

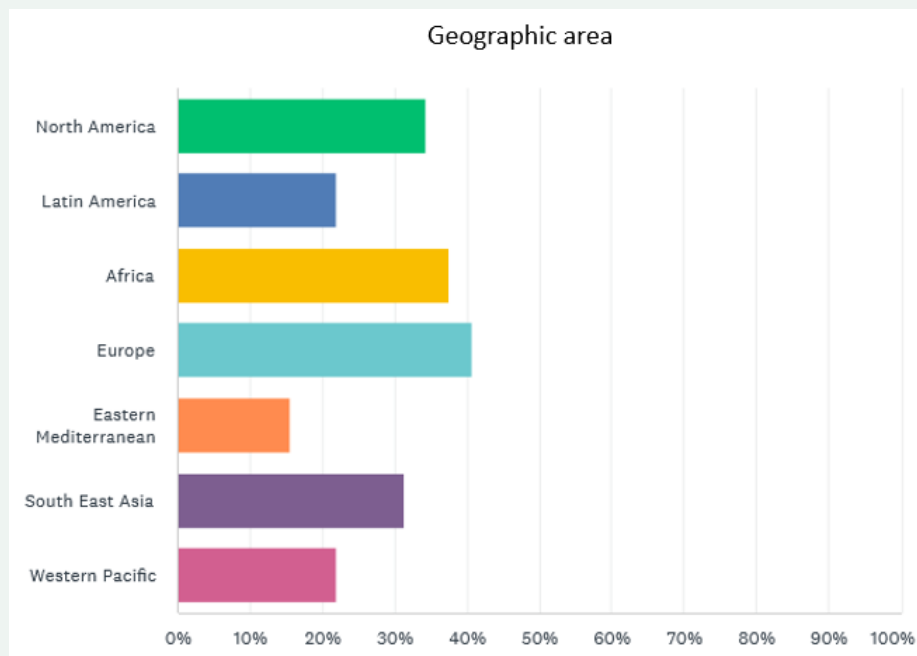
ILCM

ILCM 2023 – Membership Survey

HIGHLIGHTS:

Since its inception in 2021, the ILCM has cultivated a wide variety of members, ranging from small hepatitis organisations to CCA umbrella groups; from well-established pan-cancer foundations to medical associations, pharmaceutical companies and individual champions. Patient groups/ advocates (PAGs) account for 90% of the ILCM.

ILCM members come from all regions of the world. Members from Europe are currently the most represented within the movement (with Eastern Mediterranean region being the least represented).



The key areas of focus of our PAG members are: service delivery/patient support, awareness and policy/advocacy (~60%). A few members also engage with research and capacity building. Only a small number of members have large staff numbers to support the running of diverse tasks & programs.

With regards to the themes/ topics covered by our members, these differ as we have many pan-cancer and liver disease PAGs in the movement. Specifically on the subject of liver

cancer, their main activities centre around awareness and advocacy work. Patient education and patient service, on the other hand, are less represented. Awareness work focuses mainly on prevention, early detection and access to care. Furthermore, even though many ILCM discussions have repeatedly addressed issues such as stigma, economic burden and workplace issues, no member currently specifically addresses these areas systematically in their work when it comes to liver cancer.

When it comes to members' self-assessment of their strengths, the areas of patient support, community reach, advocacy & policy and research & science are equally featured.

In terms of funding, a minority of ILCM members (>10%) receive financial state support. Most members depend on donations, grants from the pharmaceutical industry, and research funding.

That said, most members receive in-kind support from a medical advisory board (> 75 %). Interestingly though, only ~60 % of ILCM PAG members have partnerships with scientific organisations (mainly these partnerships are with local scientific bodies), meaning that there's room to explore possible collaborations with the major scientific umbrella organisations, such as EASL, ILCA, AASLD, ALEH and APASL.

It is also noteworthy that the vast majority of ILCM members do not have celebrity ambassadors. Only 17% count on the support of these public figures – the PAGs in case are based in North America/ Western Pacific area.

On the question of biggest hurdles in raising awareness of liver cancer, the survey reports that competition with other cancers/diseases is the highest one. Further, limited data, lack of knowledge and understanding of liver cancer are problematic too.

When asked which support would be most helpful, almost half of ILCM survey respondents said it would be strategic advocacy training. That said, basic clinical training and updates on scientific data would also be helpful to support the community.



Regarding members' day-to-day work, support is sought from ILCM through the provision of communication materials (e. g. fact sheets or social media posts) and policy resources (e. g. white papers, consensus statements).

Finally, almost everyone would be in favour of having more opportunities to participate in international policy & advocacy meetings, strengthening best practice sharing and networking.