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Recommendations to address information gaps on Asian American health: Results from Project AXIS (Asian American EXchange and Information Source)

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Background/Significance

In partnership with the National Library of Medicine (NLM), and the Asian & Pacific Islander American Health Forum (APIAHF), the NYU Center for the Study of Asian American Health (CSAAH) completed a mixed methods needs assessment to better understand the informational needs of gatekeepers serving Asian American (AA) communities. Findings informed recommendations to address information gaps and to identify opportunities to warehouse, and disseminate health information for AAs.

Methods

The project was led by a national advisory committee of 7 leaders in AA health. Advisory committee members guided survey and focus group guide development, participant recruitment, and reviewed and informed data analysis and the creation of recommendations.
3 focus groups were conducted online with gatekeepers across the US, including healthcare providers, community-based organizations, social service providers, researchers and other community gatekeepers (N=23). A national online survey was completed by healthcare consumers and gatekeepers (N=256).

Table 1: Top challenges faced in accessing reliable AA health information

	Provider/ Gatekeeper		Patient/ Consumer	
	N	%	N	%
Information specific to Asian American sub-groups	39	58.2	103	54.5
Language-specific information	31	46.3	51	27
Disease-specific information	25	37.3	91	48.1
Current health statistics on Asian American populations	30	44.8	89	47.1
Accurate clinical or scientific information	14	20.9	67	35.4
Materials that are translated accurately	24	35.8	50	26.5
Health information and literature specific to patient populations	13	19.4	54	28.6
Health information for low literacy populations	17	25.4	21	11.1

Results

Survey findings indicated that the majority of healthcare consumers surveyed identified accessing reliable health information disaggregated by sub-group as a top challenge. While many had heard about NLM's online resources, Medline and PubMed, few knew about the Asian American Health Web Portal or the Refugee Health Information Network (RHIN). Key focus group themes included the challenge of finding disaggregated and local data, as well as finding written patient-level information on specific health topics that was correctly translated and culturally relevant

Recommendations

Key recommendations to address information gaps included the need to:

1. Build partnerships with trusted AA organizations, universities, and foundations to facilitate information dissemination;
2. Coordinate and assemble linguistically and culturally relevant, local, state, and national disaggregated data and health information into one central location;
3. Focus on missing information, such as emerging and smaller AA populations, including Bhutanese, Hmong, Burmese, and Nepalese; and
4. Create a user-friendly, interactive, multi-media website targeting AA gatekeepers to warehouse the information.

Table 2: Preferred channels for accessing AA health information

	Provider/ Gatekeeper		Patient/ Consumer	
	N	%	N	%
Social media sites	25	37.3	76	40.2
Internet	54	80.6	164	86.8
Email or e-newsletters	42	62.7	110	58.2
Mobile telephone or tablet	7	10.4	33	17.5
TV	5	7.5	38	20.1
Newspapers	15	22.4	26	13.8
Other print materials	32	47.8	44	23.3
Radio	1	1.5	3	1.6

Table 3: Select key themes and quotes from provider focus groups

Key Themes	Sample Quotes
Looking outside the US for health information	"We were researching how breast cancer affected younger women in the Korean community and there wasn't specific research done just among Asian American women that was recent. So we actually had to go back and reference a study that was done abroad, actually in Korea…"
Information gaps related to language and sub-groups	"Some of the things that we're encountering is, we work with a lot of smaller emerging populations and so, for example, the city or state prioritizes which materials are going to be translated. They also do it in terms of the size of the population and their language access needs. So a lot of the times we don't have information, let's say for example, in Nepali or Hmong. These are languages in New York where the community is smaller, so oftentimes health information is not even available for certain communities."

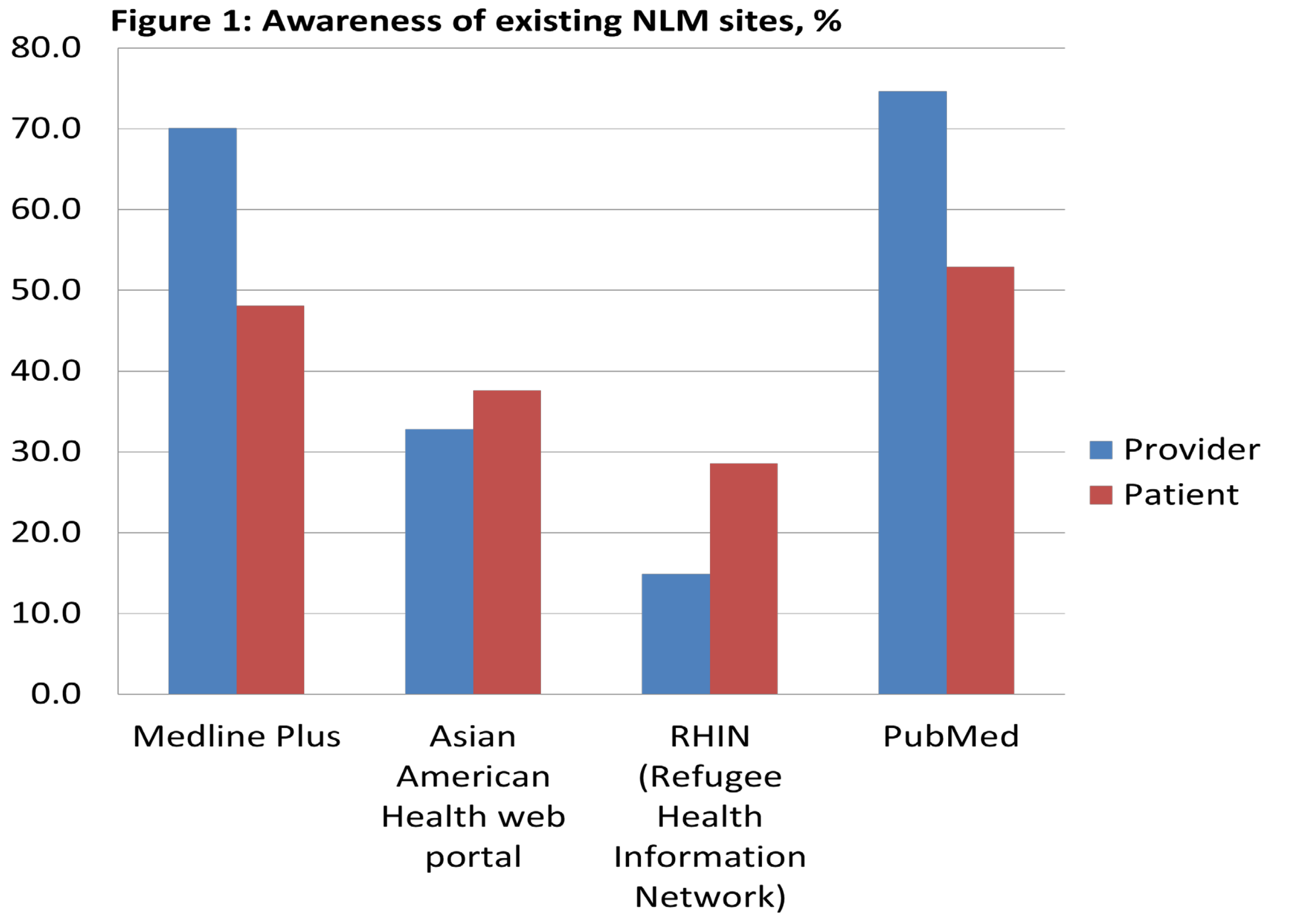
Figure 1: Awareness of existing NLM sites, %

Advisory Committee Members

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- Michael Byun (Executive Director, ASIA, Inc., OH)
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