks in Treatment Centers…

Towards the conclusion of our thesis project development, as we designed for funnels into support groups and community organizations, we began to reflect more broadly on offline, place-based integrations of the headway model.

We asked ourselves where people might find headway, in what locations or contexts they might be curious, have time, experience a need headway would meet; which or if any element of headway's present trifold service model would raise interest and be of use; how they would feed into that system, how they would receive back out of it, and whether it would require user account creation on platform for even micro-interactions.

Our idea is the Encouragement Kiosk (working title). Kiosks could be placed in waiting rooms, infusion areas, and other places in clinics and hospitals where cancer patients tend to have to linger for passive treatment or while waiting for the next event. Kiosks can be branded warmly, positively, welcomingly, offering helping thoughts and words and a place to reach out for quick connections with other survivors who understand. In essence, at the kiosk, users can access Beacons.

Users get access to the Beacon functionality of headway. They are prompted to identify what kind of message they're making (e.g. this is a rant, this is a question, this is encouragement, this is a need, this is confusion, this is a fear), write it, and then enter an email address or phone number to receive responses that survivors send.

In the confirmation email/text, they're also given a link to the headway app in case they want to explore the full service. And each time a headway user responds to their post in Beacons, the user gets a text or email with the response!

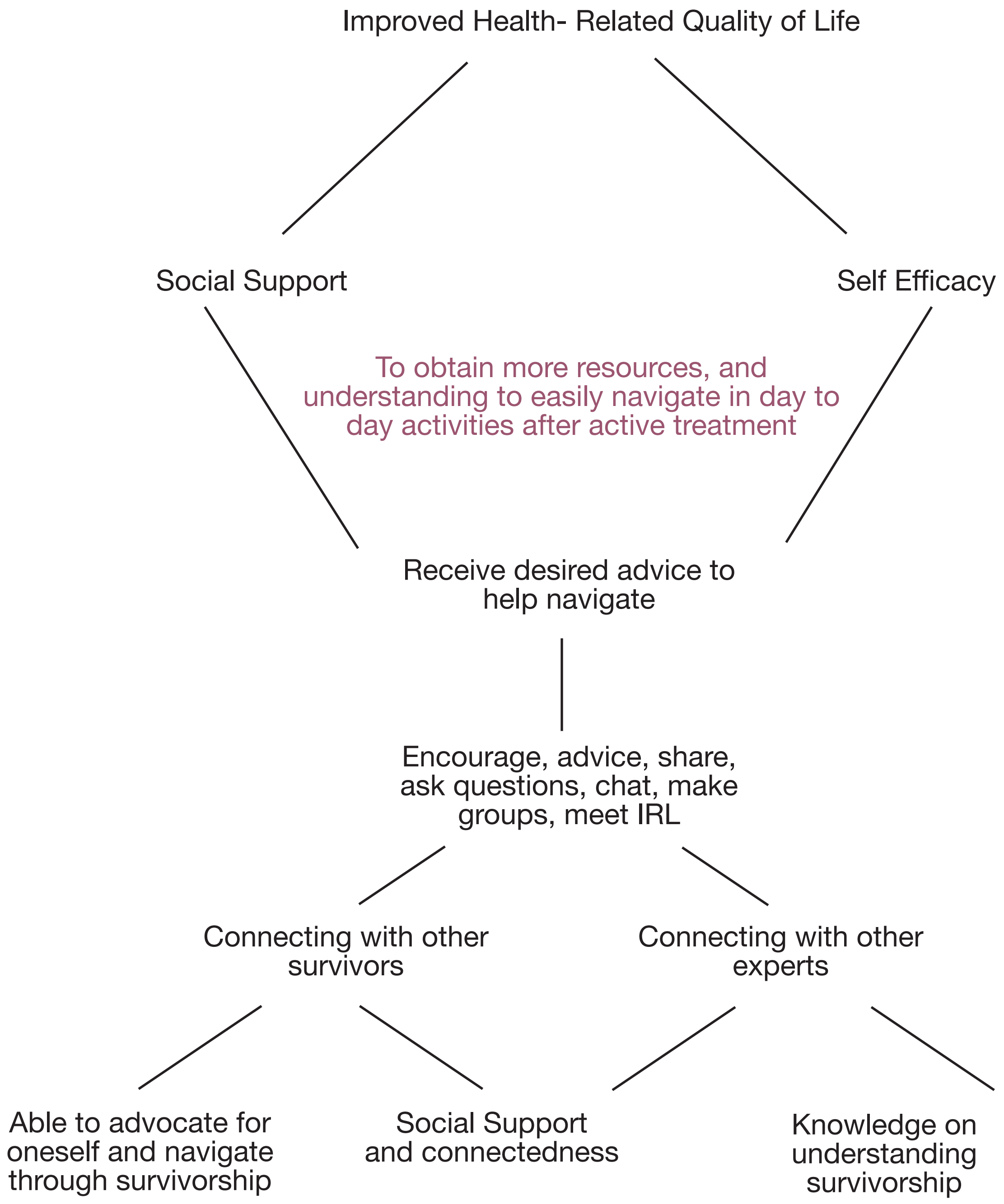
They can also browse some of the recent Beacons others have posted. To respond, they'll be encouraged to get the app and join the community.

This increases the impact online users can make by extending the reach of Beacons into important spaces in the cancer experience, catching survivors in contexts where this kind of outreach is timely, and novel. We think this is an exciting element of participation in Beacons.

The Kiosks also generate awareness of headway in a practical, useful, participatory way. People can quickly experience not just the value proposition but the community that makes it a reality.

A visual representation of Encouragement Kiosks at Healthcare centers

Theory of Change



Improved Health- Related Quality of Life

Social Support

Self Efficacy

To obtain more resources, and understanding to easily navigate in day to day activities after active treatment

Receive desired advice to help navigate

Encourage, advice, share, ask questions, chat, make groups, meet IRL

Connecting with other survivors

Connecting with other experts

Able to advocate for oneself and navigate through survivorship

Social Support and connectedness

Knowledge on understanding survivorship

Monitoring & Evaluation

	Indicator	Definition	Baseline	Target	Data Source	Frequency	Responsible	Reporting
Goal	HRQOL	CDC Questionaire	[baseline]	improvement on baseline	survey questionairre administered in-app	baseline, midpoint, endline over 1 year timeline from user sign-up	project M&E staff	Annual report made for community orgs, institutions about the impact of the app
	To navigate through survivorship with confidence in day to day life activities	Self-reported self-efficacy	[baseline]	improvement on baseline	Referrals, more signups	Annual	project M&E staff	Annual report made for community orgs, institutions about the impact of the app
Outcomes	Increased Job Satisfaction Lowered rates of workplace absenteeism lowered rates of joblessness	self-reported	Baseline (monthly)	improvement on baseline	Survey sample, gathered in app	Every 4 months	project M&E staff	Internal metrics, shared throughout org.
	Users having useful interaction on site	Rating posts and comments as positive, helpful, useful, etc.	User-reported satisfaction with platform	improvement on baseline	data gathering through machine learning algorithms scraping content	Every 4 months	project M&E staff	Internal metrics, shared throughout org.
	Number of group and IRL meets	Survivors reporting connection with IRL support group, or successfully forming their own through platform tool	Baseline (monthly) of users reporting looking for group	improvement on baseline	in-app survey [n= representative sample of user base]	Every 4 months	project M&E staff	Internal metrics, shared throughout org.
Outputs	Number of users on platform	Users who access and interact with platform in a 30 day period	0	+ 5% month-on-month	in-app logins	calculated monthly	project M&E staff	Internal metrics, shared throughout org.
	Number of new signups per month	Number of new users who sign up	0	+ 5% month-on-month	in-app logins	calculated monthly	project M&E staff	Internal metrics, shared throughout org.
	Number of referrals Exchange of contact info	Users who suggest the usage of the apps to other users	0	+ 3% month-on-month	in-app logins	calculated monthly	project M&E staff	Internal metrics, shared throughout org.

References

1. National Cancer Institute, Office of Cancer Survivorship; https://cancercontrol.cancer.gov/ocs/statistics/statistics.html
2. ibid.
3. “Global cancer survivorship: the need for integrated care”, The Economist, http://cancersurvivorship.eiu.com/
4. ibid.
5. Bluthmann, Mariotto, Rowland; 2016 // Alfano, Rowland; 2006 // Srivastava; 2017
6. ibid.
7. Nekhlyudov; 2014
8. Alfano, Rowland; 2006
9. ibid.
10. Srivastava; 2017
11. Nowrouzi, Lightfoot, Cote, and Watson; 2009
12. https://www.cdc.gov/hrqol/
13. Holt-Lunstad, Smith, Layton; 2010
14. Kirsten Bell & Svetlana Ristovski-Slijepcevic , “Cancer Survivorship: Why Labels Matter”, JOURNAL OF CLINICAL ONCOLOGY, VOLUME 31 | NUMBER 4 2013
15. Choudhury, and De; 2014

Bibliography

“A Curriculum for People Moving into Employment.Pdf,” n.d.

“A National Action Plan for Cancer Survivorship.Pdf,” n.d.

Alfano, Catherine M., and Julia H. Rowland. “Recovery Issues in Cancer Survivorship: A New Challenge for Supportive Care.” The Cancer Journal 12, no. 5 (2006): 432–443.

Ames, Carole. “Classrooms: Goals, Structures, and Student Motivation.” Journal of Educational Psychology 84, no. 3 (1992): 261.

“Assessing Social Support Companionship and Distress.Pdf,” n.d.

Aziz, N, and J Rowland. “Trends and Advances in Cancer Survivorship Research: Challenge and Opportunity.” Seminars in Radiation Oncology 13, no. 3 (July 2003): 248–66. https://doi.org/10.1016/S1053-4296(03)00024-9.

Bell, Kirsten, and Svetlana Ristovski-Slijepcevic. “Cancer Survivorship: Why Labels Matter.” J Clin Oncol 31, no. 4 (2013): 409–411.

“Cancer and Quality of Life in Spousal Dyads_ Spillover in Couples with and without Cancer-Related Health Problems.PDF,” n.d.

“Cancer Survivors in the United States- Prevalence across the Survivorship Trajectory and Implications for Care.Pdf,” n.d.

“Cancer Survivorship and Identity among Long-Term Survivors.Pdf,” n.d.

“Cancer Survivorship- Why Labels Matter.Pdf,” n.d.

“C&C Manager’s Kit.Pdf,” n.d.

Cole, Helen, Hayley S. Thompson, Marilyn White, Ruth Browne, Chau Trinh-Shevrin, Scott Braithwaite, Kevin Fiscella, Carla Boutin-Foster, and Joseph Ravenell. “Community-Based, Preclinical Patient Navigation for Colorectal Cancer Screening among Older Black Men Recruited from Barbershops: The MISTER B Trial.” American Journal of Public Health 107, no. 9 (2017): 1433–1440.

“Community-Based Preclinical Patient Navigation for Colorectal Cancer Screening Among Older Black Men Recruited From Barbershops.Pdf,” n.d.

“Concerns Across the Survivorship Trajectory- Results From a Survey of Cancer Survivors.Pdf,” n.d.

“Critical Issues in Transition and Survivorship for Adolescents and Young Adults With Cancers.Pdf,” n.d.

Cyranowski, Jill M., Nicholas Zill, Rita Bode, Zeeshan Butt, Morgen A. R. Kelly, Paul A. Pilkonis, John M. Salsman, and David Cella. “Assessing Social Support, Companionship, and Distress: National Institute of Health (NIH) Toolbox Adult Social Relationship Scales.” Health Psychology 32, no. 3 (2013): 293–301. https://doi.org/10.1037/a0028586.

De Choudhury, Munmun, and Sushovan De. “Mental Health Discourse on Reddit: Self-Disclosure, Social Support, and Anonymity.” In ICWSM, 2014.

DeAngelo, Linda Elizabeth. “Auditor Independence,‘Low Balling’, and Disclosure Regulation.” Journal of Accounting and Economics 3, no. 2 (1981): 113–127.

“Defining Cancer Survivors Their Needs and Perspectives on Survivorship.Pdf,” n.d.

Deimling, Gary T., Karen F. Bowman, and Louis J. Wagner. “Cancer Survivorship and Identity among Long-Term Survivors.” Cancer Investigation 25, no. 8 (January 2007): 758–65. https://doi.org/10.1080/07357900600896323.

“Economic Stress Among Low-Income Women With Cancer.Pdf,” n.d.

Ell, Kathleen, Bin Xie, Anjanette Wells, Frances Nedjat-Haiem, Pey-Jiuan Lee, and Betsy Vourlekis. “Economic Stress among Low-Income Women with Cancer: Effects on Quality of Life.” Cancer 112, no. 3 (February 1, 2008): 616–25. https://doi.org/10.1002/cncr.23203.

“Evaluating Survivorship Care Plans_Results of a Randomized Clinical Trial of Patients With Breast Cancer.Pdf,” n.d.

“Evaluation of Effectiveness of Survivorship Programmes.Pdf,” n.d.

“Family-Focused Preventive Interventions With Cancer Cosurvivors- A Call to Action.Pdf,” n.d.

“Follow-up Care of Cancer Survivors.Pdf,” n.d.

Given, B. A., P. Sherwood, and C. W. Given. “Support for Caregivers of Cancer Patients: Transition After Active Treatment.” Cancer Epidemiology Biomarkers & Prevention 20, no. 10 (October 1, 2011): 2015–21. https://doi.org/10.1158/1055-9965.EPI-11-0611.

Grunfeld, Eva, Jim A. Julian, Gregory Pond, Elizabeth Maunsell, Douglas Coyle, Amy Folkes, Anil A. Joy, et al. “Evaluating Survivorship Care Plans: Results of a Randomized, Clinical Trial of Patients With Breast Cancer.” Journal of Clinical Oncology 29, no. 36 (December 20, 2011): 4755–62. https://doi.org/10.1200/JCO.2011.36.8373.

———. “Evaluating Survivorship Care Plans: Results of a Randomized, Clinical Trial of Patients With Breast Cancer.” Journal of Clinical Oncology 29, no. 36 (December 20, 2011): 4755–62. https://doi.org/10.1200/JCO.2011.36.8373.

Halpern, Michael T., and Keith E. Argenbright. “Evaluation of Effectiveness of Survivorship Programmes: How to Measure Success?” The Lancet Oncology 18, no. 1 (2017): e51–e59.

Holt-Lunstad, Julianne, Timothy B. Smith, and J. Bradley Layton. “Social Relationships and Mortality Risk: A Meta-Analytic Review.” PLoS Medicine 7, no. 7 (2010): e1000316.

“ILL#185550836-ZVT.Pdf,” n.d.

“Integrating Primary Care in Cancer Survivorship Programs- Models of Care for a Growing Patient Population.Pdf,” n.d.

“Integrating Primary Care Providers in the Care of Cancer Survivors.Pdf,” n.d.

“Integrating Primary Care Providers in the Care of Cancer Survivors.Pdf,” n.d.

Jacobs, Linda A., and Lawrence N. Shulman. “Follow-up Care of Cancer Survivors: Challenges and Solutions.” The Lancet Oncology 18, no. 1 (2017): e19–e29.

Kang, Ruogu, Stephanie Brown, and Sara Kiesler. “Why Do People Seek Anonymity on the Internet?: Informing Policy and Design.” In Proceedings of the SIGCHI Conference on Human Factors in Computing Systems, 2657–2666. ACM, 2013.

Kantsiper, Melinda, Erin L. McDonald, Gail Geller, Lillie Shockney, Claire Snyder, and Antonio C. Wolff. “Transitioning to Breast Cancer Survivorship: Perspectives of Patients, Cancer Specialists, and Primary Care Providers.” Journal of General Internal Medicine 24, no. S2 (November 2009): 459–66. https://doi.org/10.1007/s11606-009-1000-2.

Lawn, Sharon, Julia Fallon-Ferguson, and Bogda Koczwara. “Shared Care Involving Cancer Specialists and Primary Care Providers - What Do Cancer Survivors Want?” Health Expectations 20, no. 5 (October 2017): 1081–87. https://doi.org/10.1111/hex.12551.

“Life-after-Treatment-next-Chapter-in-Your-Survivorship-Journey.Pdf,” n.d.

Litzelman, Kristin, Paige A. Green, and K. Robin Yabroff. “Cancer and Quality of Life in Spousal Dyads: Spillover in Couples with and without Cancer-Related Health Problems.” Supportive Care in Cancer 24, no. 2 (February 2016): 763–71. https://doi.org/10.1007/s00520-015-2840-4.

“Long Term Evaluation of Survivorship Registry.Pdf,” n.d.

“Lung-Cancer-Screening.Pdf,” n.d.

Mayer, Deborah K., Shelly Fuld Nasso, and Jo Anne Earp. “Defining Cancer Survivors, Their Needs, and Perspectives on Survivorship Health Care in the USA.” The Lancet Oncology 18, no. 1 (2017): e11–e18.

“Mental Health Discourse on Reddit.Pdf,” n.d.

Moor, J. S. de, A. B. Mariotto, C. Parry, C. M. Alfano, L. Padgett, E. E. Kent, L. Forsythe, S. Scoppa, M. Hachey, and J. H. Rowland. “Cancer Survivors in the United States: Prevalence across the Survivorship Trajectory and Implications for Care.” Cancer Epidemiology Biomarkers & Prevention 22, no. 4 (April 1, 2013): 561–70. https://doi.org/10.1158/1055-9965.EPI-12-1356.

“Motivating and Counseling the Unemployed.Pdf,” n.d.

Nathan, Paul C., Brandon Hayes-Lattin, Jeffrey J. Sisler, and Melissa M. Hudson. “Critical Issues in Transition and Survivorship for Adolescents and Young Adults with Cancers.” Cancer 117, no. S10 (May 15, 2011): 2335–41. https://doi.org/10.1002/cncr.26042.

Nekhlyudov, Larissa. “Integrating Primary Care in Cancer Survivorship Programs: Models of Care for a Growing Patient Population.” The Oncologist 19, no. 6 (2014): 579–582.

Nekhlyudov, Larissa, Denalee M. O’malley, and Shawna V. Hudson. “Integrating Primary Care Providers in the Care of Cancer Survivors: Gaps in Evidence and Future Opportunities.” The Lancet Oncology 18, no. 1 (2017): e30–e38.

———. “Integrating Primary Care Providers in the Care of Cancer Survivors: Gaps in Evidence and Future Opportunities.” The Lancet Oncology 18, no. 1 (2017): e30–e38.

Nekhlyudov, Larissa, Denalee M O’malley, and Shawna V Hudson. “Integrating Primary Care Providers in the Care of Cancer Survivors: Gaps in Evidence and Future Opportunities.” The Lancet Oncology 18, no. 1 (January 2017): e30–38. https://doi.org/10.1016/S1470-2045(16)30570-8.

Nelson, Joshua David. “Patient-Centered Design Concepts for Cancer Care Interactions and Experiences during Chemotherapy,” 2013.

“Nelson_washington_0250O_11915.Pdf,” n.d.

Ness, Sheryl, Janine Kokal, Kelliann Fee-Schroeder, Paul Novotny, Daniel Satele, and Debra Barton. “Concerns across the Survivorship Trajectory: Results from a Survey of Cancer Survivors.” In Oncology Nursing Forum, Vol. 40, 2013.

Niemelä, Mika, Catherine A. Marshall, Thilo Kroll, Melissa Curran, Susan Silverberg Koerner, Sami Räsänen, and Francisco García. “Family-Focused Preventive Interventions with Cancer Cosurvivors: A Call to Action.” American Journal of Public Health 106, no. 8 (2016): 1381–1387.

Nowrouzi, Behdin, Nancy Lightfoot, Kristy Cote, and Rhonda Watson. “Workplace Support for Employees with Cancer.” Current Oncology 16, no. 5 (2009): 15.

Ogedegbe, Gbenga, Andrea N. Cassells, Christina M. Robinson, Katherine DuHamel, Jonathan N. Tobin, Carol H. Sox, and Allen J. Dietrich. “Perceptions of Barriers and Facilitators of Cancer Early Detection among Low-Income Minority Women in Community Health Centers.” Journal of the National Medical Association 97, no. 2 (2005): 162.

“OR_FiveTypes_Infographic_WEB.Pdf,” n.d.

“Perceptions of Barriers and Facilitators of Cancer Early Detection among Low-Income Minority Women in Community Health Centers.Pdf,” n.d.

Poll-Franse, Lonneke V. van de, Nicole Horevoorts, Mies van Eenbergen, Johan Denollet, Jan Anne Roukema, Neil K. Aaronson, Ad Vingerhoets, et al. “The Patient Reported Outcomes Following Initial Treatment and Long Term Evaluation of Survivorship Registry: Scope, Rationale and Design of an Infrastructure for the Study of Physical and Psychosocial Outcomes in Cancer Survivorship Cohorts.” European Journal of Cancer 47, no. 14 (September 2011): 2188–94. https://doi.org/10.1016/j.ejca.2011.04.034.

“Provision of Integrated Psychosocial Services for Cancer Survivors.Pdf,” n.d.

Recklitis, Christopher J., and Karen L. Syrjala. “Provision of Integrated Psychosocial Services for Cancer Survivors Post-Treatment.” The Lancet Oncology 18, no. 1 (2017): e39–e50.

“Recovery Issues in Cancer Survivorship.Pdf,” n.d.

Reed, Sarah C., Ann H. Partridge, and Larissa Nekhlyudov. “Shared Medical Appointments in Cancer Survivorship Care: A Review of the Literature.” Journal of Oncology Practice 11, no. 1 (2014): 6–11.

“Resources for Life After Cancer MSKCC.Pdf,” n.d.

Rife, Sean C., Kathryn Kerns, and John Updegraff. “Support Seeking in Response to Stress: Person-Level Moderators, Contextual Factors, and the Role of Online Venues,” 2018.

“Self_Measures_for_Love_and_Compassion_Research_SOCIAL_SUPPORT.Pdf,” n.d.

“Shared Care Involving Cancer Specialists and Primary Care Providers – What Do Cancer Survivors Want.Pdf,” n.d.

“Shared Medical Appointments in Cancer Survivorship Care- A Review of the Literature.Pdf,” n.d.

“Social Relationships and Mortality Risk - A Meta-Analytic Review.Pdf,” n.d.

“SOCIAL SUPPORT SEEKING IN RESPONSE TO STRESS.Pdf,” n.d.

“Support for Caregivers of Cancer Patients - Transition After Active Treatment.Pdf,” n.d.

“Support Seeking in Response to Stress.Pdf,” n.d.

“TAYL-Workbook.Pdf,” n.d.

“The Evolution of Cancer Survivorship Care.Pdf,” n.d.

“Transitioning to Breast Cancer Survivorship- Perspectives of Patients, Cancer Specialists, and Primary Care Providers.Pdf,” n.d.

“Trends and Advances in Cancer Survivorship Research.Pdf,” n.d.

Waxman, Bernard M. “Routing of Multipoint Connections.” IEEE Journal on Selected Areas in Communications 6, no. 9 (1988): 1617–1622.

“Why Do People Seek Anonymity on the Internet.Pdf,” n.d.

Wilkerson, Julia, Kald Abdallah, Charles Hugh-Jones, Greg Curt, Mace Rothenberg, Ronit Simantov, Martin Murphy, et al. “Estimation of Tumour Regression and Growth Rates during Treatment in Patients with Advanced Prostate Cancer: A Retrospective Analysis.” The Lancet Oncology 18, no. 1 (January 2017): 143–54. https://doi.org/10.1016/S1470-2045(16)30633-7.

“Working With Cancer Report.Pdf,” n.d.

“Workplace Support for Employees with Cancer.Pdf,” n.d.

THE WAY FORWARD

Wrapping up, we have three next steps.

First, we're carrying forward our user testing by expanding from survivor-to-survivor interaction and involving the experts. We want to see if the experts respond to anything, what they say, and whether survivors find value in it. We're also interested in if the institutions with which those experts are affiliated find the network to be a source of market intelligence for better serving cancer survivors.

Second, we're polishing our designs and looking forward to user testing the platform at higher fidelity.

Third, we're continuing to talk with our partners to pursue opportunities to implement the network as part of the great efforts they're already making.

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