Patient Engagement Survey

Social Networks to Improve Patient Health

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Advisor Analysis

Social networks—both face-to-face and virtual—have been shown to positively impact behaviors such as weight loss and smoking cessation. Is the health care industry ready to more widely leverage this mechanism for increasing healthy behaviors among patients?

What are the top three situations in which social networks are most useful in health care delivery?

- Chronic disease management: 85%
- Promotion of healthy behaviors (weight loss, physical activity, healthy eating): 78%
- Emotional support: 41%

Base = 601 (multiple responses)

In our most recent NEJM Catalyst Insights Council Patient Engagement Survey, “Social Networks to Improve Patient Health,” 99% of respondents acknowledge that social networks are potentially useful in health care delivery, especially for chronic disease management (named by 85% of respondents) and promotion of healthy behaviors such as weight loss, physical activity, and healthy eating (78%).

The NEJM Catalyst Insights Council members surveyed—composed of health care executives, clinical leaders, and clinicians—see significant opportunity to improve health by either building or leveraging existing social networks. The seminal research by the medical sociologist Nicholas Christakis shows the strong linkage of behaviors leading to obesity, smoking, and alcohol use within social networks.
Facebook and other social media sites illustrate in everyday life the power of social connectedness and the influences individuals have on one another’s behavior. Historically, care delivery has focused exclusively on individual patients. Awareness is growing that social networks in health care, such as PatientsLikeMe and Connected Living, can help people improve health behaviors. Peer networks can provide information and community to patients who otherwise might struggle alone with a new or existing disease.

Approximately three-fourths of Insights Council member respondents report their organization uses some type of social network as part of their care delivery platforms, but 90% report that these approaches are not yet mature or only slightly mature. However, more than 60% of respondents believe that when social networks do mature, the impact on patient engagement, quality of care, and provider engagement will be major to moderate—a significant endorsement of the potential of social networks in support of patient health.

Why are clinicians and health care leaders interested in tapping into social networks? The most obvious reason is that health systems have begun to take on financial risk for populations of patients. When health systems assume risk, they are no longer focused solely on treating disease and are incented to consider an array of options for keeping people healthy. Social networks provide the opportunity for innovative care at a relatively low cost (respondents score cost investment lowest among challenges to scaling these tools). Insights Council members single out disease-specific patient support groups and caregiver support groups as the social network approaches with the most potential (chosen by 75% and 66% of respondents, respectively).

Face-to-face communication (whether through group sessions or trainings) is named as the most useful mode of communication for social networks (by 69% of respondents). However, it seems inevitable that technology developments and an effort to more meaningfully engage younger patients will push virtual connections, such as social media sites, higher on the list. Social media platforms are a potentially more stable channel for connections with and among patients. For example, people switch cell phone numbers more frequently (largely due to cost issues) than they do Facebook user names.

In verbatim comments, some survey respondents express concern about HIPAA and other privacy regulations in the use of social media sites. It must be acknowledged, though, that for many years patients have been tapping into social networks such as Alcoholics Anonymous, without concerns about privacy being a barrier. What has been missing is the formal involvement and endorsement by health systems. Insights Council respondents also say they are worried patients will receive flawed information
about their diagnosis and treatment on social networks. Council members also are looking for reimbursement models that justify the time necessary to develop, implement, and measure the impact of social networks.

Patients, physicians, and nurses—voted the top three parties who should be involved in developing social networks—will have to give careful thought how to make best use of these platforms. They will have to consider which tools they should use, whether to build or buy, how to integrate into workflows, and how to engage providers and patients successfully and sustainably. We are in the initial stages of this work and look forward to supporting maturation of social networks to improve outcomes.

Social Networks to Improve Patient Health
by NEJM Catalyst

Insights Report · December 2017

Charts and Commentary

We surveyed members of the NEJM Catalyst Insights Council, who comprise health care executives, clinical leaders, and clinicians, about the impact and effect of social networks on health care delivery. The survey covers the social network approaches with the most potential, the social network approaches currently used by health care organizations, the situations in which social networks are most useful, modes of communication, respondents’ involvement in developing social networks, challenges in scaling tools, the maturity of social networks, and their impact. Completed surveys from 601 respondents are included in the analysis.

Patients, physicians, and nurses—voted the top three parties who should be involved in developing social networks—will have to give careful thought how to make best use of these platforms. They will have to consider which tools they should use, whether to build or buy, how to integrate into workflows, and how to engage providers and patients successfully and sustainably.
Disease-specific patient support groups top the list of most useful social network–based approaches. Diabetes is among the diseases that respondents say are well suited for patient support groups. Caregiver support groups (encompassing family and friends) rank second. Respondents cite caring for Alzheimer’s disease patients as an example of where this type of social network is useful. A higher percentage of clinicians (69%) than executives (60%) think caregiver support groups have the potential to be most effective. Social media tools, despite ranking second in approaches currently used for health care delivery, fall to the bottom of the list. A higher percentage of executives (46%) than clinicians (35%) think social media has the potential to be most effective.

**Patient Support Groups Have the Most Potential**

When you think of social networks for health care delivery, which three of the following approaches has the potential to be most effective?

- Patient support groups (disease specific) 75%
- Caregiver (family and friends) support groups 66%
- Patient-to-patient support via peer coaches or other types of peer support 52%
- Clinic-based (e.g., shared medical appointments, group visits) 50%
- Social media tools (e.g., Facebook) 39%

<table>
<thead>
<tr>
<th></th>
<th>45 and under</th>
<th>46+</th>
</tr>
</thead>
<tbody>
<tr>
<td>Respondents aged 45 or younger think a clinic-based approach to social networks has high potential for effectiveness.</td>
<td>61%</td>
<td>48%</td>
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<tr>
<td>Respondents 46 and older think caregiver support groups have high potential for effectiveness.</td>
<td>57%</td>
<td>68%</td>
</tr>
</tbody>
</table>

Base = 601 (multiple responses)

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Disease-specific patient support groups also rank first among organizations that currently use social networks in delivering care. More executives (80%) and clinical leaders (78%) than clinicians (68%) report currently using social networks. Social media tools and caregiver support groups rank second and third among most used social networks. Just over a quarter of respondents say their organizations don’t use social networks in care delivery, which indicates room for growth. One respondent whose organization currently does not use social networks says they “have the potential to be time/resource saving as well [to] improve information sharing between peer/patients in a more relaxed exchange with each other.”

**Patient Support Groups Are the Most Used Social Network Format**

Which approaches to social networks for health care delivery does your organization currently use?

- Patient support groups (disease specific) 47%
- Social media tools (e.g., Facebook) 34%
- Caregiver (family and friends) support groups 31%
- Clinic-based (e.g., shared medical appointments, group visits) 29%
- Patient-to-patient support via peer coaches or other types of peer support 18%
- Organization does not use social networks for health care delivery 26%

Base = 601 (multiple responses)

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Council members are nearly unanimous that social networks are useful in health care delivery; only 1% of respondents disagree. Chronic disease management and promotion of healthy behaviors (such as weight loss, physical activity, and healthy eating) far outweigh other situations in which social networks are rated useful, such as preventive care and acute disease care. A higher percentage of clinicians (81%) than clinical leaders (73%) consider social networks useful for promoting healthy behaviors. That dynamic flips for palliative care/end-of-life care, for which clinical leaders score higher (25%) than clinicians (16%). Several respondents say social networks could be useful in providing cues to patients with chronic illnesses for when to seek care and head off costly ER visits.

**Chronic Disease Management and Healthy Behavior Promotion Are the Best Uses of Social Networks**

**What are the top three situations in which social networks are most useful in health care delivery?**

- Chronic disease management: 85%
- Promotion of healthy behaviors (weight loss, physical activity, healthy eating): 78%
- Emotional support: 41%
- Preventive care: 34%
- Post-acute care recovery: 24%
- Palliative care/end-of-life care: 20%
- Acute disease management: 5%
- Social networks not useful in health care delivery: 1%

*Base = 601 (multiple responses)*

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By a wide margin, respondents point to face-to-face group sessions or trainings as the most useful modes of communication for social networks. Social media sites are tied for the next spot with face-to-face, one-on-one sessions with social network members and patients. Executives (56%) view social media sites as more useful than clinicians (46%), while more clinicians (56%) than executives (43%) favor face-to-face, one-on-one sessions. One respondent comments that face-to-face group sessions afford patients the opportunity to communicate with one another and then bring important questions about their care to their provider.

**Face-to-Face Group Sessions Are the Most Useful Mode of Communication**

*What are the top three most useful modes of communication for social networks?*

- Face-to-face group sessions or trainings: 69%
- Social media sites (e.g., Facebook): 50%
- Face-to-face, one-on-one sessions with social network members and patients: 50%
- Text messages: 39%
- Websites: 38%
- Telephone calls: 33%

Base = 601 (multiple responses)

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Patients are the top stakeholder in developing social networks, followed by clinicians (physicians and nurses). Peers/peer mentors, home-based caregivers, and family/friends are well down the list. One survey respondent says health care organizations should begin with patients and families/friends, ask them what they want or need, and then provide it, “rather than assuming we know what they want or need.” Another says providers must “follow the patient’s lead in the type of social network they prefer and respect if they wish to remain in a face-to-face or paper world.”

Patients, Physicians, and Nurses Should Be Involved in Developing Social Networks

<table>
<thead>
<tr>
<th>Role</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patients</td>
<td>91%</td>
</tr>
<tr>
<td>Physicians</td>
<td>76%</td>
</tr>
<tr>
<td>Nurses</td>
<td>71%</td>
</tr>
<tr>
<td>Social network coordinators</td>
<td>61%</td>
</tr>
<tr>
<td>Family/friends</td>
<td>61%</td>
</tr>
<tr>
<td>Home-based caregivers</td>
<td>52%</td>
</tr>
<tr>
<td>Social media coordinators</td>
<td>49%</td>
</tr>
<tr>
<td>Peers/peer mentors</td>
<td>44%</td>
</tr>
</tbody>
</table>

Base = 601 (multiple responses)

Follow the patient’s lead in the type of social network they prefer and respect if they wish to remain in a face-to-face or paper world.
Time investment by the health care team ranks as the biggest challenge when it comes to scaling social networks for health care delivery. A higher percentage of clinicians (71%) than clinical leaders (61%) view time as the top challenge. Provider adoption and patient adoption come next on the list, while cost investment falls to the bottom of challenges in scaling social networks. One respondent comments on provider adoption as an obstacle, saying that even as part of a “huge” network, there are still not enough basic staff to give more face-to-face time to patients who have that need. Another respondent says, “social networks generate a faux equivalence of advice,” which could undermine provider input.

Time Is the Biggest Challenge in Scaling Social Network Tools

What are the top three biggest challenges in scaling social network tools for health care delivery?

- Time investment by health care team: 66%
- Provider adoption: 59%
- Patient adoption: 47%
- Infrastructure development for technological approaches: 40%
- Providing supervision and follow-up: 40%
- Cost investment: 36%

Base = 601 (multiple responses)
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"Social networks generate a faux equivalence of advice."
A large majority of Insights Council survey respondents consider social networks slightly mature or not mature at all. This assessment is consistent across executives, clinical leaders, and clinicians. No respondents consider social networks a mature tool for delivery of care. One respondent whose organization has deployed social networks says they have helped assist patients after tertiary care from their home environment. “Connecting patients to other patients for support has been a very successful opportunity,” the respondent says, adding that social networks have helped identify and address gaps in care transitions.

Social Networks for Health Care Delivery Are Far from Mature

How mature are social networks as a tool for health care delivery?

![Circle chart showing the maturity levels of social networks]

- 10% Mature
- 47% Not mature
- 43% Slightly mature

Base = 601

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“Connecting patients to other patients for support has been a very successful opportunity.”
When social networks mature, nearly all respondents think they will have a major to moderate impact on patient engagement, while a large majority think mature social networks will have a significant impact on quality of care and provider engagement. Just over half of respondents say mature social networks will influence the cost of care. Many Insights Council members expect patient engagement in chronic disease management to be positively impacted by social networks. For instance, one says his or her organization has found success in engaging patients through social networks focused on diabetic therapy and self-management.

Social Networks Will Have a Major or Moderate Impact on Health Care's Quadruple Aim

When social networks are mature, what level of impact will they have on different aspects of health care?

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<thead>
<tr>
<th></th>
<th>Major impact</th>
<th>Moderate impact</th>
<th>Slight impact</th>
<th>No impact</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient engagement</td>
<td>44%</td>
<td>47%</td>
<td>8%</td>
<td>0%</td>
</tr>
<tr>
<td>Quality of care</td>
<td>29%</td>
<td>49%</td>
<td>20%</td>
<td>2%</td>
</tr>
<tr>
<td>Provider engagement</td>
<td>18%</td>
<td>44%</td>
<td>33%</td>
<td>5%</td>
</tr>
<tr>
<td>Cost of care</td>
<td>18%</td>
<td>36%</td>
<td>37%</td>
<td>9%</td>
</tr>
</tbody>
</table>

Base = 601

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Verbatim Comments from Survey Respondents

“How has or could the use of social networks improve health care delivery in your organization?”

“As we transition away from fee for service payment, this is an additional tool we can use to improve population health.”
— Clinician at a mid-sized nonprofit health system in New England

“Improve care for people with serious illness or elders in low income communities, address social isolation and loneliness.”
— Department chair at a large for-profit physician organization in the Northeast

Communication has been one of the biggest issues we face today. A lot of information is given to patients and their care givers in a very short period of time without the necessary feedback as to their understanding of the material/information provided. This creates a need for the patient to go to other sources of information and at times they have a fragmented understanding of their situation. This adds to cost and quality due to noncompliance to instructions, seeking more information leads to more unnecessary testing, etc.”
— VP of a mid-sized community hospital in the Mountain West

“Linking patients with similar disorders to one another for communication, support in coming for regular clinic visits, reaching out to newly diagnosed patients.”
— Clinician at a large nonprofit hospital in the Midwest

“It would greatly address the conundrum and gap with patients feeling understood, supported and cared for.”
— Director of service line at a mid-sized government nonprofit in the South

“As we move into Population Health, developing CIN’s, telehealth, these social networks can become very effective.”
— Executive at a large nonprofit health system in the Pacific West
“We need to track out patient’s QOL and PROs electronically, especially when they live so remotely.”
— Clinician at a large nonprofit hospital in the South

“Unless we can remove commercial interests from social media I don’t think of it as a proper place for disease management or health care delivery. Every business is drooling over opportunities offered by Facebook and similar sites. Health care is different and personal and patients are at their most vulnerable; offering social media opportunities here, even for what can be argued as appropriate, might turn out to be the most unethical thing we ever did as health professionals. As a physician, I do not support its use in this context.”
— Program director at a mid-sized nonprofit hospital in the Midwest

“Facilitate better communication of facts.”
— Director of a small community hospital in the Northeast

“Decrease time and energy involvement of healthcare team for education and support for patients and families.”
— Clinician at a small for-profit clinic in the South

“Group visits for diabetes, weight loss, and pain have been helpful, plus classes around meditation, cooking, yoga. Pts and providers are very enthusiastic, but little data.”
— Chief Medical Officer at a small nonprofit clinic in the Pacific West

“Social networks work best paired with a social activity - art for Alzheimer’s for example.”
— VP of large nonprofit hospital in the Northeast
Methodology

• The Patient Engagement Survey: Social Networks to Improve Patient Health was conducted by NEJM Catalyst, powered by the NEJM Catalyst Insights Council.

• The NEJM Catalyst Insights Council is a qualified group of U.S. executives, clinical leaders, and clinicians at organizations directly involved in health care delivery, who bring an expert perspective and set of experiences to the conversation about health care transformation. They are change agents who are both influential and knowledgeable.

• In August 2017, an online survey was sent to the NEJM Catalyst Insights Council.

• A total of 601 completed surveys are included in the analysis. The margin of error for a base of 601 is +/-4.0% at the 95% confidence interval.

NEJM Catalyst Insights Council

We’d like to acknowledge the NEJM Catalyst Insights Council. Insights Council members participate in monthly surveys with specific topics on health care delivery. These results are published as NEJM Catalyst Insights Reports, such as this one, including summary findings, key takeaways from NEJM Catalyst leaders, expert analysis, and commentary.

It is through the Insights Council’s participation and commitment to the transformation of health care delivery that we are able to provide actionable data that can help move the industry forward. To join your peers in the conversation, visit join.catalyst.nejm.org/insights-council.

NEJM Catalyst wishes to thank Michele Heisler, MD, MPA, Professor of Internal Medicine, Health Behavior, and Health Education at the University of Michigan, for assistance in constructing this survey.
Respondent Profile

**Audience Segment**
- Executive: 30%
- Clinician: 47%
- Clinical Leader: 24%

**Organization Setting**
- Other: 37%
- Hospital: 38%
- Physician organization: 14%
- Health system: 11%

**Type of Organization**
- For profit: 29%
- Nonprofit: 71%

**Number of Beds** (Among hospitals)
- 1 - 50: 7%
- 51 - 199: 14%
- 200 - 499: 30%
- 500 - 999: 26%
- 1000+: 23%

**Number of Sites** (Among health systems)
- 1 - 5: 14%
- 6 - 20: 26%
- 21 - 49: 18%
- 50+: 42%

**Number of Physicians** (Among physician organizations)
- 1 - 9: 23%
- 10 - 49: 11%
- 50 - 99: 15%
- 100+: 52%

**Net Patient Revenue**
- > $5 billion: 11%
- $1 - $4.9 billion: 24%
- $500 - $999.9 million: 11%
- $100 - $499.9 million: 15%
- $10 - $99.9 million: 22%
- < $9.9 million: 18%

**Region**
- Northeast: 29%
- Midwest: 22%
- South: 31%
- West: 18%

Base = 601
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