HARVARD | BUSINESS | SCHOOL
Kraft Precision Medicine Accelerator

ENGAGING PATIENTS

FIVE KEY PRINCIPLES

As a leader at a nonprofit focused on curing a disease, or a board member or a participant in the ecosystem focused on curing diseases, your ability to engage patients and progress toward a cure depends on building a robust database with patients' names and emails. This database is one of your organization's most important assets and is the centerpiece of your organization's activities to engage, support, and assist patients.

But getting patients to provide their name or email can be challenging. Even prominent nonprofits often struggle to create patient databases, which limits an organization's ability to engage and mobilize patients.

The Kraft Accelerator's Approach: Enlist Leading Experts

The Kraft Precision Medicine Accelerator's philosophy has been to convene leading experts — "the best of the best" — to identify best practices and disseminate them broadly.

To identify best practices for acquiring, engaging, and retaining patients, the Kraft Accelerator brought together some of the world's foremost direct-to-consumer (DTC) experts. These DTC experts, who have extensive experience reaching and engaging consumers, shared how DTC techniques can be applied by nonprofits to engage patients.

In addition, the Kraft Accelerator identified thought leaders from cutting-edge cancer and cure-seeking nonprofits. These nonprofit leaders were transparent about their organizations' successes and challenges in acquiring and engaging patients.

Brad Olson, Peloton; Christine Espinoza, Marriott; Jaime Mahoney, Tea Forte; Kathy Giusti, Kraft Accelerator

Together, these DTC experts and nonprofit leaders formed the Kraft Accelerator's Direct-to-Patient (DTP) Workstream. Participating organizations are highlighted below.

Direct-to-Consumer (DTC) experts from:

Boston Red Sox, Facebook, Keurig Green Mountain, Marriott Hotels & Resorts, Peloton, Reebok, RTR, Rue La La, Tea Forte, Salesforce essentials, Wayfair

Nonprofit leaders from:

MBCalliance, Lungevity, Multiple Myeloma Research Foundation, Pancreatic Cancer Action Network, Prostate Cancer Foundation

Through extensive collaboration, the DTP Workstream identified five key principles for nonprofits to adopt in engaging patients. The participating nonprofits, and many others, are now using these principles to improve the success of their direct-to-patient engagement activities.

Five Key Principles for Engaging Patients

The DTP Workstream identified five foundational principles for patient-focused nonprofits interested in acquiring, engaging, and retaining patients. These principles are prerequisites that businesses use to engage consumers. Nonprofits must employ these principles to engage patients.

1. MAKE CAPTURING PATIENT NAMES & MAILS A STRATEGIC PRIORITY
2. DEFINE & UNDERSTAND THE TARGET
3. BUILD A MODERN ENGAGEMENT INFRASTRUCTURE
4. REACH TARGET TO ACQUIRE & RETAIN
5. MEASURE

PRINCIPLE #1: MAKE CAPTURING NAMES AND EMAILS A STRATEGIC PRIORITY

A nonprofit's list of patients and their contact information is the starting point for any effort to engage patients, conduct surveys, alert patients about clinical trials or webinars, solicit donations, build relationships, or do any patient-focused outreach.

A centralized database is a nonprofit's key tool for aggregating patient information – starting with names and emails – segmenting patients, and being able to connect with patients and support them in multiple ways on their journey. (Note: this is not a medical database with clinical, scientific, or genetic information; it is the kind of database used by modern DTC marketers.)

Getting a patient's name is the starting point; getting their email is even better, since email is the most frequently used method of communicating.

Because building this database is so central to a nonprofit's ability to engage patients, the focus on patients' names and emails must be embedded as a top priority in the organization's strategy. It must be embraced by the CEO and leadership team, with investments in the database, in strategies to increase the number of patients in the database, and in metrics to measure success (see page 6).

There must be knowledge throughout the organization of the number of patients in the database and the organization's goal.

Case Study: LUNGevity

LUNGEVITY
Find it. Treat it. Live.

Making email acquisition a top priority

LUNGevity, the nation's leading lung cancer-focused organization, is focused on changing outcomes for people with lung cancer through research, education, and support.

As a participant in the Kraft Precision Medicine Accelerator, LUNGevity shared insights with other nonprofit leaders in areas where it was a first mover. For example, LUNGevity encourages patients to talk with their doctors about biomarker testing and targeted treatments.

LUNGevity was also a leader in creating closed Facebook groups for patients and caregivers. These groups, often categorized by subtype, are managed by LUNGevity's support team.

What LUNGevity Did

LUNGevity learned from other organizations participating in the Kraft Accelerator about the importance of building out the organization's database, qualifying which constituents are patients and collecting their emails, and focusing on email acquisition.

LUNGevity has made acquiring emails a top marketing priority, successfully using paid social media to reach its target and acquire names and emails. Once LUNGevity acquires patients' emails, it leverages its patient database to tailor content to patients and caregivers, with a goal of establishing an ongoing dialogue.

> TO HEAR FROM CONSUMER ENGAGEMENT EXPERTS THAT OUR EMAIL DATABASE IS ONE OF OUR MOST IMPORTANT ASSETS—THAT REALLY DROVE EVERYTHING HOME.
>
> ANDREA FERRIS, CEO, LUNGEVITY

Andrea Ferris, CEO, Lungevity

PRINCIPLE #2: DEFINE & UNDERSTAND THE TARGET

When creating the patient database, it is important to identify both the primary and secondary targets.

- **Primary Target: Patients.** For most nonprofits, the patient is the primary target, as patients are the focus of most engagement activities.

  However, in situations where a patient has a rapidly progressing disease or is experiencing cognitive issues, the caregiver may be the primary target.

- **Secondary Targets: Caregivers, family members, donors, researchers, healthcare providers, drug developers, others.** While patients are usually the primary target, engaging with other stakeholders is also important.

  Secondary targets may include scientists, who want to be alerted about possible grants, and clinicians, who want to stay abreast of the latest trials and treatment options. Also, industry partners like pharma and biotech may be secondary targets.

Thoroughly Understand the Target

DTC experts advise developing a deep understanding of the primary target on multiple dimensions. This includes understanding patients' demographics, ethnography, emotions, journeys, and key moments on their journey.

A recomended practice is to segment patients based on distinct characteristics – such as newly diagnosed or experiencing a relapse – and use different methods and messages to engage each segment.

PRINCIPLE #3: BUILD A MODERN ENGAGEMENT INFRASTRUCTURE

Collecting names and contact information, and using this information to drive engagement, requires a modern infrastructure consisting of technology, human capabilities, and data.

Technology: Adopt a CRM

Nonprofits need a modern customer relationship management (CRM) system to aggregate data and orchestrate engagement activities.

Common CRMs for nonprofits include Salesforce and Blackbaud. These are cloud-based software-as-a-service (SaaS) solutions that can be implemented relatively quickly with minimal upfront investment.

Human Capabilities: Have Data Expertise

Nonprofits need a "data owner" who has deep knowledge of the CRM. Options include: 1) training an IT person; 2) hiring a data expert; or 3) contracting with an outsider.

While the technology implementation needs to be owned by IT, to get the most value from the CRM, the overall implementation is best overseen by a business or marketing leader. Also, while data ownership should be concentrated, use of the CRM is typically widespread, requiring training for users.

Adam Grossman, Boston Red Sox; Margaret Lawrence, Wayfair; Melissa Studzinski, Sparks Enterprise; Lori Marcus, Kraft Accelerator

Data (marketing data, not medical data).

Data provides a more complete picture of patients and their behavior. It can inform decisions and personalize engagement. Data:

- Defines who a person is (patient, caregiver, family member, donor, clinician, etc.)
- Shows where a patient is in their journey
- Can be used to create segments for targeted, personalized communications
- Informs decision making about strategies and engagement campaigns

Best practices from DTC experts and nonprofits:

- **Code your data.** Coding is essential to know *who* a person is, with separate coding for patients, caregivers, family members, donors, clinicians, scientists, and other stakeholders; and *where* a patient is in their journey.
- **Clean your data.** If the data is not accurate, it has little value. Ensure your data is clean, accurate, and stored in consistent, specified formats.

Case Study: Prostate Cancer Foundation

Prostate Cancer Foundation
Curing Together.

Coding data to segment audience, customize communications

The Prostate Cancer Foundation (PCF) is the #1 philanthropic organization funding prostate cancer research.

When PCF began working with the Kraft Accelerator, it was already committed to becoming more digitally sophisticated and had a massive database with lots of names. However, PCF wasn't able to determine which names were patients, family members, caregivers, or just individuals interested in learning about prostate cancer.

What PCF Did

Through participation with the Kraft Accelerator, PCF's leaders learned about the importance of coding their data to be able to specifically identify patients.

Now, when a person comes to PCF's website for a patient guide, PCF asks a few simple questions to identify the person's situation. This data is used to segment PCF's audience and provide targeted, customized communications to each segment.

> THE KRAFT ACCELERATOR HELPED US LEARN WHAT OTHERS WERE DOING AND PROPELLED OUR EFFORTS TO IDENTIFY PATIENTS IN OUR DATABASE. WE'VE BECOME BETTER AND FASTER.
>
> JONATHAN SIMONS, MD, CEO, PROSTATE CANCER FOUNDATION

Jonathan Simons, MD, CEO, Prostate Cancer Foundation (on far right)

PRINCIPLE #4: REACH TARGET TO ACQUIRE & RETAIN

The two primary purposes of direct-to-patient outreach are to acquire and retain patients.

Purpose	Acquire	Retain
Goal	**Initiate** a new relationship	**Deepen** and sustain existing relationships
Desired outcome	Patient **provides name and email** by going to website or contacting call center	Patient **shares information and data** via survey and data capture.

Messaging Best Practices

Effective messaging by patient-focused nonprofits:

Provides value. To get patients to provide their name and email, they must receive value. Value can be information to manage their health or information about trials or drugs. Understand how patients think about value and communicate the value your organization provides.

Builds trust. Messaging must build emotional loyalty and trust. Communicate in a human, transparent way, feature stories about patients and experts, and build a community.

Is inspirational. Make messaging optimistic, inspirational, and emotional. Convey that each patient's participation makes a difference.

Identifies and leverages triggers. Most diseases have triggers when patients are more likely to seek information. Understand these triggers and have messaging that resonates with each.

Creates urgency. Messaging should convey the need to act now!

Reaching Patients

Reaching your target differs if acquiring new patients or retaining existing patients.

Acquiring	Retaining
Use vehicles with broad reach: ▪ Social media (especially paid), like Facebook ▪ SEO (search engine optimization) ▪ Paid advertising, such as Google AdWords ▪ Non-social channels, like pamphlets in doctors' offices ▪ Partnerships with complementary organizations	Use data in your CRM about patients to engage them through targeted, personalized communications: ▪ Emails and texts ▪ Push notifications ▪ Online newsletters ▪ Events like webinars and summits

More About Social

Social sharing has always existed but is now digital.

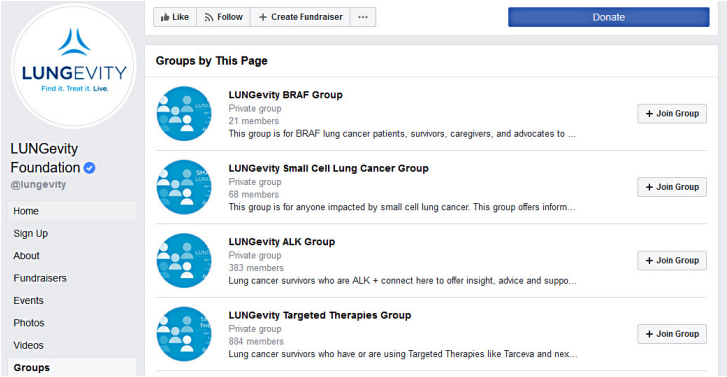
- Social media enables bi-directional communication, which is critical for engagement.
- Understand all available social media channels and decide which best fit your goals.
- Use each channel surgically for its best and highest purpose (as resources allow)
- Do not copy/paste/re-post the same content on every channel; tailor the content to the channel

Rules for Social

- Focus on quality, not quantity
- Transparency is the point of entry
- Listening is more important than speaking
- Contribute to the community
- Response in real time is necessary
- Find your unique value proposition

Facebook reaches all groups and allows for extreme targeting

- **70 million members** of health-related groups
- (Paid) is a vehicle to **target messaging to key audiences**
- (Groups) **fosters community**; is a way to listen and strategically engage



Example showing some of LUNGevity's Facebook Groups

Best practices: post regularly, be authentic, find your voice, use compelling visuals and videos, invite conversation, respond to comments, and use ads.

Instagram

- Focus on **visuals**, **storytelling**, and **video**.
- Use Instagram stories to **deepen the connection** with engaged users.

Google reaches everyone through its search engine and display ads, but the costs are high and results can be questionable. Keys are targeting and optimizing.

Twitter can **build awareness and advocacy**. Follow key opinion leaders and comment thoughtfully.

PRINCIPLE #5: MEASURE

DTC experts use metrics, scorecards, and dashboards to measure their engagement activities. These metrics show trends, what is/isn't working, opportunities for improvement, and where to invest.

Why Scorecards?

DTC experts and nonprofit thought leaders agree that scorecards highlight an organization's most important engagement goals, creating focus. Scorecards show how the organization is performing on key metrics over a period of time, typically monthly, and provide easily reviewable performance data. Scorecards offer a "single source of the truth" that everyone buys into and are consistent and repeatable. For an example of an scorecard see page 7.

Engagement Metrics

A good scorecard doesn't measure everything; it is a snapshot of the most important metrics. DTC experts see the following engagement metrics as critical:

Metric Category	Examples of Minimum Metrics to Track
Website	▪ # of monthly users ▪ Average session duration ▪ Bounce rate (% of visitors who navigate away after viewing only 1 page)
Email	▪ Total # of validated patient/caregiver email addresses (look at patients as a % of total patient population) ▪ Email open rate (# of emails clicked and opened as a % of total emails sent) ▪ Email click-through rates (of those emails opened, the % that clicked on any link in the email)
Facebook	▪ # of followers ▪ Reach (# of people who saw your posts) ▪ Engagement (# of times people engaged with your posts, including shares, likes, comments, etc.) ▪ Engagement rate (engagement as a % of total reach)
Twitter	▪ # of followers ▪ Impressions (# of times a tweet was seen, regardless of unique viewership) ▪ Engagement (# of times people have engaged with your tweets) ▪ Engagement rate (engagement as a % of total impressions)
Call center	▪ # of calls received (can look at unique calls and/or new callers)

Measurement Best Practices

Best practices related to measuring engagement include:

- **Track longitudinally.** Engagement metrics have greater value when tracked over time.
- **Measure the journey.** Understand the steps on the patient journey that matter most and measure how the organization is performing during those critical moments.
- **Customize reporting.** Create scorecards with different metrics for different stakeholders: For the board, minimal topline metrics; for the CEO and leadership team, a deeper scorecard; for the marketing team, more granular metrics.
- **Focus on the format.** A useful scorecard is not just about the data; it is in a simple, clear format that is easy for users to access and review.
- **Highlight changes.** Include a way to highlight major differences vs. goals (higher or lower) and changes versus the previous time period, along with indicated actions.

Scorecards focus the organization on those engagement metrics that matter most. Scorecards create alignment, bring discipline, and enable everyone to see what is/isn't working.

Scorecard of Total Reported Engagement Metrics																
	Monthly Baseline	Jan	Feb	Mar	Apr	May	Jun	Jul	Aug	Sep	Oct	Nov	Dec	**Annual Goal**	Diff vs. Goal	Reasons for Difference?
# Patients Living with this Cancer																
EMAIL																
# TOTAL valid US emails in your data base (includes friend, memorial, event, etc)																
Total # of validated PATIENT emails																
Email Open Rate (# emails clicked & opened as a % of TOTAL emails received)																
Email Click Through Rates (of those opened, the % that clicked on any link in the email)																
WEBSITE																
Monthly Users																
Average Session Duration																
Bounce Rate (% of visitors to a particular website who navigate away from the website after viewing only one page)																
FACEBOOK																
# FB Follower																
FB Reach (# people that saw your posts)																
FB Engagement (# times people have engaged with your post, includes shares, likes, comments, etc)																
FB Engagement Rate (Engagements as a % of total reach)																
TWITTER																
# Twitter Followers																
Twitter Impressions (# times tweet was seen, regardless of unique viewership)																
Twitter Engagement (# times people have engaged with your tweets)																
Twitter Engagement rate (engagement as a % of the total Impressions)																
CALL CENTER																
#calls to call center (note: you can look at # unique calls or # new callers)																

Example of a scorecard showing key engagement metrics

Consumer engagement experts and nonprofit thought leaders at a Kraft Accelerator convening