ELEVAY®

Patient Insight. Elevated Healthcare.

US HEALTHCARE PARTNER REPORT 2024

Key Findings for Advocates, Professional Societies & CBOs

TOP RATED ELEVAY Patient Insight. Elevated Healthcare. HEALTHCARE ADVOCACY 2021/2022

US INDUSTRY PARTNERS

TOP PARTNERS IN PATIENT ADVOCACY

1. **Janssen** — *Ranking in the top 2 for all measured areas, leading in Programmatic Support, Expanding Access & Education, Group Relationships, & DE&I Leadership*
2. **BMS** — *Making a significant jump up the rankings, BMS leads all organizations in Policy Support & Corporate Image & Reputation*
3. **Merck** — *Merck also demonstrated immense growth. It was noted for its programmatic support, proactive approach to patient access support, & dissemination of information to the patient community.*
4. **Pfizer** — *Taking a few steps back this year, Pfizer had a strong showing, leading in Health Equity Perception by the community & have two second-place showings in Group Relationships and DE&I Leadership.*
5. **Eli Lilly** — *Lilly is noted for its commitment to a patient-centric approach & ranks in the top five for four of the eight domains measured.*
6. **Amgen** — *Amgen edges out Sanofi by one point this year with its third-place ranking for DE&I Leadership & Group Relationships.*
7. **Sanofi** — *Sanofi is recognized as the leader in Social Determinants of Health work in the community & ranks in the top five for Corporate Image & Reputation.*
8. **Takeda** — *Takeda enters the top 10 for the first time with top 10 rankings in Programmatic Support, Policy Support, Expanding Access & Education, Group Relationships, & DEI Leadership.*
9. **AstraZeneca** — *AZ also reached the top 10 this year with top-10 rankings in Programmatic Support, Policy Support, Corporate Image & Reputation, & SDOH Leadership.*
10. **Novartis** — *The final organization to debut in the top 10 this year, Novartis shows strong growth, with top-10 rankings in Programmatic Support, Corporate Image & Reputation, and SDOH Leadership.*

SUPPORT DESIRES FROM NON-PROFIT ORGANIZATIONS

PROGRAMMATIC SUPPORT:

CONFERENCES, MEDIA & SYMPOSIA

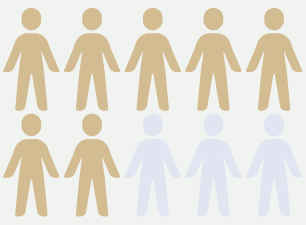
is largest gap in desired support vs the perceived support being provided, followed by Disease Awareness & Education, & Sharing Scientific Information

POLICY SUPPORT:

POLICY DISCOURSE OPPORTUNITIES

is largest gap in desired support vs the perceived support being provided, followed by Patient Care Comment Development, & Payer Engagement Support.

TELEMEDICINE UTILIZATION



7.1 out of 10

Approve of Telemedicine use with ***7.68%*** disapproving & ***21.37%*** neutral on its use.

46.15% of respondents note improved shared-decision making with Telemedicine

PREPARING PATIENTS FOR USE

67.52%

of respondents provide patient education materials for patients to use in Telemedicine sessions, with ***47.01%*** providing checklists, and ***46.15%*** providing sample questions patients can use during their session.

21.37% of respondents have not taken action, up from ***13%*** in the prior year.

ADVOCACY ENGAGEMENT IN POLICY

% ADVOCACY ORGS ENGAGED IN POLICY

57.63%

This is down from ***71%*** two years prior and up from the previous year of ***54%***.

42.37% are not involved in policy due to resource constraints while of those engaged, ***38.46%*** have a quarter of their staff or more devoted to policy work.

POLICY STAFF RESPONSIBILITIES

- ***68.64%*** work independently or with partners to drive reforms
- ***66.10%*** develop & understand state & federal legislation
- ***66.10%*** comment to federal agencies
- ***38.98%*** write papers and guidance

BENEFITS OF WORKING WITH INDUSTRY IN STATE & FEDERAL POLICY

- *Sharing Info & Briefings to Educate*
- *Regular comms to collaborate & align on shared goals*
- *Advocate for drug affordability & coverage reimbursement*

IMPORTANT POLICY ISSUES FOR ADVOCATES

THE MOST PRESSING POLICY ISSUES INCLUDE:

84.61% – **Disease Awareness & Education**

59.98% – **Health Literacy**

54.85% – **Health Equity & SDOH**

ACCUMULATORS/MAXIMIZERS

21.18%

of respondents are well aware of accumulators & maximizers, up from ***15%*** the prior year

33.9%

of respondents feel copay programs are used more by under-represented groups with ***26.27%*** feeling this is not the case and still ***39.83%*** remaining unsure

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NON-MEDICAL SWITCHING (NMS)

67.31%

perceive a ***HIGH*** or ***EXTREMELY HIGH*** impact of Non-Medical Switching on the patients they represent with 77% perceiving an impact on the patients.

23.73%

of respondents are currently not working on Non-Medical Switching issues within their organization.

NMS & HEALTH EQUITY

51.69%

feel Non-Medical Switching impacts Health Equity

11.85%

disagree that Non-Medical Switching impacts Health Equity

ALTERNATIVE FUNDING PROGRAMS

MUCH WORK TO BE DONE

Only ***12.71%*** of panelists claim to be educated about alternative funding programs with ***39.83%*** having little to no knowledge of AFPs.

PATIENTS IN THE DARK

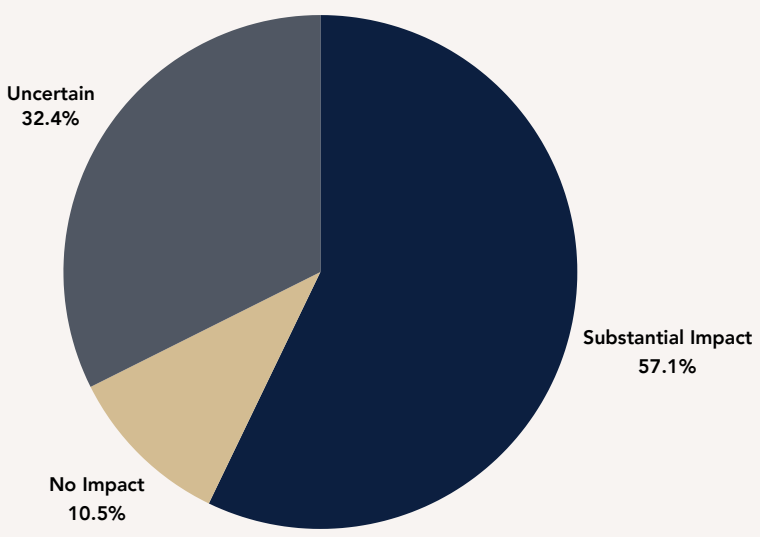
Only ***2.54%*** of panelists feel the patients they represent are well educated about alternative funding programs with ***61.86%*** claiming their patients are uneducated about AFPs.

HEALTH EQUITY IMPACTED

More than half of the respondents perceive a substantial impact on Health Equity & patient care by Accumulators, Maximizers & AFPs

- ***8.47%*** perceive little to no impact on health equity, while ***32.30%*** remain uncertain.

IMPACT ON PATIENT CARE



ICER INSIGHTS & FEEDBACK

ICER KNOWLEDGE & IMPACT

47.45%

of respondents are unaware of ICER's impact, up from ***42.5%*** in the prior year.

34.75%

of respondents claim to be knowledgable of ICER's impact, down from ***39.5%*** in the prior year

POSITIVE OR NEGATIVE FOR PATIENTS?:

12.71% (+)

27.97% (-)

- Down from 19% the prior year, respondents that saw ICER positive felt it would reduce price of drugs and patient out of pocket.
- Remaining a consistent 27% from the prior year, respondents that saw ICER negatively reflect on the lack of patient input in their processes and analyses

ICER METHODOLOGY & QALYS

QALY EDUCATION

22.03%

- are knowledgable or well versed in QALYs & their use

35%

- report not being knowledgable about QALYs & their use

QALYs & HEALTH DISPARITIES

41.25%

claim QALYs advance health disparities

9.31%

disagree that QALYs advance health disparities

DEEP CONCERNS REMAIN...

"Patients and people with disabilities have long-held deep concerns about reliance on cost-effectiveness assessments based on the Quality-Adjusted Life Year (QALY) to determine what treatments will be covered benefits for patients.

The QALY metric puts a lower value on the life of patients with disabilities or chronic conditions, suggesting their lives are worth less compared to those without such conditions. This discriminatory approach risks undervaluing treatments that can significantly improve quality of life for these individuals.

Consequently, it raises ethical questions and concerns regarding equitable access to care, where every person's life should be valued equally regardless of their health status. It's critical that coverage decisions prioritize inclusivity and patient value rather than rely solely on generalized cost-effectiveness assessments."

- Patient Advocate

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THE INFLATION REDUCTION ACT & PERCEIVED PATIENT IMPACT

IRA PERSPECTIES

48.81%

perceive a ***POSITIVE*** impact on the patients they represent with respondents noting a reduction in out-of-pocket expenses for patients

22.87%

perceive a ***DETRIMENTAL*** impact on the patients they represent with respondents noting a potential reduction in medication access and innovation

CARE AVAILABILITY

46.61%

perceive a likely impact on the availability of care due to the IRA with only ***15.61%*** responding that the IRA is unlikely to impact patient access to care

50.09%

of respondents anticipate a likely impact on patient cost sharing due to the IRA with ***10.17%*** anticipating little impact on patient cost sharing adnd still another *39.83%* remaining neutral on the subject.

43.22% OF RESPONDENTS ARE NOT EDUCATING THIER CONSTITUENTS ON THE IRA

HEALTH EQUITY & SOCIAL DETERMINANTS OF HEALTH

IMPACT ON PATIENTS

75%

of respondents percieve the patients they represent are impacted by Health Equity & SDOH issues. **56%** of these respondents note its extremely likely or likely to impact the patients they represent

SDOH INITIATIVES OF FOCUS

Respondents note the following key SDOH issues impacting their constituents:

- *33% - Social/Economic Inequality*
- *31% - Individual Education*
- *11% - Social Support Networks*
- *10.20% - Affordable Housing*

IMPACT ON PATIENT CARE

57%

of respondents note they are inclined to devote time and resources to Health Equity & SDOH initiatives (***18% extremely likely***). Unfortunately, ***20%*** are unlikely to devote time and resources to H.E. and SDOH (***9.48% extremely unlikely***)

INITIATIVES TO ADDRESS H.E. & SDOH

- ***72.41%*** of respondents are providing education and outreach (down from 84% the prior year
- ***69.83%*** are bringing attention to H.E. & SDOH via social media (down from 72% the prior year)
- ***50%*** are developing new programs and initiatives
- ***43.1%*** are advocating for policy changes addressing H.E. & SDOH 9down from 47% the prior year)
- ***41.48%*** are partnering with other organizations (down from 74% the priro year)

RESOURCE ALLOCATION FOR SDOH & H.E. DECLINED WITH ONLY 43% REPORTING DEDICATED RESOURCES ON HAND

HEALTH LITERACY IN THE PATIENT POPULATION

YoY HEALTH LITERACY CHANGES

29%

of respondents claim *Health Literacy* has ***increased*** YoY

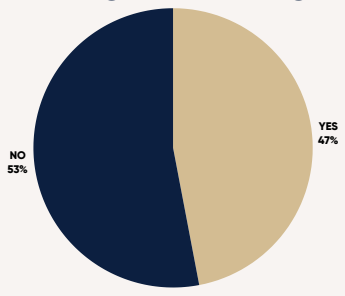
13%

of respondents claim *Health Literacy* has ***decreased*** YoY

58%

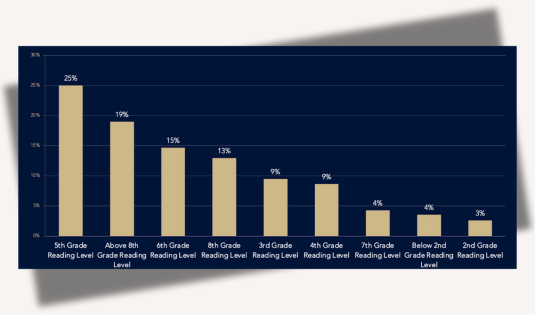
of respondents claim Health Literacy has ***Stayed Consistent*** YoY

HEALTH LITERACY PROGRAMS DEVELOPED FOR PATIENTS



HEALTH LITERACY BY GRADE LEVEL

5TH - 6TH GRADE	-	40%
8TH GRADE OR BETTER	-	32%
3RD - 4TH GRADE	-	9%
2ND GRADE OR BELOW	-	7%



"There is a major health literacy gap for those who are deeply affected by social disparities in healthcare. Their lack of knowledge about copay accumulator/maximizer programs and alternative funding programs shows a distinct correlation."

Immunology: Lupus, Patient Advocacy

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PATIENT-FOCUSED DRUG DEVELOPMENT BEST PRACTICES

FDA ENGAGEMENT:

75.21%

of respondents note involvement in Patient Listening Sessions facilitated by the FDA

- ***31.62%*** of respondents participate in ***FDA Advisory Committees***
- ***17.95%*** of respondents participate in ***FDA Patient Representative Programs*** with another ***17.95%*** reporting participation in ***EL-PFDD Meetings with CDER.***

BEST PRACTICES FOR PATIENT-FOCUSED CLINICAL TRIALS

86.32%

of respondents recognize the involvement of the patient community & engaging patients in trial design discussions as the top best practice in clinical trials.

82.05%

of respondents note ***Diversity in Patient Enrollment*** as a best practice.

76.92%

of respondents note ***Addressing Barriers to Access or Leveraging Virtual Capabilities and Spreading Awareness of Clinical Trial Importance*** as a best practice in clinical trail development.

ENGAGEMENT WITH EMPLOYERS & CBOs

LARGE EMPLOYER ENGAGEMENT

27.35%

of respondents are engaging with employers over the benefits of the patients they represent. This is an increase from ***15%*** in the prior year.

- ***72.65%*** of respondents are not engaging with employers.

28.13%

of respondents have engaged with employers over five times in the last year.

75%

of respondents are providing employers with education and information on the patient's disease state to engage with employers.

WORKING WITH COMMUNITY-BASED ORGANIZATIONS

52%

of respondents report effective, positive relationships with community-based organizations, with ***23.93%*** reporting extremely effective relationships.

CBO INVOLVEMENT INITIATIVES

1. Establishing/Expanding Community Outreach Events ***(35.04%)***
2. Disease-State Awareness & Education ***(29.91%)***
3. Enhance Patient Education Programs ***(28.46%)***

COALITION REPRESENTATION

34.19%

of respondents feel somewhat well represented by broad coalitions with 10% feeling under-represented and another 19.66% reporting neutral feelings on thier reprsentation.

FOR MORE...

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