

FROM SURVEY TO RESOURCE HUB: CHRONIC LYMPHOCYTIC LEUKEMIA (CLL) GLOBAL SUPPORT PROVISION



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AIM

Engage identified global network of organisations providing support services and resources for those affected by chronic lymphocytic leukemia (CLL) to understand, map and inform opportunity for global connection, shared learning and to build shared expertise.

BACKGROUND

CLL Advocates Network (CLLAN), a global network of 36 patient advocacy organisations from 29 countries who support those affected by chronic lymphocytic leukemia (CLL), conducted a worldwide survey to understand support services and resources provided by organisations with CLL support in their service delivery remit.

The purpose of the survey was to collect information about individual organisations' service deliveries, service limitations and overall organisational health to inform CLLAN strategy to improve access and support services for those affected by CLL regardless of location.

While CLLAN have a strong membership group, this survey targeted both member and non-member organisations to truly understand and represent the global insights and opportunities.

A key deliverable of this survey was the creation of a global resource hub, a searchable directory of CLL support services and resources by organisation and location.

METHOD

Preliminary desktop research was carried out to identify patient advocacy organisations that are specifically focused on CLL, blood cancer or all cancers. They were invited via direct email to take part in a 63-question web-based survey between May 6 and August 2, 2021.

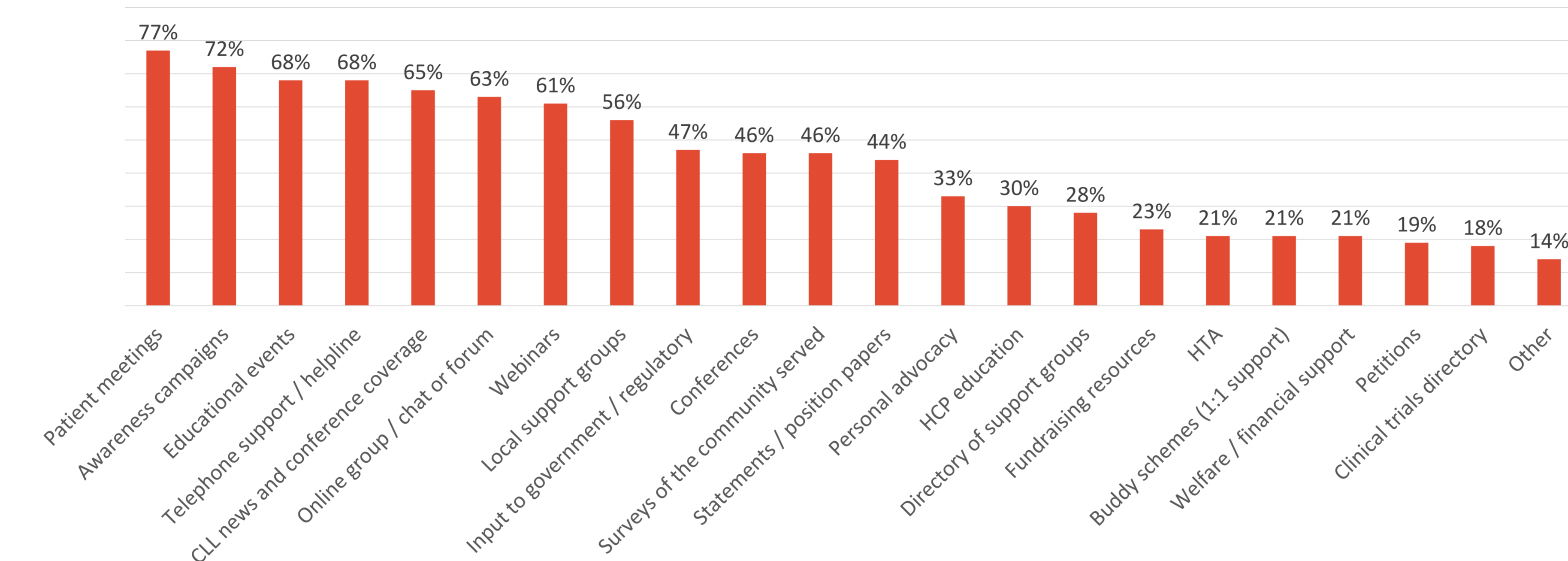
The survey aimed to capture:

- Organisation location and service details (support, advocacy and education) both current and would like to
- Information developed for different patient clusters, and how these are delivered

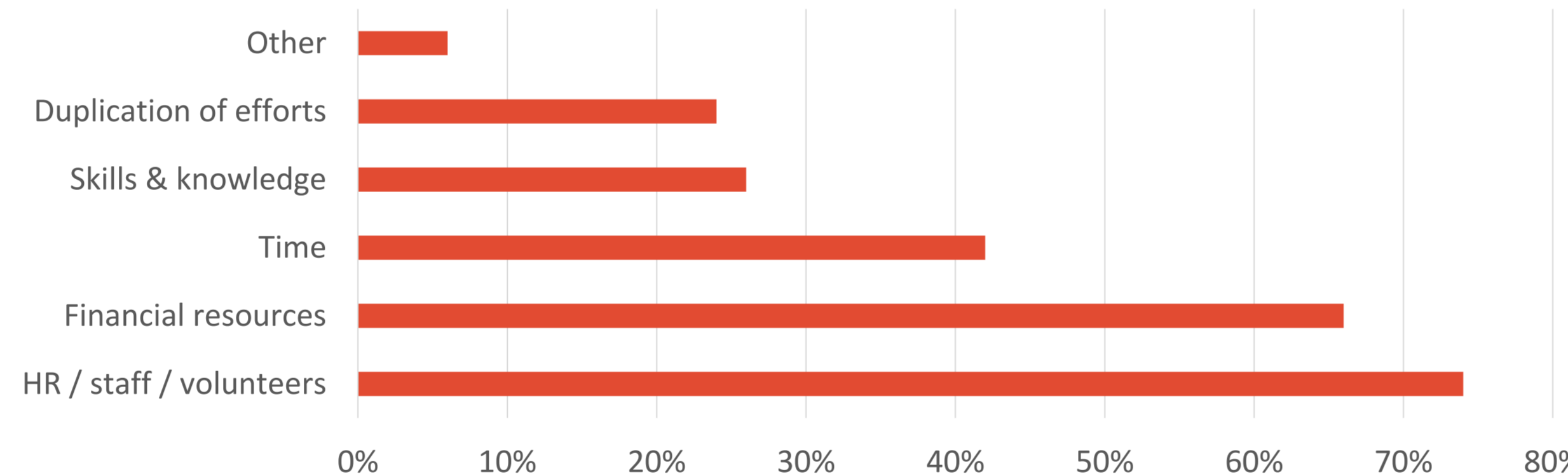
The survey was available in 7 languages and marketed to 158 organisations in 69 countries. 57 organisations representing 40 countries participated in the survey with a response rate of 36%.

KEY FINDINGS

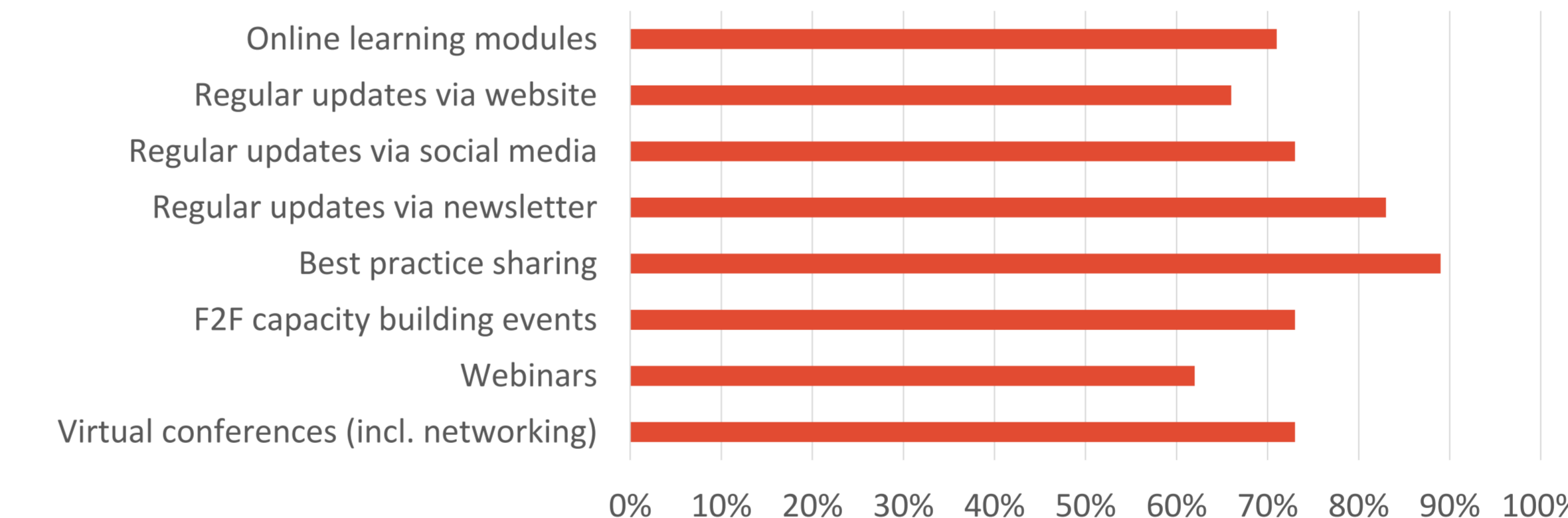
PROVISION OF SUPPORT SERVICES FOR CLL BY RESPONDENTS



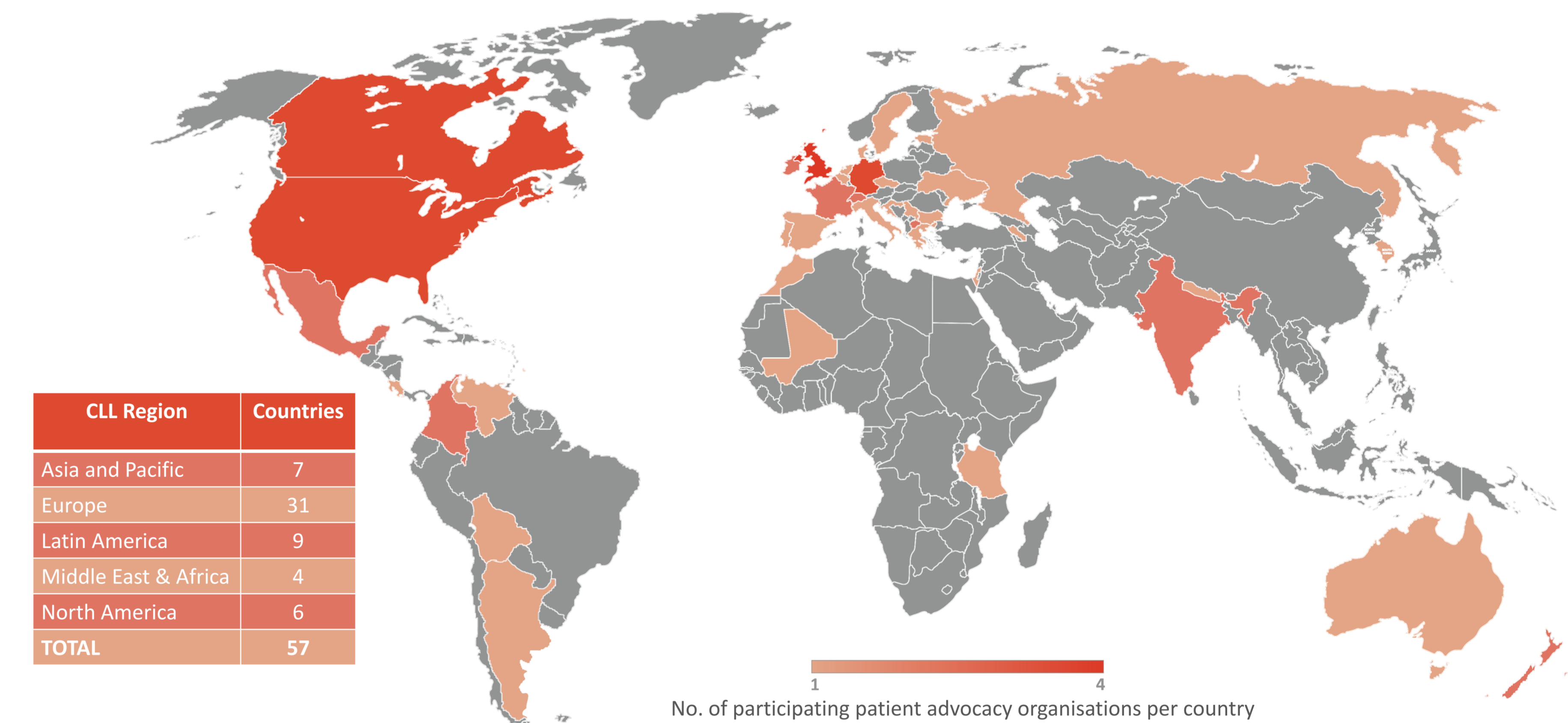
BARRIERS TO PROVIDING CLL SUPPORT FOR CLLAN MEMBERS AND NON-MEMBERS



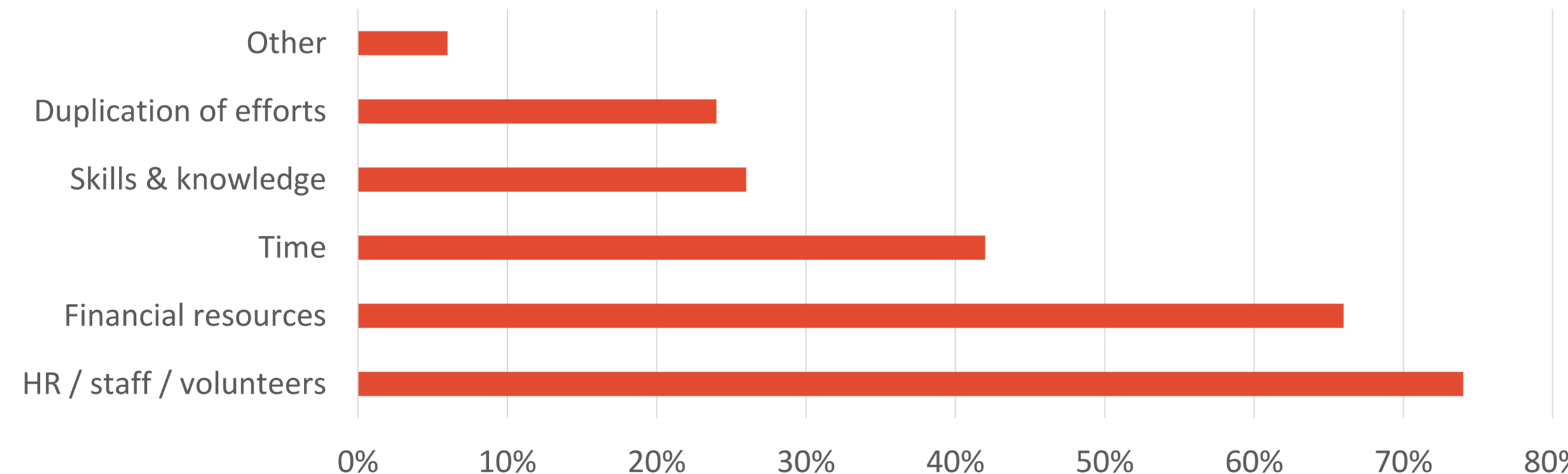
% OF RESPONDENTS WHO ARE LIKELY/VERY LIKELY TO USE CLLAN RESOURCES



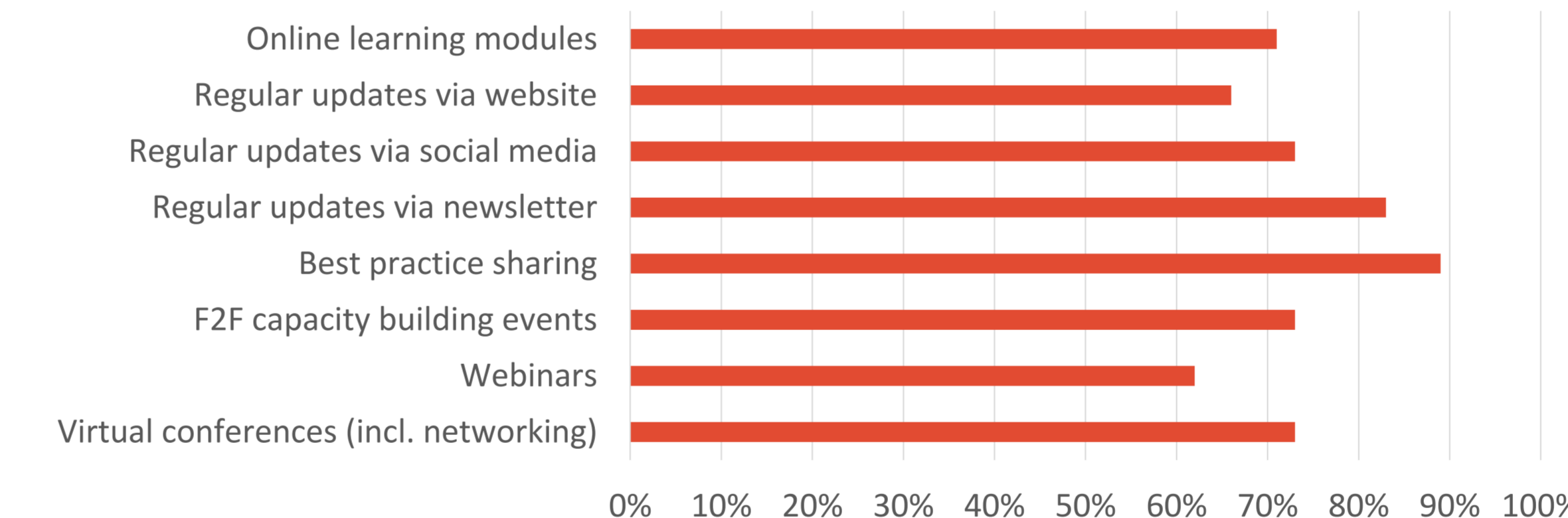
GEOGRAPHICAL REPRESENTATION OF RESPONDENTS



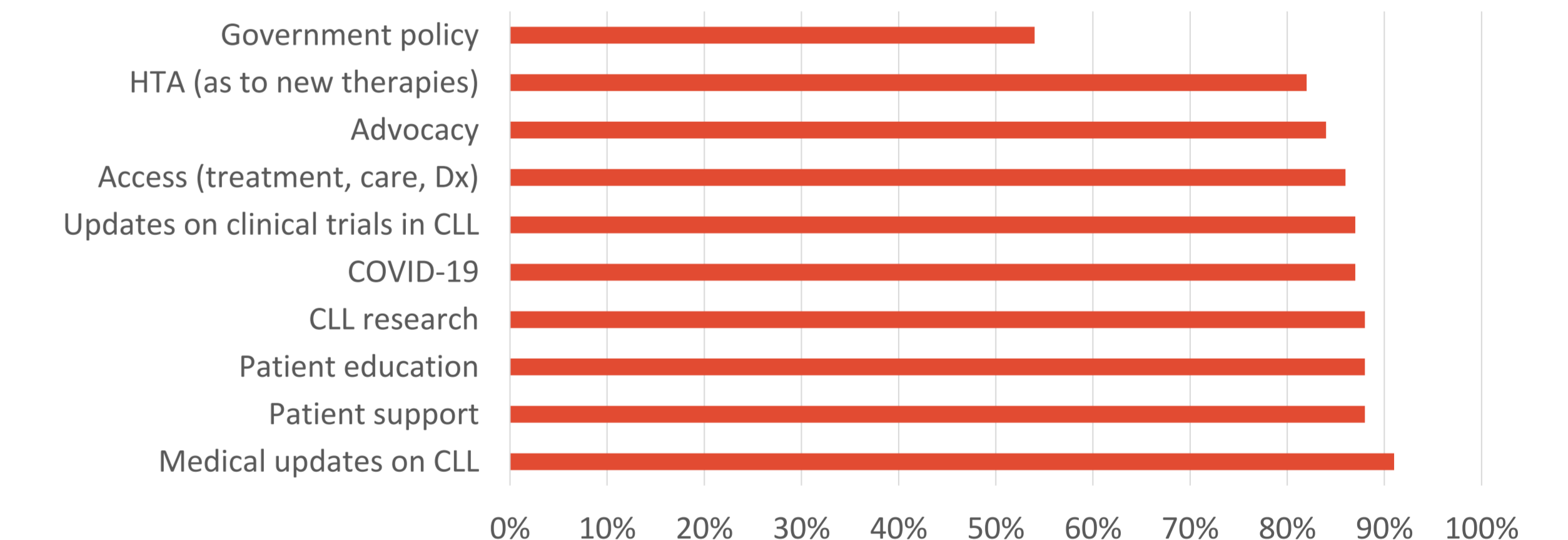
BARRIERS TO PROVIDING CLL SUPPORT FOR CLLAN MEMBERS AND NON-MEMBERS



% OF RESPONDENTS WHO ARE LIKELY/VERY LIKELY TO USE CLLAN RESOURCES



TOPICS OF INTEREST AT EVENTS/IN RESOURCES



CONCLUSION & RECOMMENDATIONS

Survey responses have demonstrated need and appetite for participation in networked activities when building capacity, provision of materials and shared learning to stakeholders.

Through survey insights, CLL Advocates Network built the first global directory of CLL support resources & services by bringing together available information in a shared central database providing open access to the international CLL community. The resource hub was launched in June 2022 and is a searchable database with a significant number of organisations profiled with services provided to CLL patients around the world.

The survey has revealed gaps in support service provision in many countries and has emphasised the importance of an open access central database of resources to provide information to those in countries who may not have them. Beyond this survey CLLAN will be exploring how to support and improve capacity in organisations with limited infrastructure or funding models to ensure that geography isn't a barrier to essential support services and information.

Healthcare professionals remain a key partner both with people affected with CLL and patient organisations that represent them. The survey has identified areas of growth to support people affected by CLL outside of their treating centre, and collaboration between healthcare teams and patient organisations to address this are a recommendation of this survey analysis.

CONTACT INFORMATION

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