LYMPHOMA COALITION

GLOBAL HEALTH LITERACY REPORT CARD

Spotlight on Health Literate Systems and Patient Experience

2024

About Lymphoma Coalition

Lymphoma Coalition (LC) is a worldwide network of patient organisations with a full or partial focus on providing support to those affected by lymphoma, including chronic lymphocytic leukaemia (CLL).

The need for a central hub of consistent, reliable, and current information was recognised, as well as the need for lymphoma patient organisations to share resources and best practices. Four lymphoma organisations started LC in 2002, and it incorporated as a not-for-profit organization in 2010. Today, there are more than 90 member organisations from over 55 countries. LC's current strategy is focused on ensuring impact between two key pillars: information and advocacy.

Vision

Equity in lymphoma outcomes across borders.

Mission

Enabling global impact by fostering a lymphoma ecosystem that ensures local change and evidence-based action.

Disclaimer

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Summary

"Health literacy is important for all, primarily because it can prevent many health problems. It allows people to take greater responsibility for their own health and the health of their families."[1]

According to the World Health Organization, a globally relevant perspective of health literacy "acknowledges, respects and works within local social and cultural contexts to enable meaningful activities to improve health and equity outcomes." [6] The ability of a person to read and understand written information is an important factor in determining their clinical outcomes, with some experts proposing that health information should be written at no more than an eighth-grade reading level to support optimal impact. [3]

Health literacy is a strong predictor of health outcomes, with low health literacy associated with poorer health status.[4] For people to be knowledgeable about their health and actively engaged in their healthcare journey, health-related information must be credible and accessible. It is becoming more common that people are expected to understand their disease biology, navigate increasingly complicated treatment options, complete paperwork, and participate in decisions that can drive their health outcomes. Individuals are expected to understand complex health-related information to support health decision-making and management.[4] Yet health systems and the methods, tools, and strategies to deliver information regarding health continue to present significant challenges and barriers to individuals with low health literacy. [4]

Health literacy is influenced by the skills or competencies that people possess and the healthcare systems in which they operate. This includes the methods health professionals use to share information, the practical delivery of information and how patients receive and understand health-related information. [1]

Studies show that low or inadequate levels of health literacy are likely to have a negative impact on communication between patients and clinicians. For instance, patients with low health literacy are likely to have less interaction during medical appointments and be less likely to engage in shared decision-making with healthcare professionals.[5] Further, people with low or inadequate health literacy are expected to complete complicated forms or follow prescription instructions without having the skills or abilities to clearly understand the terminology, directions, or content. When this occurs, patient experience and health outcomes may be poorly affected. [4]

Globally, there are different ways to produce, share, and exchange health information across countries, cultures, environments, and settings. [6] Health literacy is often influenced by organisational systems and structures, as well as the availability of resources that enable people to access, understand and use information.

As interest in the field of health literacy and health literacy research continues to grow, the definitions and concepts associated with health literacy continue to evolve. In the past decade, greater interest and focus on interventions that support health literacy in clinical environments have emerged. This promotes greater patient involvement in reaching informed healthcare decisions and improving organisational health literacy in healthcare and delivery of health-related services.

Increasingly, health literacy is approached from two core dimensions, namely individual health literacy and organisational literacy. [1] Individual health literacy focuses on personal health literacy skills or the "ability to find, understand and use health information and understand how to navigate the healthcare system." Organisational health literacy is broadly viewed as "policies, processes and/or materials that directly affect how people engage with the health system." [1]

In today's digital landscape, many patients use social media channels and websites while others seek clinical information from health professionals, source evidence-based scientific information, or contact their community resources. Oftentimes, patient organisations or groups help fill their gap in knowledge, provide practical advice after diagnosis, or offer access to key resources and support systems. [10]

Now, more than ever before, healthcare organisations and health systems that are 'health literate' are playing a critical role in helping people navigate, understand, and use health resources, including applying information to support decision-making, access healthcare services and improve their health outcomes. [7] Research shows that health literacy interventions intended to support individuals and improve patient experience require core components that include improved communication and interactions between patients and clinicians, healthcare professionals and the healthcare system. [8] Healthcare professionals have a vital role in providing information and when done well, may help to increase patient confidence and support shared decision-making.

The World Health Organization's Integrated Conceptual Framework for Health Literacy Development recognises the importance of communication and interaction with health workers as an essential area in advancing health literacy plans and promoting effective ways of learning. It also takes into consideration potential barriers such as service responsiveness, service quality, and cultural safety, as well as information and communication technologies, such as smartphones and other electronic devices. [6]

To support health literate environments, it is crucial that health systems, policymakers, and healthcare professionals understand, consider, and address the key factors associated with population health literacy. It is also important to understand how those factors impact patient experience and contribute to health inequities and disparities. Increasingly, countries around the world are adopting national health literacy policies and implementing strategies to support a systemic approach to improving health literacy within the population. More countries are also addressing health system practices to support better health outcomes for people. [9,1]

Policy and system-level interventions are critical as health literacy is a key contributor to the high cost and demands on healthcare systems. These costs are further intensified by higher rates of hospital admission and medical care services, less effective adherence to medication regimes, complications with chronic conditions and comorbidities, and prolonged periods of recovery. [9] Policy and system-level initiatives that improve health literacy have a direct impact on the improvement of health outcomes and are key to ensuring health literate organisations and healthcare systems. This is especially noticeable among people who struggle to understand and use health resources, services, and health information. [4, 7]

A recent report published by Lymphoma Coalition (LC), Health Literacy in Asia-Pacific National Health Literacy Policies & Strategies in the Region highlights that many countries are focusing resources on improving people's health literacy, establishing health literacy monitoring and evaluation measures, and integrating national health literacy strategies. [1] For instance, China has implemented measures to assess and increase health literacy, greatly increasing the proportion of the population with adequate health literacy from 6% in 2008 to 23% in 2020. Other countries, like Australia, are focusing on improving health literacy environments at the systems level to address low health literacy in 60% of their adult population. [1]

While interventions to support health literate environments are essential, it is also important to understand the impact of health literacy on patient satisfaction and experience. LC conducts a Global Patient Survey (GPS) every two years to understand patient experience in lymphomas, as well as the impact of treatment and care. The 2024 Global Health Literacy Report Card aims to explore health literacy, health literate and care environments worldwide. This includes an examination of GPS data that aligns with the domains of health literacy and patient experience in relation to healthcare information and guidance, as well as communication between the patient and their doctor.
Global research conducted by LC highlighted in this report underscores the significance of patient-doctor communication in healthcare and how communication can either negatively or positively influence patient experience, patient satisfaction and patient understanding across key areas of diagnosis, treatment, and care.

Health Literate Systems

- The way in which healthcare professionals share and deliver information to patients in a clinical setting is a critical component of informed decision-making.
- Low health literacy unfairly affects vulnerable populations in comparison to the general population and leads to challenges in accessing healthcare services, as well as greater degrees of unmet needs.
- Health literacy is a 'whole of society' approach, involving health literacy development, policies, strategies, and interventions that advocate for improved health system responsiveness.
- Spoken and written communication between healthcare professionals and patients is essential to helping patients navigate the healthcare system, inform health decision-making, and promote self-management of their disease.
- Many countries, organisations, and health systems are approaching health literacy and health interventions from two distinct yet interconnected core dimensions – namely, individual health literacy and organisational health literacy.

Patient Experience [10]

- Less than one quarter (18%) of patients felt very well informed about the processes and stages of their healthcare.
- Most patients (78%) in South America reported that their doctor always explains their lymphoma or CLL and care plan in a way they can easily understand, while only 53% reported the same in Asia-Pacific.
- Only two-thirds of patients (66%) reported that they were told their lymphoma subtype at diagnosis, despite lymphoma being a complex disease with more than 80 subtypes.
- When patients in the survey were asked if diagnostic and test results were explained to them by their medical team, 60% said they were explained and they understood them. This leaves 2 out of every 5 patients with incomplete or missing information.
- Overall, patient-reported understanding of terms and language differed across regions. For instance, patient respondents from Europe reported a greater understanding of the term progressive disease (64%) than their counterparts in North America (57%) and Asia-Pacific (49%). The term indolent disease was better understood by patient respondents in North America (50%) than those in Asia-Pacific (49%) and Europe (35%).

Plain Language Summary

Health literacy is an important part of health management and a major contributor to health outcomes. Worldwide, many individuals struggle to understand valuable information that helps them to manage their disease, care, and treatment. This can result in more hospital stays or not being able to correctly follow the advice of their doctor or instructions for medical prescriptions.

Healthcare systems, such as hospitals, medical clinics, and doctor offices, can help individuals by providing reliable information about their disease using language that is easier to understand. Healthcare providers, such as doctors and nurses, play a key role in patient diagnosis, providing care and treatment and improving patient experience. Healthcare providers do this by offering patients important information, asking about their preferences, and involving them in shared decision-making about their healthcare.

Global research conducted by LC points to the importance of doctor-patient communication and highlights the need for doctors to support patient understanding, explain diagnostic tests and results to patients in a way they understand, along with exploring patient preferences and understanding.

Introduction

Increasingly, the relevance and implications of health literacy on social, economic and health outcomes are key factors that emphasise the need to address health literacy rapidly at governmental, policy and health systems levels.

The World Literacy Foundation estimates that in 2024, 1 in 5 people are unable to read at all and approximately 3 billion people worldwide struggle with basic level reading and writing skills that present sizable economic, social and health impacts. [12] Studies show individuals with low health literacy are likely to experience disparities in health and healthcare access in addition to excess hospitalisations or care visits, greater degrees of unmet needs, and poorer knowledge of their disease and medication regimes. Additionally, vulnerable populations are at a greater disadvantage in relation to health outcomes and healthcare access due to factors that include social, structural, historical, and geographical forces. [5]

With increasingly complex healthcare pathways, including care and treatment, the ability to understand medical information is essential as people strive to reach informed health-related decisions. The way in which information is shared or delivered by health professionals to patients in a clinical setting is critically important. Healthcare professionals have a major role to play in providing information that, when done well, is likely to increase patient confidence and support shared decision-making. [4]

Despite growing evidence and acknowledgement of the implications of low levels of health literacy in relation to health conditions, self-management of health, and health outcomes, interventions to measure and improve population health literacy are largely inconsistent. There are variances in practices and policies between regions, across countries, and within communities. [11]

As highlighted in a 2023 report by Lymphoma Coalition that examines current health literacy policies and explores advocacy to improve health literacy that affect system-level change in Asia-Pacific, some countries are implementing policy measures. These practices are helping to speed up the development, planning and implementation of public health strategies, health literacy interventions, and targeted health literacy policies. [11]

Globally, we see a similar trend, with many countries adopting national health literacy strategies to support a universal approach to improving health literacy within the population while helping to address health system efficiencies. [9, 1]

Health Literacy Definitions and Concepts

The definition and concept of health literacy is evolving. A globally relevant health literacy perspective is one that, "acknowledges, respects and works within local social and cultural contexts to enable meaningful activities to improve health and equity outcomes." [6]

Scholarly and research interest in health literacy has increased, primarily over the past five years, with a shift towards focusing on topics that address health literacy measurement, environmental research, public health, and health education. [13] Over the past 30 years, health literacy research and theories were more prominent in Australia, North America, and some Western European countries such as Germany and the Netherlands. More recently, heath literacy research has evolved to include the experiences of different countries, cultural practices, and traditional knowledge and the way in which people learn. There are parts of the world where health decisions are approached jointly and supported by family, community, and/or cultural belief. This is especially relevant in terms of health literacy development in countries where joint cultures dominate, including Africa, Asia, Central and Eastern Europe, the Middle East, much of Oceania and South America. [6]

Today, many countries, organisations, and health systems are approaching health literacy and health interventions from two distinct yet interconnected core dimensions:

- Individual (or personal) health literacy is often defined as, "the degree to which individuals have the ability to find, understand and use information and services to inform health-related decisions and actions." [14]
- Organisational health literacy is often defined as, "the degree to which organisations equitably enable individuals to find, understand and use information and services to inform health-related decisions and actions." [14]

The definition of health literacy has evolved over decades. Increasingly, different definitions specific to the levels of health literacy are used, often expanding to consider and address the broader circumstances and context of making health decisions and receiving care. [15] The Milken Institute report, Health Literacy in the United States Enhancing Assessments and Reducing Disparities, provides a more comprehensive overview of health literacy. [15]

- Functional health literacy relates to basic reading and writing skills necessary to understand health information, including medical prescriptions and labels. [14, 15]
- Interactive health literacy applies to cognitive literacy and social skills necessary to obtain information through communication and apply to scenarios that include participation in conversations with health professionals about health and treatment options. [14, 15]
- Critical health literacy supports individuals as they analyse critical information to inform and help them control determinants of health. [14, 15]

Additionally, the report points to the relationship between health literacy and the ability of an individual to understand health factors, which plays a critical role in how individuals might interact with the environment and health system. [15]

Improving health literacy can improve health equity. The World Health Organization report, Health literacy development for the prevention and control of noncommunicable diseases, Volume 2, A globally relevant perspective, explores the relevancy of four key facets of health literacy in the context of improving health outcomes and equity. (Table 1) [6]

Table 1: World Health Organization Definition of Health Literacy Facets

Community health literacy refers to health literacy knowledge, resources and abilities including health-promoting customs embedded in cultural beliefs and norms, relationships between community and external information sources, and how communities trust and circulate information.	**Health literacy development** refers to how healthcare systems, organisations and policymakers increase knowledge through enabling environments that support people in accessing, understanding, appraising, and using information related to health and healthcare using different oral, written, and digital channels.
Heath literacy of an individual refers to the knowledge, confidence and comfort people accumulate in their day-to-day lives and through social interactions and across generations.	**Health literacy responsiveness** refers to how healthcare systems, organisations and policymakers create enabling environments that accommodate diverse traditions, health literacy needs, preferences that optimize equitable access and promote engagement with health information and services.

Source: World Health Organization (2022)

Health Literate Systems and Environments

Health is a fundamental human right, recognised in 1948 by the World Health Organization (WHO) Constitution and the Universal Declaration of Human Rights. Health is essential to many human rights treaties that have since followed.

The World Health Organization regards health as a "state of complete physical, mental and social well-being, and not merely the absence of disease". [11] Health, and the right to the highest attainable standard of health, is closely intertwined with other rights and includes "both non-discriminatory access to quality, timely and appropriate health services and systems, and to the underlying determinants of health." [16] Additionally, the United Nations Educational, Scientific and Cultural Organization (UNESCO) asserts that literacy is a fundamental human right that, "favours human development as an instrument to improve health." [11]

In 2016, the Global Alliance for Literacy (GAL) was launched within the UNESCO Framework of Lifelong Learning to advance global literacy. The focus was to target countries where the adult literacy rate is below 50% across key areas of shared priority that include a focus on strengthening strategies and policy development in literacy and monitoring progress and assessing literacy skills. In 2020, GAL adopted a strategy to advance literacy and numeracy in member countries by advancing five areas of focus: policy and planning; equity and inclusion; innovation; data and monitoring; and partnerships and cooperation. [11] A report produced by GAL in 2021, Counting the cost: Achieving literacy in countries of the Global Alliance for Literacy, notes that nine member countries were reported to have the highest number of youth and adults with no or low, basic literacy skills, and 14 countries had adult literacy rates below 50% as of 2017. [17] Conclusions in the 2021 report assert that while progress has been made in terms of improving population literacy, the projected costs to reach near universal literacy levels is substantial. Key cost factors include a much-needed financial investment in youth and adult education as well as allocation of funding to support adult literacy programmes, skills training, and lifelong learning. All these areas are impacted by the sustainable development of society and economy and the need for proficient literate populations. [17]

Global State of Population Literacy

The multi-disciplinary field of health literacy has moved outside of solely the medical arena to include public health, social sciences, and other aspects of care that are critical to supporting health and health outcomes. Beyond learning and proficiency in reading, writing, and counting, the scope of literacy is considered much broader with an expanded focus that includes digital skills and media literacy.

Increasingly, individuals are required to rapidly interpret, understand, and communicate in a fast-changing world with new technologies and sources of information. [11] Digital technology and social media are tools that can spread evidence-based health information to educate, inform and help further develop health literacy. However, they can also undermine health information sharing with widespread misinformation that causes confusion and provides conflicting details. [6]

The UNESCO Institute for Statistics (UIS) indicates that global literacy levels have improved with "more than 86% of the world's population knowing how to read and write compared to 68% in 1979." However, statistics show that at least 763 million adults cannot read and write, two-thirds of whom are women. Further, almost one-half of the population with no basic literacy and numeracy are estimated to be living in Southern Asia; 27% living in sub-Saharan Africa; 10% in East and South-East Asia; 9% in Northern Africa; 4% in Western Asia, and approximately 4% in Latin America and the Caribbean combined. [11, 18]

In recognition of the impact literacy levels play in accessing information on health, the environment and the economy, the United Nations Sustainable Development Goals (SDG) Target 4.6 urges the international community to achieve literacy and numeracy "in all youth and a substantial proportion of adults, both men and women" by 2030. [17]

A 2021 report published by the UNESCO Institute for Lifelong Learning highlighted the projected costs associated with literacy in 29 countries. Using a simulation model, the report estimated that the cost of achieving SDG Target 4.6 is US $190 billion in the nine countries that account for 80% of the total cost, namely: Bangladesh, Brazil, China, Egypt, India, Indonesia, Mexico, Nigeria, and Pakistan. Additionally, the report proposed that to reach near universal literacy in 29 countries, an additional US $17 billion is needed, with 85% of the additional funding designated to countries with low performing education systems and poor economic growth. [17]

Global Health Literacy Landscape

Heath literacy is one of three key pillars in the WHO Shanghai Declaration on information (2016) that defines a commitment to recognise health literacy as a critical determinant of health, support intersectoral strategies to strengthen health literacy, increase the ability for people to control their own health, and ensure that environments support health through policies, transparent information and clear labelling.

Noncommunicable diseases (NCDs) are one of the major challenges of the twenty-first century. Health literacy plays a central role in the ability of people to reach health-related decisions and is a key enabler to accelerating progress toward achieving NCD. Targets outlined in the Sustainable Development Goals, primarily by helping to support "people, communities and organisations to understand, recognise and take effective actions to protect and promote their own health." [6]

According to the World Health Organization, improving health literacy in populations is a 'whole of society' approach that involves the need to develop health literacy policies, strategies and interventions that advocate for improved health system responsiveness. [6] To support health literacy development, it is suggested that there are five key actions that people need to take in relation to health information and services: [6]

❶ Access → ❷ Understand → ❸ Appraise → ❹ Remember → ❺ Use

Additionally, to achieve sustainable outcomes in health literacy, a multisectoral approach is essential to shaping environments that are 'health-promoting' across four main levels, namely public policy, and society; organisations; community and interpersonal responses; and individuals.

Some countries around the world have developed health literacy policies aimed toward improving health outcomes and accelerating health literacy progress at national levels, including Austria, Canada, Germany, Norway, Portugal, Scotland, Switzerland, and the United States. Other countries have integrated health literacy policies that focus on establishing multisectoral collaborations and improving communications between healthcare providers and patients to advance health literacy progress, including Australia, China, Israel, New Zealand, Sweden, and Thailand. [6]

In Europe, the European Health Literacy Survey (2009-2012) that was implemented to measure health literacy in the adult population in the region, found limited health literacy reported in a substantive proportion of the general population. In 2019, the World Health Organization conducted a population health literacy survey in 17 participating countries to investigate general health literacy as well as communication, digital health literacy and more, using "health literacy and health-related quality of life as a mediator for health costs." [19] Survey results confirmed that disadvantaged vulnerable subpopulations reported lower general literacy and health literacy levels, experiencing poor self-perceived health and financial deprivation. [20] A set of recommendations were presented based on the survey findings including a focus on health policy to measure and monitor health literacy regularly, interventions to improve health literacy in relation to mental health, strategies to help make systems more health literate and user-friendly, research to analyse data in greater detail, and interventions to improve communication between health professionals and patients. [19]

The WHO Action Network on Measuring Population and Organizational Health Literacy (M-POHL) project measures organisational health literacy in hospitals and primary care organisations in Europe, in addition to connecting research with evidence-based policy and practices. M-POHL aims to "enhance health literacy in the WHO European Region by ensuring the availability of high-quality and internationally comparative data to support evidence-based political decisions and targeted practice interventions." [21] Coordinated by an International Coordination Centre at the Austrian National Public Health Institute, Health Literacy 2024-2026 is a health literacy population survey project of M-POHL. The study population is residents from different participating countries, aged 18 and above.[22] As of 2024, there are 23 participating countries and five observing countries from the WHO European Region.

Health Literate Care

Healthcare information, healthcare delivery and navigating health systems present challenges for individuals with limited health literacy. To support patient outcomes and improve patient experience, spoken and written communication between healthcare professionals and patients – specifically, communicating and confirming patient comprehension of information – is essential to help patients navigate the healthcare environment, health decision-making, and self-management. [24]

To ensure that patients have access to resources they understand, healthcare professionals must apply their knowledge, skills, and practices to support a health literate environment where all patients thrive. [24] Resources such as the Agency for Healthcare Research and Quality (AHRQ) Health Literacy Universal Precautions Toolkit provide healthcare professionals with evidence-based guidance to help improve spoken and written communication; encourage self-management and empowerment of patients and promote supportive systems.(Figure 1)

Figure 1: Health Literacy Knowledge and Skills for Health Professionals

To Improve Spoken Communication	To Improve Self-Management and Empowerment
• Communicate clearly • Use the teach-back method • Follow up with patients • Conduct Brown Bag Medicine Reviews • Address language differences • Consider culture, customs, and beliefs	• Encourage questions • Make action plans • Help patients plan • Help patients remember how and when to take their medicine • Get patient feedback
To Improve Written Communication	**To Improve Supportive Systems**
• Access, select, and create easy-to-understand materials • Use health education material effectively • Welcome patients by reducing literacy barriers	• Link patients to non-medical support • Direct patients to medicine resources • Connect patients with literacy and math related sources • Make referrals easy

Source: AHQR Health Literacy Universal Precautions Toolkit (https://www.ahrq.gov/health-literacy/quality-resources/tools/literacy-toolkit/index.html)

The health literacy level of healthcare professionals is also an important factor. In addition to medical knowledge and clinical skills, statistical literacy (or the ability to critically appraise and apply medical literature) is widely integrated into research. The relevancy and application of statistics also extends to clinical practice and patient-physician encounters.[20] As the field of medicine rapidly evolves and changes, the ability for health professionals to succinctly appraise, assess and apply medical or health literature to support evidence-based patient care requires statistical literacy. [20]

Statistics form an important part of the knowledge base for healthcare professionals, from researching literature to conducting studies. [25] The integration of statistical literacy in evidence-based clinical practice can be improved with the inclusion of statistical literacy training in educational curriculums and programs for health professionals. [26]

A three-year study of 163 students conducted in the United States by the University of Kentucky, College of Health Sciences evaluated a curricular model for statistical literacy that examined and explored ways to embed statistical applications in medical curriculums, with a focus on key areas such as research questions, biostatistical methods interpretation, access and of medical literature, and the evaluation and application of research. [26] With the medical landscape requiring healthcare providers to be knowledgeable and skilled in statistical literacy, study conclusions pointed to the requirement of healthcare providers to be proficient in identifying the best evidence to support and ensure patient care, and for education programs for health professionals to include statistical literacy as an integral curriculum component. [26]

Case Study: Health Literacy in the United States

According to the United States Census Bureau, there are more than 335 million people living in the United States making it the third most populous country in the world and yet, only 12 percent of adults in the country are proficiently health literate. [15]

Health literacy is a key driver of health outcomes. Studies show that adults with lower health literacy are more likely to have trouble completing forms and understanding prescribed medication labelling, with adults aged 65 and older having the lowest health literacy levels. The difficulty adults experience in relation to print materials and documents, as well as functional challenges in accessing health information and using e-Health tools, may be key factors. [15] Other factors that are likely to contribute to health literacy include race/ethnicity, culture, socioeconomic status, insurance coverage, education, and the choice or sources of information that adults use for health purposes. [15]

In 2003, the first and only population-wide national assessment of health literacy in the United States was conducted. Over 19,000 adults from 38 states participated in the assessment that measured how well Americans performed real-world tasks based on printed health information, including how they interpreted directions for taking medicines. The National Assessment of Adult Literacy (NAAL) findings concluded that approximately 77 million people in the United States (over a third of the adult population) experience difficulty following directions on a prescription drug label due to basic or below basic health literacy. Lower health literacy skills were more evident in adults who were publicly insured or uninsured in comparison to those with private insurance.

Additionally, the Programme for the International Assessment of Adult Competencies (PIAAC), also referred to as the Survey of Adult Skills, measures the proficiency of adults across three core dimensions of literacy, numeracy and digital problem-solving. Developed initially by the Organisation for Economic Cooperation and Development (OECD), it is a cyclical study of adult cognitive skills that was first conducted in 2011. In the United States, in 2018, the mean literacy score for adults in the country ranked higher (271) than the OECD average of 266. Between 2012 and 2017, no significant overall changes in the number of adults in the United States (age 16 to 65) was evident with respect to proficiency in literacy, with 19% of adults with a Level 1 literacy (or the lowest level of literacy) and 48% with a Level 3 literacy (or above). [27]

Health Literacy Initiatives: Healthy People 2030

First introduced in 1979 following a landmark report from the Surgeon General, the United States Department of Health and Human Services' (HHS) Healthy People 2030 Initiative recognises the importance of health literacy by declaring health literacy a foundational principle and addressing it from both a personal and organisational perspective.

Building on the knowledge and lessons learned in response to public health priorities, Healthy People 2030 highlights the need to eliminate health disparities by attaining health literacy in addition to promoting the need for health organisations to responsibly support patient understanding of health information. [3, 28] Healthy People 2030 actions focus on key areas that include setting measurable objectives to guide evidence-based policies that are scalable and replicable, ensuring accurate data is accessible, fostering community impact to improve health and well-being, and stimulating research and innovation. [29]

According to the Centers for Disease Control and Prevention National Center for Health Statistics Healthy People 2020 Final Review, more than 73% of the targets associated with health communication and health information technology goals were met and/or exceeded with the movement toward reaching the target deemed to be statistically significant.[30]

Additionally, as highlighted in a 2023 report produced by the Milken Institute, there are six Healthy People 2030 objectives in health literacy. As of 2017, HHS statistical data reports that two of the six objectives were below the target range. First, the objective to increase the proportion of adults whose healthcare provider checked their understanding of health literacy had a baseline (% of adults) of 26.6%, below the target of 32.2%. Second, the objective to increase the percentage of adults whose healthcare providers involved them in decisions as much as they wanted indicated a baseline of 52.8%, below the target of 62.7%. [15] (Figure 2)

With respect to the Healthy People 2030 objective to decrease the proportion of adults who report poor communication with their healthcare provider, many people continue to experience difficulty in communication. Almost 9% of adults in the United States (aged 18 years and older) reported poor provider communication related to areas such as listening, explanations, disrespect, and time. [15]

As noted by the Milken Institute, three objectives remain in the development stage, namely:

1. Increase the proportion of persons who report their healthcare providers always listened carefully to them.
2. Increase the proportion of adults with limited English proficiency who say their providers explain things clearly.
3. Increase the health literacy of the population. [15]

Figure 2: Six Healthy People 2030 Objectives in Health Literacy.

Objectives	Baseline (% of Adults)	Target
Increase the proportion of adults whose health care provider checked their understanding	26.6% (2017)	32.2%
Decrease the proportion of adults who report poor communication with their health care provider	8.9% (2017)	8.0%
Increase the proportion of adults whose health care providers involved them in decisions as much as they wanted	52.8% (2017)	62.7%
Increase the proportion of persons who report that their health care providers always listened carefully to them	Developmental status	
Increase the proportion of adults with limited English proficiency who say their providers explain things clearly	Developmental status	
Increase the health literacy of the population	Developmental status	

Source: Milken Institute (2023).

Plain Language in Healthcare

In 2010, the Plain Writing Act, 2010 was signed into law in the United States requiring federal agencies to use clear communication that can be understood. In recognition that people with limited health literacy skills benefit from the use of plain language, the Act ensures health information is more easily understood, concise and jargon-free. The Plain Language Action and Information Network was tasked with the development of guidelines and continues to assess and revise the federal plain language guidelines.

The HHS 2020 Plain Writing Act Compliance Report highlights national examples of compliance in healthcare. For instance, the Centers for Medicare & Medicaid Services produced a handbook to help more than 40 million beneficiary households across the country understand complex Medicare benefits by using plain writing. Other divisions and agencies introduced specialised training for employees and staff on plain writing, including the National Institute for General Medical Services. [30]

The HHS also produced the National Culturally and Linguistically Appropriate Services (CLAS) Standards to advance health equity, improve quality and help eliminate health care disparities. The National CLAS standards provide a blueprint for health and healthcare organisations to help ensure that effective, equitable, understandable, and respectful care and services are responsive to cultural health beliefs, preferred languages, health literacy, and other needs. The Standards focus on three core areas: (1) Governance, Leadership and Workforce (2) Communication and Language Assistance (3) Engagement, Continuous Improvement and Accountability.

The Patient-Centered Outcomes Research Institute (PCORI) is an independent, nongovernmental organisation that helps patients and healthcare providers make informed decisions about healthcare choices. Supported by the translation efforts of the PCOR Translation Center, PCORI translates health research findings into plain language summaries that are easy for patients and the public to understand and useful in helping inform their healthcare decisions. [31]

Health Literacy Measurement Tools

Funded by the National Institutes of Health's National Library of Medicine, the Health Literacy Tool Shed is an online database of health literacy measures that provides information about health literacy measurement tools. Most health literacy measures found in the Health Literacy Tool Shed database focus on use of the Test of Functional Health Literacy in Adults, a tool that is commonly used to assess health literacy in the healthcare setting by measuring reading comprehension and numeracy literacy.

The Agency for Healthcare Research and Quality uses different tools to measure the reading comprehension of individuals in a medical context. Two of the tools commonly used by AHRQ include:

- The Rapid Estimate of Adult Literacy in Medicine-Short Form (REALM-SF). The REALM-SF is used in a clinical setting to help identify patients with limited literacy, applying a 7-item word recognition test to provide clinicians with a valid quick assessment of patient health literacy.

- The Short Assessment of Health Literacy-Spanish and English (SAHL-S&E), a tool that presents different test terms for people to read aloud before choosing a word they perceive to be closer in meaning from two options. The SAHL-S&E helps to measure both comprehension and pronunciation of health-related terms. [32]

Case Study: Population Health Literacy Measurement in China

Currently, there are more than 1.4 billion people living in China, 17.76% of the total world population - making China the second most populated country in the world. [33] In 2021, the health literacy level in the country was 25.4% with an estimated 75% of the adult Chinese population (ages 16-69) lacking the capacity to obtain, understand and act on health information despite health literacy levels increasing over the years. [8]

The concept of health literacy was introduced in China in 2005, changing the profile of health literacy in the country significantly between 2008 to 2020 due, in part, to policies and strategies focusing on improving the individual health literacy of citizens. [34]

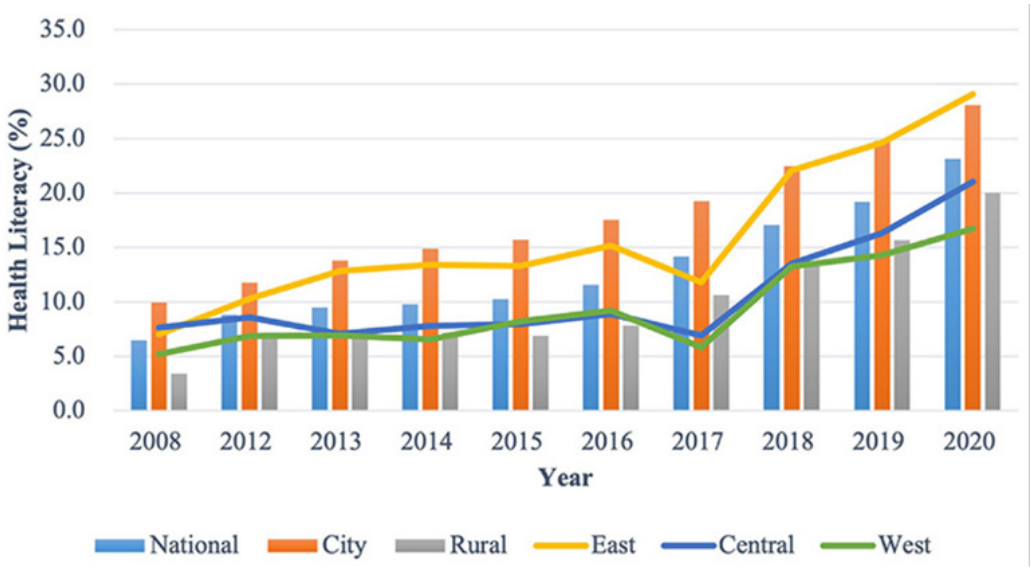
To measure health literacy, the Chinese Health Literacy Scale is used, developed by experts from policy, health and clinical medicine and designed based on the Chinese Resident Health Literacy – Basic Knowledge and Skills (Trial) that was issued in 2008 by the National Health Commission of the People's Republic of China. The scale contains three basic domains:

1. Basic knowledge and attitudes
2. Healthy behaviour and lifestyle
3. Health-related skills

A 2022 study of the development and progress of health literacy in China between 2008 to 2020 indicates that levels have increased, growing from 6% of the population in 2008 to 23% in 2020. The study found that people living in cities reported higher adequate health literacy than those residing in rural areas, and health literacy of those in the Eastern region of the country were higher than those in Central and West China. [34]

The following figure illustrates the distribution of the overall health literacy level in China, by year and region, showing an increase from 6.48% to 23.15%, reflecting an average annual growth rate of 1.13%. [34] The following figure illustrates higher health literacy levels in the city with an increase from 9.94% to 28.08%. Similar growth is found in the rural areas increasing from 3.43% to 20.02%.

Figure 3: Distribution of overall health literacy level in China. [34]



This change was achieved by first establishing a National Plan of Health Literacy Promotion Initiatives for Chinese Citizens (2008-2010). China also published an initial policy paper to guide the implementation of health literacy initiatives across the country and improve population health literacy. [1]

In 2014, the 12th Five-Year Plan for the public health service system in China lead to the Action Plan to Promote Health Literacy (2014-2020) with the objective to raise the national health literacy level to 20% by 2020. [1] That same year, the National Health Literacy Promotion Action Plan (2014-2020) aimed to build 'health promotion counties' across China as targeted populations – schools, hospitals communities and more - shared common cultures, values, and health promotion needs. [1]

Healthy China 2030

Healthy China 2030 is the most recent national health strategy for China, cementing the integration of health in all policies and ensuring that health is a national policy priority. [36] There are several initiatives to meet health literacy targets. [1] Healthy China 2030 is based on four key strategic pillars, with health literacy as a prominent evaluation indicator.[1]

1. Equitable access and outcomes in health and healthcare.
2. Healthcare systems transformation.
3. Technology and innovation.
4. Environmental and climate sustainability.

A 2022 study of the economic costs of limited health literacy in China based on evidence from the National Health Literacy Surveillance data points to limited health literacy contributing to rising healthcare costs in the country. In China, the first National Health Literacy Surveillance survey conducted in 2008 surveyed approximately 80,000 residents across 31 provinces, aged 15-69 as part of a national health literacy promotion effort with annual funding of (at least) 40 million USD. [37]

As highlighted in a 2023 report by Lymphoma Coalition, Health Literacy in Asia-Pacific National Health Literacy Policies & Strategies in the Region, China is the only country in Asia-Pacific to undertake population health surveys on an annual basis, providing essential data to track gains in health knowledge and skills. [1]

Case Study: Health Literacy in South America

Brazil

In South America, Brazil experiences health system challenges that impact access to high-quality, affordable, and universally accessible care. Despite the increasing global awareness of health literacy as a driver of health outcomes, there are very few research studies that specifically address health literacy measurement in the population, or studies that closely examine health literacy intervention in the country. One of those few studies, a 2022 consensus study, conservatively estimated the level of inadequate health literacy in specific populations, namely those with chronic diseases and the elderly, is between 45% to 66%. [38]

Healthcare delivery in the country

In 2020, the population of Brazil was 213 million people. Today, that number has increased to more than 217 million.[2] With 62% of the population aged 29 or under, current growth projections suggest that the population of Brazil will reach its peak of 229 million people by 2045.[39]

In the context of health literacy and healthcare delivery, bridging cultural and language barriers is often challenging for health leaders and healthcare professionals to address. This affects and can hinder the degree to which people understand health information and navigate increasingly complex healthcare systems. Additionally, health literacy is often a key contributor to inequities and barriers that disproportionately affect people, particularly those individuals most impacted by socioeconomic factors and geographic isolation. [40] According to a 2019 cross-sectional study that assessed functional health literacy in Brazil, 27% of caregivers reported having trouble understanding health information due to inadequate level of health literacy. Further, the study noted that a higher proportion of caregivers with lower education had inadequate or marginal health literacy. [41]

In 1988, Brazil launched the Unified Health System (SUS), one of the "largest and most complex public health systems in the world" tasked with providing primary and specialised care, and ensuring the population has comprehensive, universal, and free access to healthcare services. [42] However, despite the provision of free healthcare and efforts to improve access to healthcare services and resources across the country, concerns regarding quality of care, shortages of healthcare professionals, and inadequate training for the healthcare workforce persist. [43] With high levels of inadequate health literacy, healthcare professionals in the country experience challenges in meeting and satisfying the needs of health service users. Health literacy interventions suggest that to effectively construct literate health teams in clinical settings, a model of healthcare professional competencies in relation to health literacy would be of benefit. [38]

Within the SUS, the primary health model is the Family Health Strategy (FHS). Created in 1994, FHS provides primary care, coordinates coverage at both secondary and tertiary levels, and implements health promotion strategies, including community services that aim to improve access and increase understanding of health services, resources, and health-related information.[44]

Colombia

In the 1990's, Colombia's public healthcare system underwent significant reform when Law 100/1993 was passed with the aim of ensuring universal health coverage for all. By changing the healthcare system, Colombia has steadily improved population health across the country, primarily by advancing healthcare reform across two pillars: (1) the right of all citizens to health; (2) the decentralised organisation of health services. [45]

Healthcare system reform and access to insurance

Today, there are more than 52 million people living in Colombia, with most (70%) between the ages of 15-64. [46] Prior to 1993, only 25% of the population had access to health insurance. By 2013, with the introduction of mandatory social health insurance as part of the system reform strategies, 96% of the population had access to health insurance with more than half covered by the subsidised system that is funded mostly through general taxation. [48]

Although Colombia's reform of their healthcare system supported greater access to services and resources, and with the more recent 2022-2031 Ten-Year Public Health Plan that establishes a policy roadmap based on social protection and health, challenges in addressing the burden of health inequalities across the country persist. [47]

Despite the focus on health literacy as a national priority, evidence on health literacy levels in the country is lacking. As very little is known about the relationship between health-related quality of life and health literacy amongst those with subsidised health insurance coverage (those with lower incomes) and contributory coverage (those with higher incomes), a study to evaluate the effects of health insurance and health literacy amongst adults was conducted across six primary care clinics in Colombia. The six participating clinics represented urban, suburban, and rural settings. Additionally, some participants reported other types of health insurance while others did not provide complete data for inclusion in the analysis.

Study results showed that adults with contributory coverage reported higher levels of health literacy than those with subsidised coverage however, health related quality of life showed no difference based on insurance type. The study suggested that further improvements to health-related quality of life might be achieved by targeting skills such as the interpretation of medical information and completion of health-related forms. [48]

Health Literacy Experience of Patients with Lymphoma

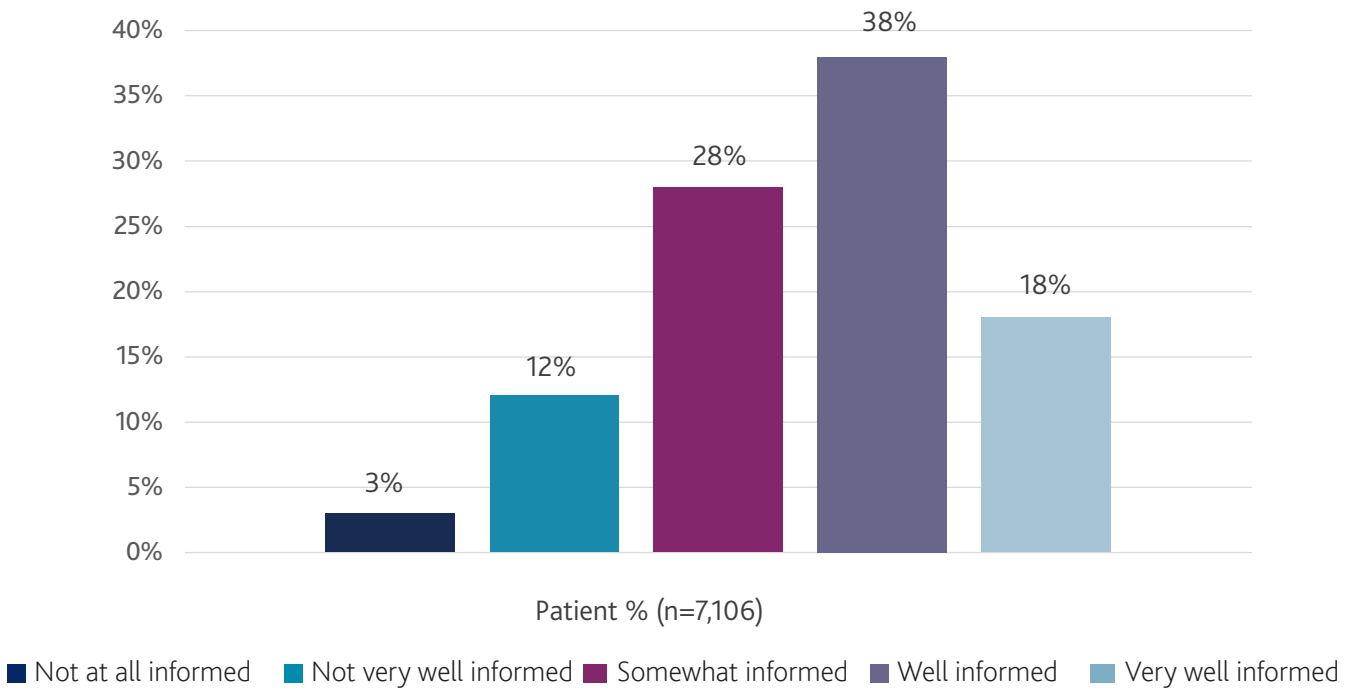
The real crux of the importance of health literacy is how it helps a patient function and cope during a complex and stressful time, within an environment they probably had little experience with prior to their diagnosis. Patients with cancer must adapt quickly to what is physically happening to them, while learning new medical language, trying to understand the goals and ramifications of treatment, and coping with the practical logistics of care.

In 2017, LC authored a report The Knowledge Age: Better Outcomes for the Informed Patient. The report concluded that when a patient has knowledge surrounding their condition, treatment options, and self-care practices, patients ask more questions, patient experience is improved, and they are more inclined to be confident in taking a sustained active role in managing their health and condition. It also noted that it is often information, leading to improved interaction with the healthcare system, that fosters this confidence. Important to understand is that having confidence as a patient does not necessarily mean that a patient will experience a better 'health outcome' as defined by clinical research. However, it may mean that they are confident in making the right choice for him/herself—leading them towards 'their good outcome'. [49]

Every two years, LC conducts an online survey to understand current patient experience and the impact of treatment and care. Portions of this in-depth survey continue to focus on the information levels of patients and how that information is obtained and supported. Background information on the survey used in this analysis can be found in the Appendix.

As a starting point for this discussion, in the 2022 Global Patient Survey on Lymphomas & CLL (LC 2022 GPS), patients were asked how informed they felt about the processes and stages of their healthcare (e.g., diagnosis, treatment, resources available for support and self-care) throughout their experience with lymphoma or CLL. Of the more than 7,100 responses, over half (56%) of patients felt well- or very-well-informed, 40% felt they had some information, but it was lacking, and 3% felt completely uninformed. (Figure 4)

Figure 4: How informed have you felt about the processes and stages of your healthcare throughout your experience with lymphoma or CLL? (Global)

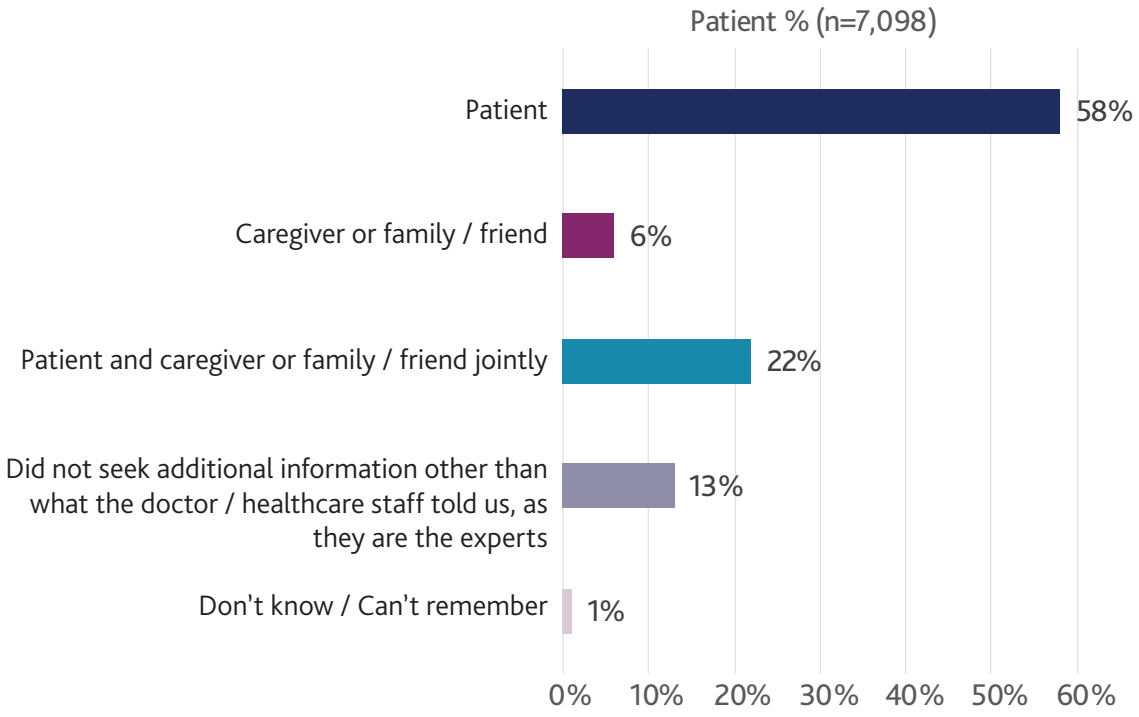


This is important data but there are a lot of nuances that must be considered to get a true reflection of the situation for patients with lymphoma.

Patients can possess varying levels of individual drive to become informed, influenced by the specificities of their condition and personal preferences. For each individual, the capacity and desire to learn will be different. [49] For some, attempting to navigate through a multitude of constantly evolving information can become a source of stress and despair. For others, failing to remain comprehensively informed will elicit this same response. It cannot be assumed that every patient will want to know everything about their disease. [49]

Despite this potential stress, most patients and/or their loved ones do seek out additional information about lymphoma. Only 13% indicated they didn't seek out any information other than what was provided by the healthcare professionals. (Figure 5)

Figure 5: Following the lymphoma or CLL diagnosis, who was seeking out information and details about the disease and potential treatments?



Studies suggest significant correlations between education level and health literacy, and between ethnicity/race/socioeconomic status and health literacy. Low health literacy is observed more frequently among those with fewer years of formal education (or lower quality education), minority ethnic groups, older adults, those who lack internet access, and those in a lower income bracket. [50, 51] Important to note is that many studies explain that limited health literacy persists even among those with adequate, or above adequate general literacy and comprehension skills. [52, 53, 54]

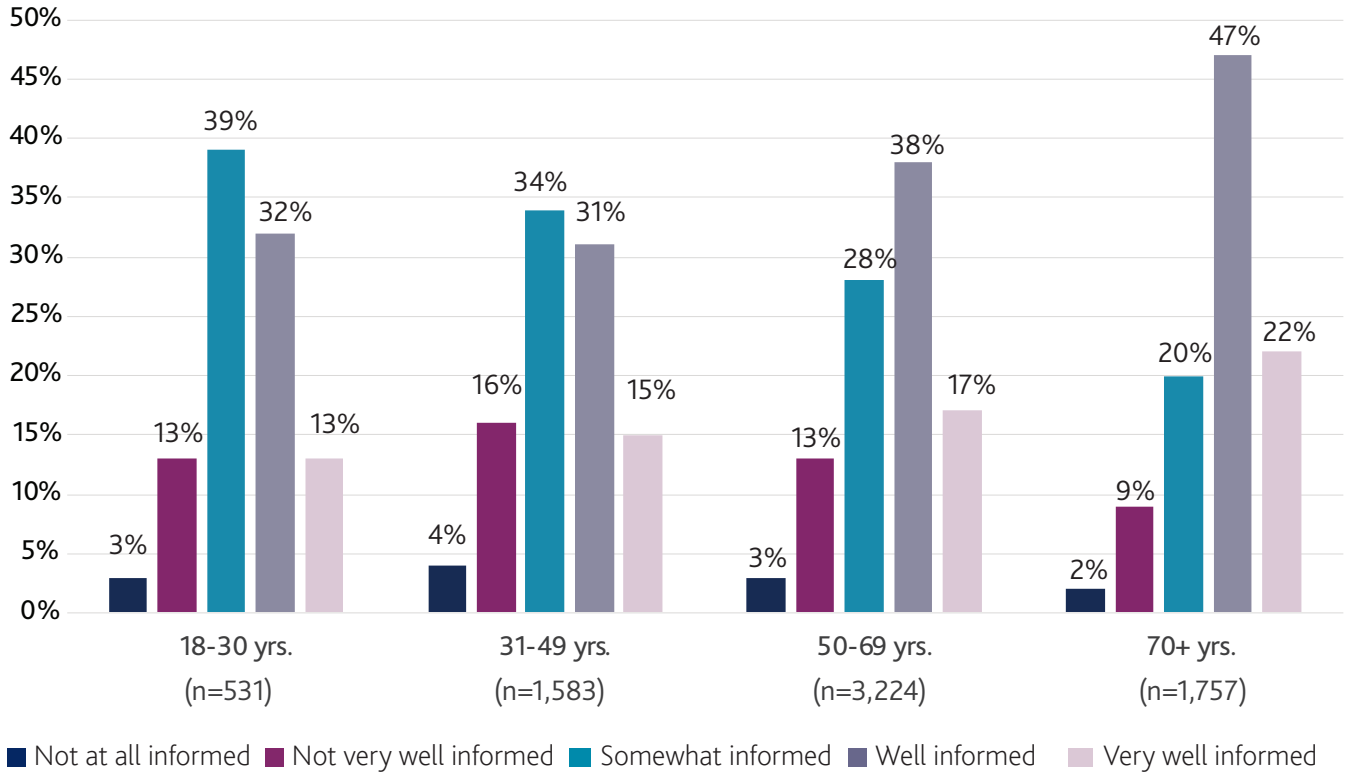
Most respondents of the LC 2022 GPS were well educated, with 70% having attended university or college, including 1 in 5 respondents having an advanced degree such as a Masters or PhD. Yet, only just over half of total survey respondents felt well informed.

To check understanding of their disease, the LC 2022 GPS asked if patients with CLL understood certain common terminology related to their disease outcomes. There were some variations by education-level of the respondents. A higher proportion of patients with a postgraduate degree (71%) reported that they completely understood the term 'stable disease' compared to 54% of patients who reported high school as their highest level of education. Overall, very few respondents indicated that they didn't understand the meaning of 'stable disease' at all. Most had a partial understanding.

Those with a secondary (54%), post-secondary (62%) and postgraduate (72%) level of education reported completely understanding the term 'progressive disease'. Only 6% of those with a post-graduate education reported having no understanding of the term and 2% reported that they had heard the term, but do not fully understand it. Comparatively, 15% of patients with only a primary education reported that they didn't understand the term progressive disease, 27% reported that they heard the term and partially understood, and 58% indicated that they completely understood. The percentage of patients completely understanding was higher for those with a primary education than those with a secondary education, pointing to factors other than schooling influencing the level or degree of understanding.

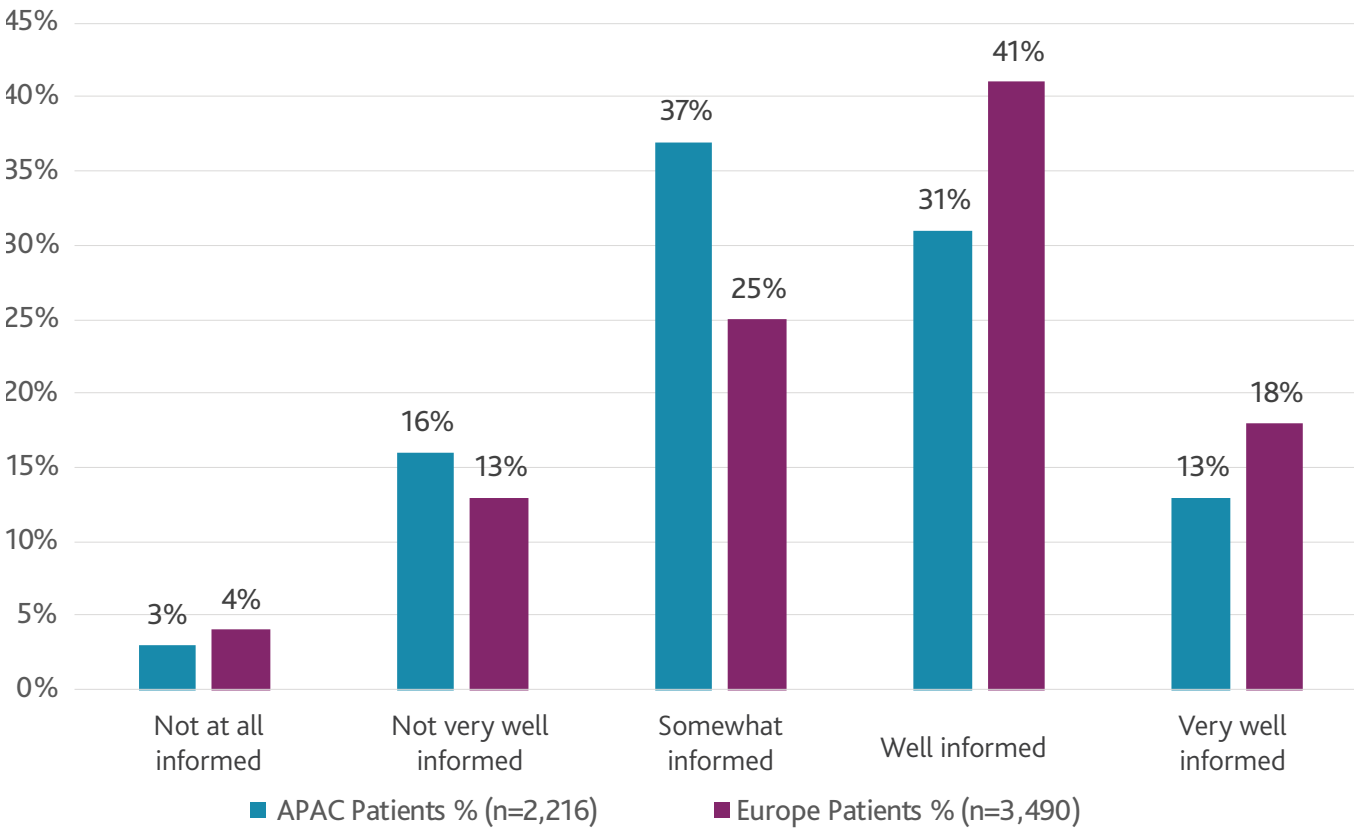
The LC 2022 GPS does include a significant number of responses from those age 70 years and above, who represent 25% of the total dataset. Even though older age has been associated with low health literacy, the respondents aged 70 years and above reported being the best informed of all the age groups. (Figure 6)

Figure 6: How informed have you felt about the processes and stages of your healthcare throughout your experience with lymphoma or CLL? (by age group)



The LC 2022 GPS also shows fluctuations by region. Using Asia-Pacific and Europe as examples, 59% of European patients felt well- or very-well-informed, compared to 44% of those living in Asia-Pacific. Many factors affect one's ability, or even willingness to seek information, including local culture and values, healthcare systems, local access to care, and the subtypes of lymphoma most prevalent in the regions. Racial, cultural, and ethnic disparities in healthcare have been well described. (Figure 7)

Figure 7: How informed have you felt about the processes and stages of your healthcare throughout your experience with lymphoma or CLL? (Regional)



Geographically, there were also some differences in understanding of common terms used in CLL to describe outcomes. A higher proportion of patients with CLL in North America (72%) and Europe (66%) reported that they completely understood what 'stable disease' meant compared to those in Asia-Pacific (53%). Additionally, 64% of patients with CLL in Europe reported that they completely understood the term 'progressive disease' in comparison to 57% in North America and 49% in Asia-Pacific. (Table 2)

Table 2: Understanding of CLL terminology by region

	Asia-Pacific (n=129)	Europe (n= 501)	North America (n=60)
Do you understand the term 'Stable Disease'?	%	%	%
No	11%	7%	10%
I have heard the term, but don't understand it	4%	3%	2%
Yes, I partially understand	33%	25%	17%
Yes, I completely understand	53%	66%	72%
	Asia-Pacific (n=117)	**Europe (n=498)**	**North America (n=60)**
Do you understand the term 'Progressive Disease'?	%	%	%
No	9%	10%	12%
I have heard the term, but don't understand it	5%	4%	2%
Yes, I partially understand	37%	21%	30%
Yes, I completely understand	49%	64%	57%

Subtype is an important factor to consider as lymphoma is complex. It is a varied group of cancers that originate in white blood cells. Lymphoma is often categorised into three major groups:

1. Chronic lymphocytic leukaemia (CLL)
2. Hodgkin lymphoma (HL)
3. Non-Hodgkin lymphoma (NHL)

When first diagnosed, many patients are informed they have NHL. However, NHL is not a disease – rather, it is a series of more than 80 lymphoma subtypes, some indolent (slow-growing), others aggressive (fast-growing), each presenting different epidemiology, diagnostic evaluation, treatment protocols, indications, outcomes and more. Treatment options for the different subtypes take into consideration several key factors including clinical staging, grade, and type of lymphoma, as well as patient characteristics such as symptoms and age. [55] Patients really need to understand their specific subtype to find relevant information. Patient knowledge of lymphoma subtype supports informed advocacy and helps patients understand their specific care pathway. [56]

To delve further into the impact subtype can have on patient information, this report spotlights six different lymphoma subtypes originating in B-cells and seven types of T-cell lymphoma, to give a perspective of how diagnosis influences patient experience. (Table 3) Both B-cells and T-cells are types of white blood cells that can become cancerous in lymphoma.

B-cell lymphomas are much more frequently diagnosed, with T-cell lymphomas accounting for approximately 10% of all cases of lymphoma. There are geographic differences, with T-cell lymphomas more common in Asia, while B-cell lymphomas are more common in the Western world. B-cell lymphomas are more likely to appear in the lymphatic system, while T-cell lymphomas are more likely to occur in other parts of the body like the skin or the nasal cavity. In general, indolent or slow-growing lymphomas are considered incurable with high rates of relapse, and the goal of treatment being life extension. Patients with an indolent lymphoma often cycle through periods of treatment, and periods off-treatment where they are actively monitored by their medical team to determine when further treatment is needed. Aggressive or fast-growing lymphomas require treatment right away, with the goal being cure. Within this group, outcomes vary, and long-term survival rates can be good in some subtypes, like Hodgkin lymphoma, and poor in others, like extranodal NK T-cell.

Table 3: Lymphoma Subtype Overview

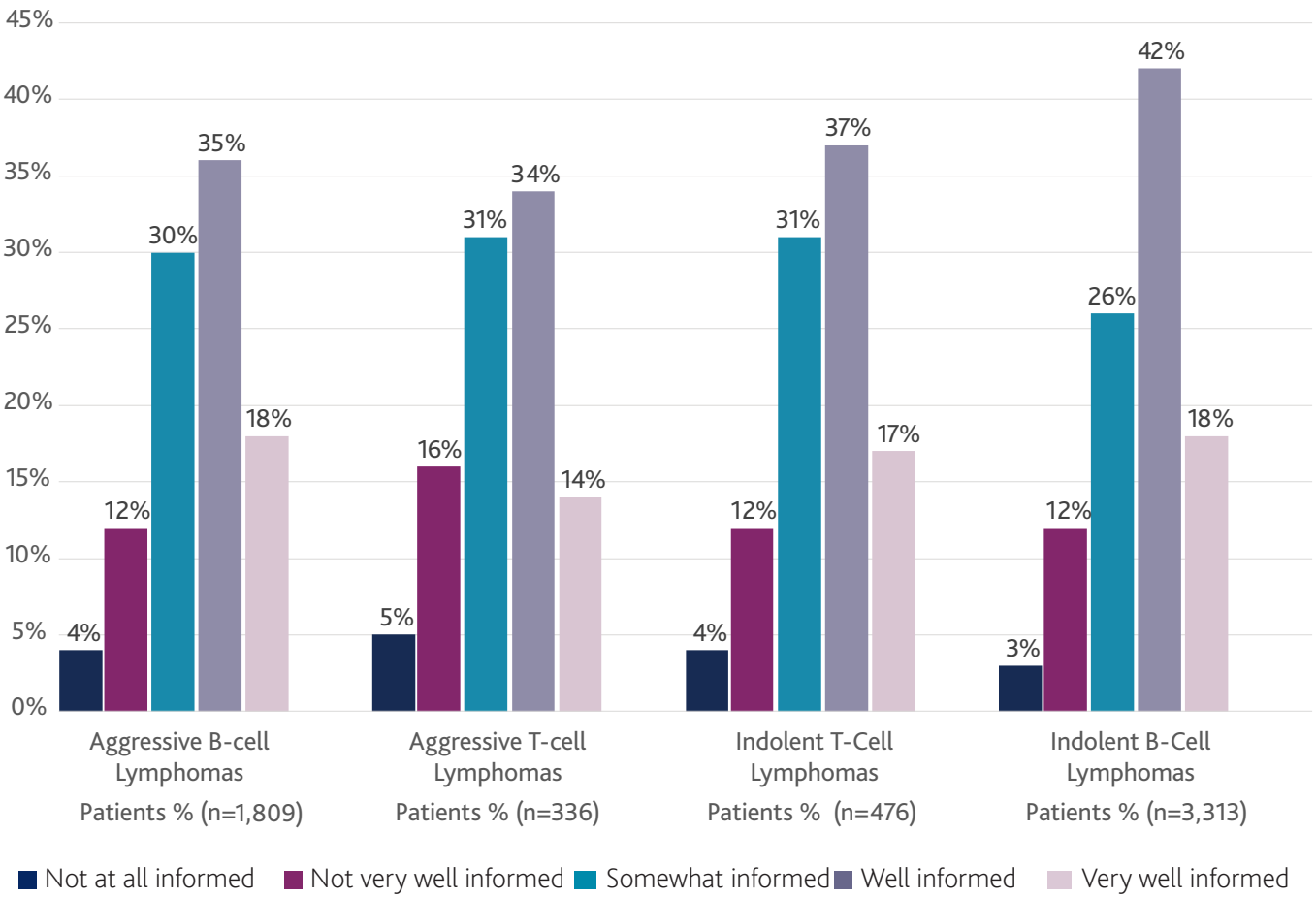
Cell of Origin	Lymphoma Subtype	Subtype Acronym	# of Patient Respondents	Usual Behaviour*
B-cell	Chronic lymphocytic leukaemia/small lymphocytic lymphoma	CLL/SLL	1,300	Indolent
B-cell	Diffuse large B-cell lymphoma	DLBCL	959	Aggressive
B-cell	Follicular lymphoma	FL	1,132	Indolent
B-cell	Hodgkin lymphoma	HL	851	Aggressive
B-cell	Mantle cell lymphoma	MCL	231	Both
B-cell	Waldenstrom's macroglobulinemia/lymphoplasmacytic lymphoma	WM/LPL	885	Indolent
T-cell	Breast implant associated anaplastic large cell	BIA-ALC	13	Indolent
T-cell	Extranodal NK T-cell	ENKTL	85	Aggressive
T-cell	Cutaneous lymphoma	CL	518	Both**
T-cell	Anaplastic large cell lymphoma	ALC	55	Aggressive
T-cell	Adult T-cell lymphoma/leukaemia	ATL	82	Aggressive
T-cell	Angioimmunoblastic T-cell	AITL	28	Aggressive
T-cell	Peripheral T-cell	PTCL	33	Aggressive

*Note: This refers to the average disease behaviour based on large datasets over time. LC acknowledges individual patient experience may vary.

**Syzary syndrome is aggressive while mycosis fungoides and other cutaneous lymphomas are indolent diseases

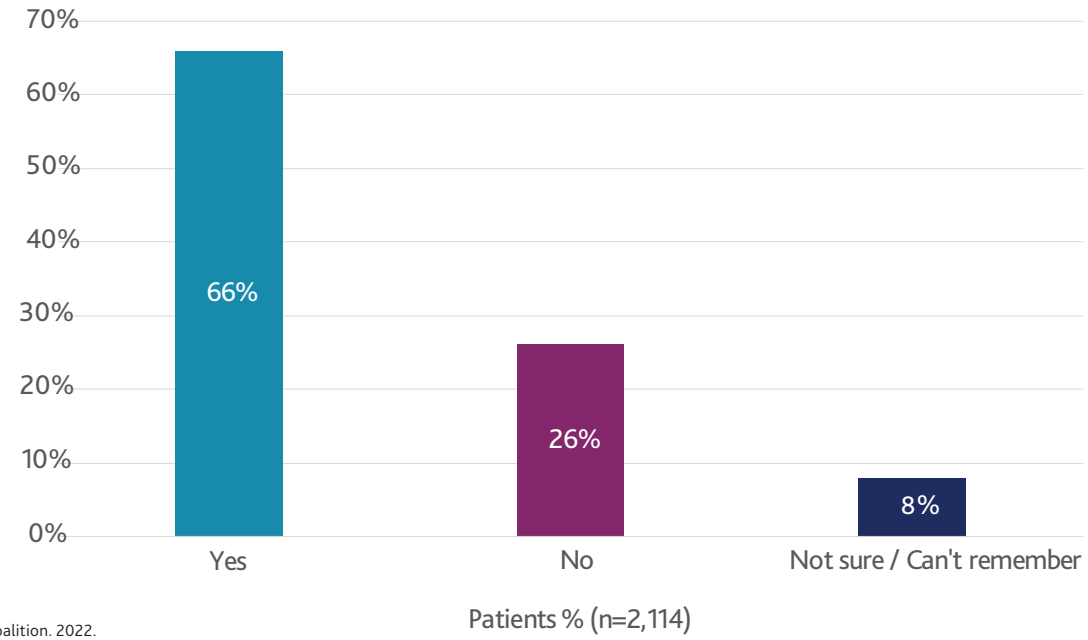
For the rarer subtypes of lymphoma, the understanding of the disease and its treatment are not as well researched, and it can be more difficult for patients to find credible information. This correlates with what the survey data showed. Patients diagnosed with an aggressive T-cell lymphoma are more likely to not feel well informed.

Figure 8: How informed have you felt about the processes and stages of your healthcare throughout your experience with lymphoma or CLL? (By Subtype)



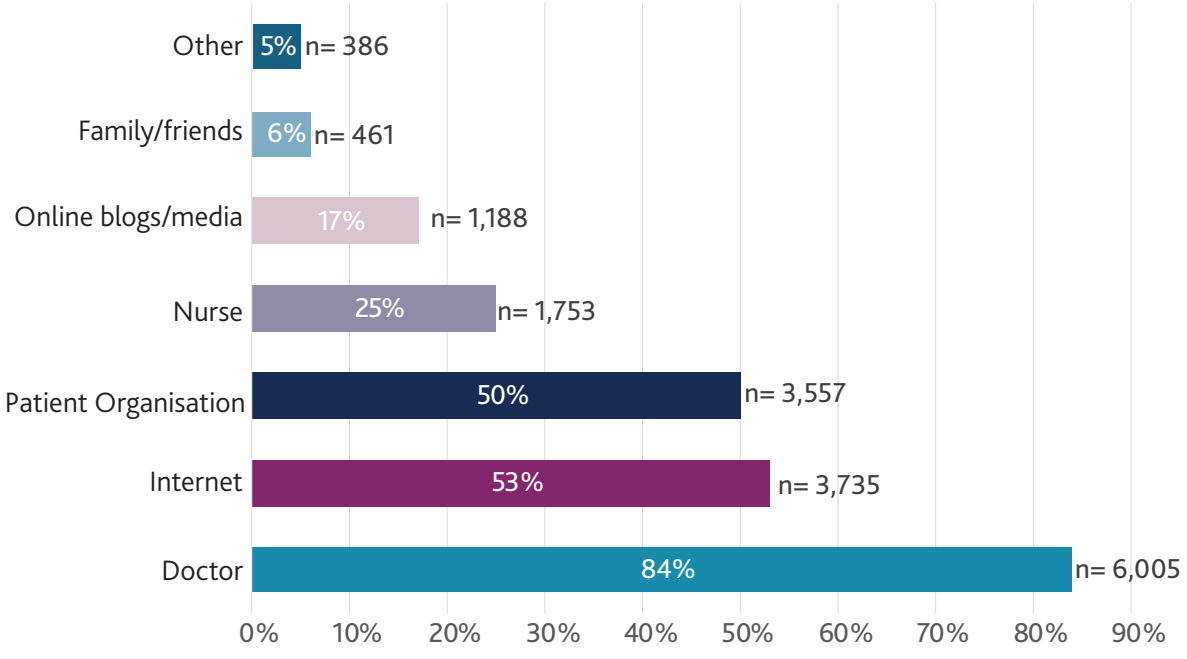
In the LC 2022 GPS, 66% of patients were told their lymphoma subtype when first diagnosed, down slightly from the 70% of patients told the same information in the LC 2020 GPS results. [10] This means a third of patients, if searching for knowledge about their condition, would be limited in their ability to find information that applies to them. With the broad spectrum of lymphoma subtypes, if they searched more generic terms like lymphoma or NHL, a good portion of the information found would not be relevant and may confuse or worsen their situation if they act on these learnings.

Figure 9: When first diagnosed, were you told the lymphoma subtype?



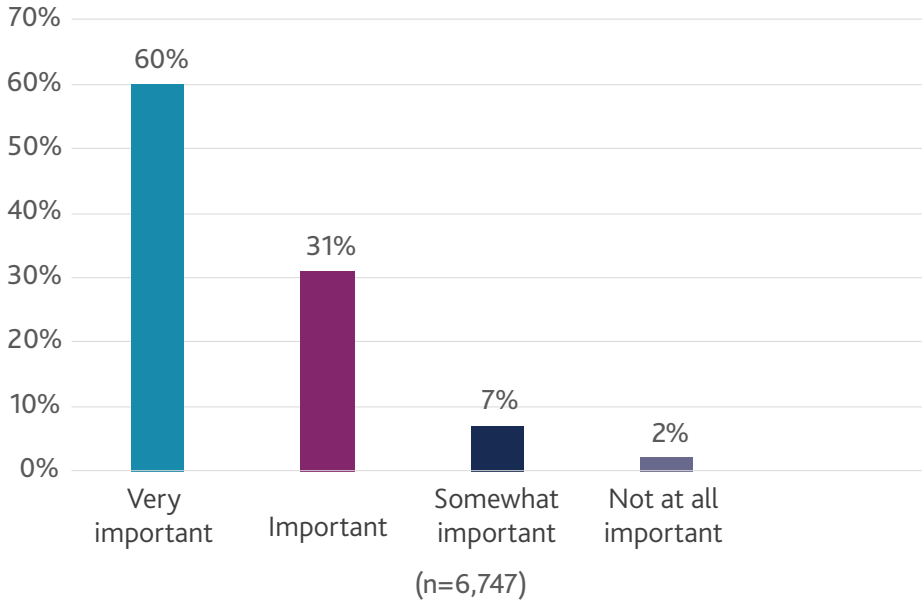
When asked what sources were preferred for getting lymphoma or CLL information, 84% identified doctors as their preferred source followed by the internet (53%) and patient organisations (50%), as shown in Figure 10. For this question, respondents could select all the options that applied to them.

Figure 10: Given your experience with lymphoma or CLL so far, what are your preferred sources, if any, for lymphoma or CLL information? (Choose all that apply)



While doctors are a preferred source for information, patients do believe doctors should check with their patients how much information the patient wants, and how involved they want to be in decisions about their care. In the LC 2022 GPS, 60%, of patients indicated it is very important the lymphoma or CLL doctor ask about their preferences for level of information and involvement in care, 31% selected important and only 7% chose somewhat important and 2% unimportant (Figure 11).

Figure 11: How important or unimportant is it to you to have the lymphoma or CLL doctor ask about your preferences for level of information and involvement in care and decision making.



When examined further, the GPS responses from patients with T-cell lymphoma differed between those with an aggressive or indolent lymphoma diagnosis. For instance, more patients with T-cell indolent lymphoma feel it is very important that they be asked about their preferences for information and involvement in care and decision-making (71%), than respondents with T-cell aggressive lymphoma (53%). (Table 4)

Table 4: How important or unimportant is it to you to have the lymphoma or CLL doctor ask about your preferences for level of information and involvement in care and decision making? (By subtype)

T-cell Aggressive (n=319)	T-cell Indolent (n=460)
%	%
Not At All Important	Not At All Important
4%	1%
Somewhat Important	Somewhat Important
14%	5%
Important	Important
29%	23%
Very Important	Very Important
53%	71%

Interestingly, there are regional differences in how patients responded to the same question. Notably, 77% of patients in North America feel it is very important in comparison to 64% in South America, 59% in Europe, 51% in Asia-Pacific, and 50% in Middle East and Africa. (Table 5)

Table 5: How important or unimportant is it to you to have the lymphoma or CLL doctor ask about your preference for level of information and involvement in care and decision-making? (Regional)

	Not At All Important	Somewhat Important	Important	Very Important
	%	%	%	%
Asia-Pacific (n=2,065)	3%	12%	34%	51%
Europe (n=3,320)	2%	5%	34%	59%
Middle East and Africa (n=34)	0%	21%	29%	50%
North America (n=1,259)	1%	2%	20%	77%
South America (n=69)	4%	6%	26%	64%

There can be major discrepancies between what a physician communicates, and what a patient takes away or understands. There is a tremendous lack of patient confidence in persistent information seeking or challenging/ disagreeing with a physician in a non-confrontational way. Additionally, limits on physician's time can discourage these behaviours. Over time, patients are conditioned to expect that doctors may be annoyed or concerned should they not understand information or ask for it to be repeated. [57] This may prevent patients from asking beneficial questions, or from seeking clarifications should they feel their questions are not answered. This does indicate a need for physician communication training and support, as well as physicians referring patients on to those who can help support information provision.

When patients in the survey were asked if diagnostic and test results were explained to them by their medical team, 60% said they were explained and they understood them. This leaves 2 out of every 5 patients with incomplete or missing information.

When examined by age, the 70+ age group had the highest percentage of patients (69%) that had diagnostic tests and results explained to them in a way they understood, compared to only 44% in the 18-30 age group having the same experience. (Table 6)

Table 6: To what extent, if at all, were diagnostic tests and results explained to you? (By age)

	18-30 (n=532)	31-49 (n=1,584)	50-69 (n=3,226)	70+ (n=1,757)
	%	%	%	%
They were not explained at all	13%	11%	10%	9%
They were not explained well, and I did not understand	19%	16%	10%	6%
They were explained, but I did not understand the information	19%	17%	12%	10%
They were explained, and I understood the information	44%	51%	62%	69%
Other (please specify)	3%	3%	5%	5%
Not sure / Don't know	2%	2%	2%	2%

When reviewing the same question by lymphoma subtypes, there are differences in the reported level of understanding and whether tests and results were explained (Table 7). Those with an aggressive form of lymphoma had more challenges than those with an indolent or slow-growing form. Only 55-57% of those with an aggressive B-cell lymphoma said they understood the information explained to them compared to 61-68% of those with indolent disease. More patients with Waldenstrom's macroglobulinemia (WM) said the results were explained and that they understood the information (68%), in comparison to 55% of those with Hodgkin lymphoma (HL).

Table 7: To what extent, if at all, were diagnostic tests and results explained to you? (By B-cell subtype)

	CLL/SLL (n=1,299)	FL (n=1,132)	WM (n=885)	DLBCL (n=959)	HL (n=851)	MCL (n=231)
	%	%	%	%	%	%
They were not explained at all	11%	10%	7%	11%	14%	8%
They were not explained well, and I did not understand	8%	12%	8%	11%	13%	12%
They were explained, but I did not understand the information	12%	12%	11%	16%	12%	17%
They were explained, and I understood the information	63%	61%	68%	57%	55%	59%
Other	3%	4%	5%	3%	5%	4%
Not sure/ Don't know	2%	1%	1%	2%	1%	0%

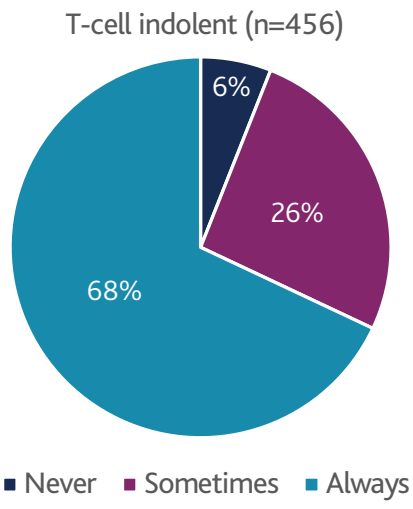
Table 8: To what extent, if at all, were diagnostic tests and results explained to you? (By T-cell subtype)

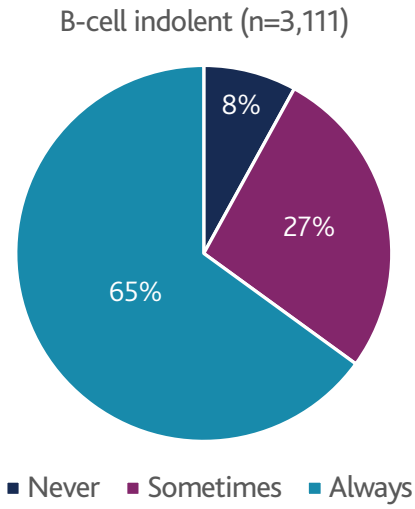
	Aggressive T-cell Lymphomas (n=337)	Indolent T-cell Lymphomas (n=477)
	%	%
They were not explained at all	9%	11%
They were not explained well, and I did not understand	13%	15%
They were explained, but I did not understand the information	19%	9%
They were explained, and I understood the information	53%	59%
Other	4%	5%
Not sure/Don't know	1%	1%

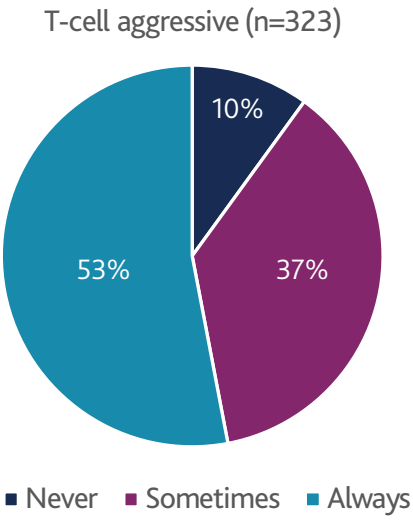
The importance of improved communication between patients and their medical team is highlighted by the fact 19-32% of patients said the results of tests were explained to them, but they didn't understand the information.

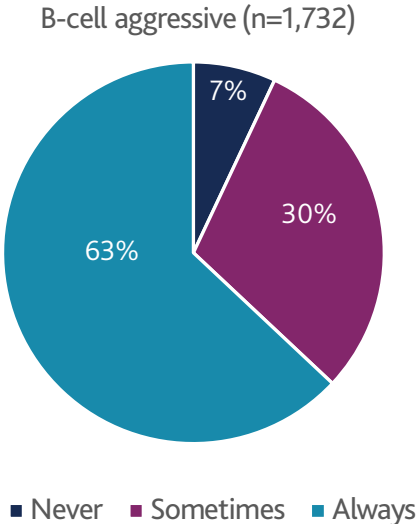
This topic was further explored by asking patients if their doctor explains their disease and cancer care plan in a way that is understandable. In this case, those with aggressive T-cell lymphoma faced the most challenges, having the smallest percent who could say their doctor always did this (53%), whereas the other categories had responses between 63-68%.

Figures 12: Does your doctor explain your lymphoma or CLL and care plan in a way that you can easily understand?



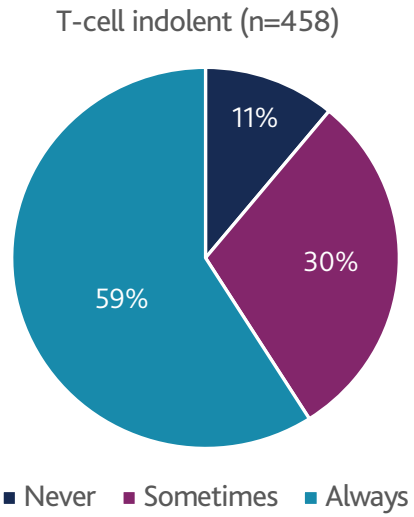


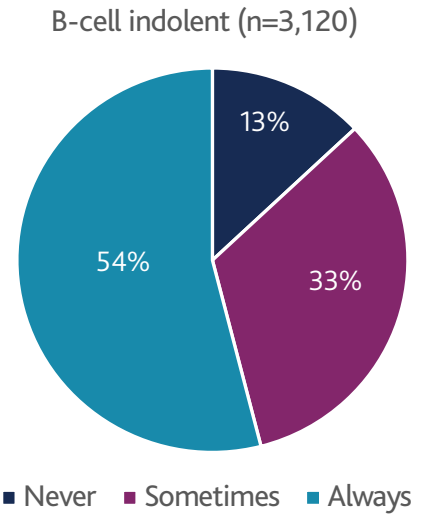


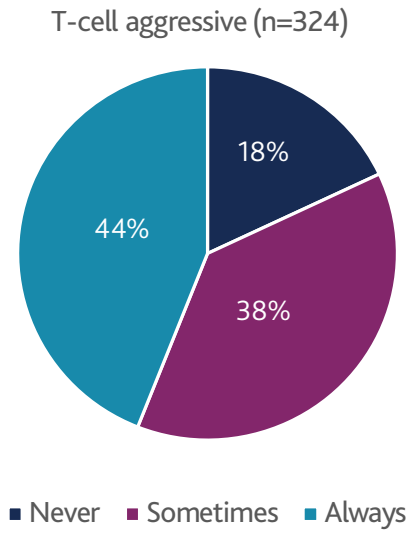


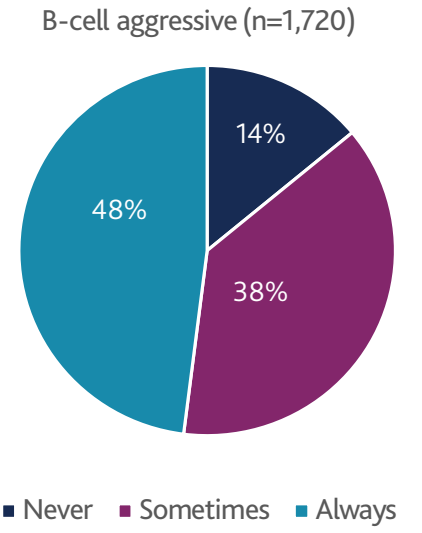
As a follow up, it is important to know if patients feel like they can ask questions if they need clarity or if the doctor, after explaining something, is checking the patient understands. In this instance, those with aggressive disease, had the most difficulty, with only 44% and 48% saying their doctors were encouraging questions and checking understanding. For indolent B-cell lymphoma, just over half of patients said the same thing (54%), while those with an indolent T-cell lymphoma were having the best results, with 59% of patients saying their doctor employs both these behaviours all the time. (Figure 13)

Figure 13: Does your doctor encourage questions and check your understanding?



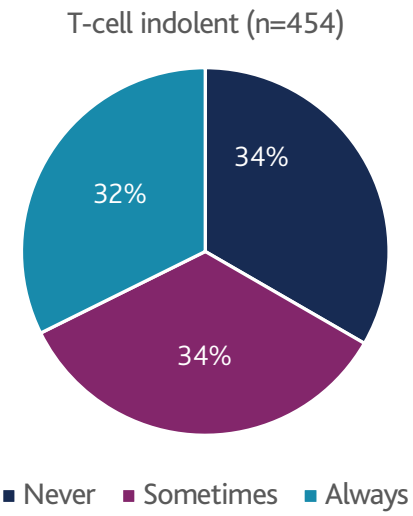


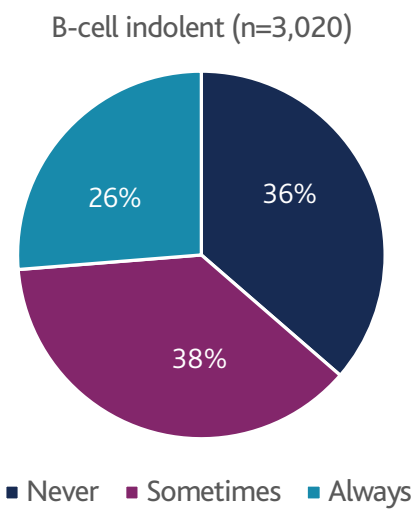


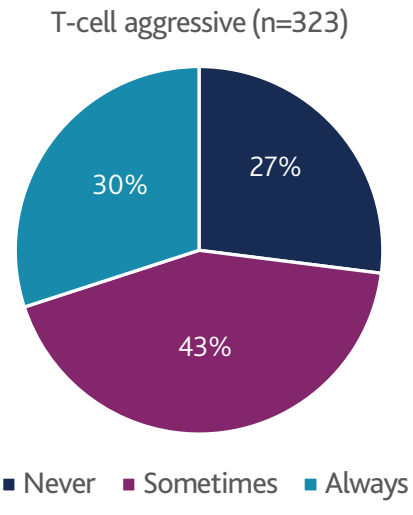


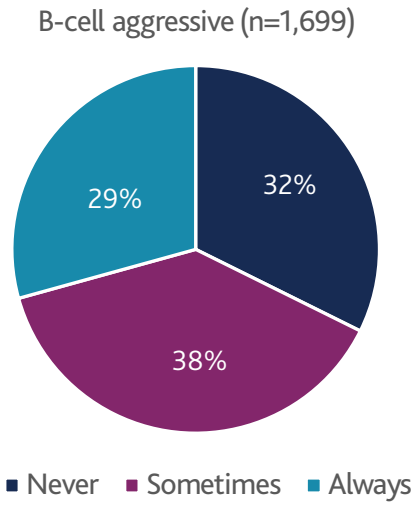
If doctors or other medical staff cannot fully support patient information needs, patients will need to seek it elsewhere. To ensure they are accessing credible information applicable to their disease, it would be helpful if they were referred to appropriate sources. Less than a third of patients say this happens in practice. This is unfortunate as it puts the onus back on the patient and their loved ones to source this knowledge, which can be difficult due to the complexity of lymphoma, their limited understanding of medical terminology, and the lack of experience sorting through information to determine its credibility and applicability. (Figure 14)

Figure 14: Does your doctor identify and recommend other resources and support



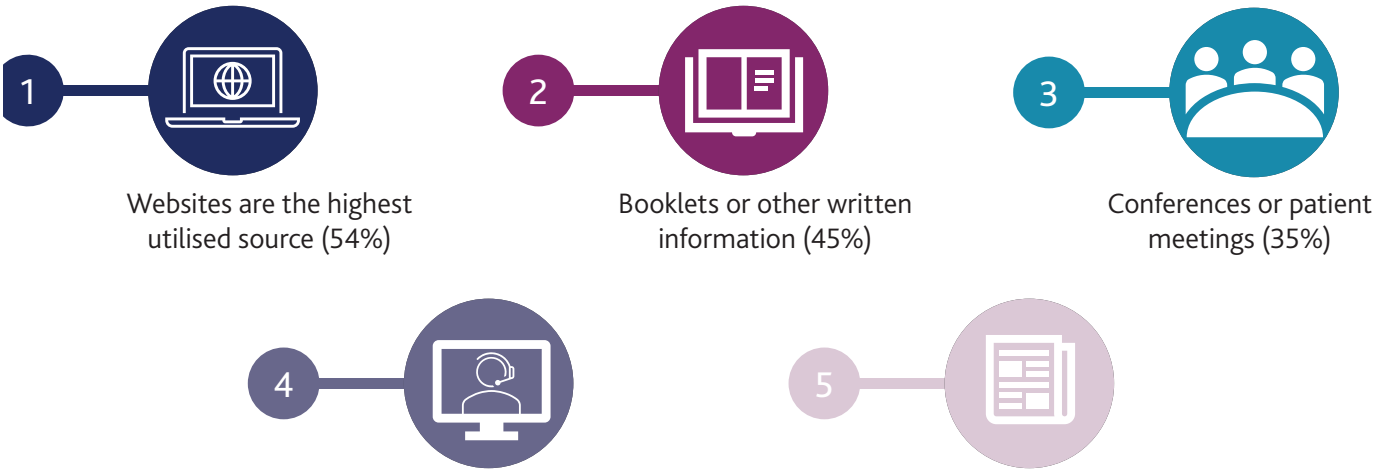






Although patient organisations provide valuable information and support to patients and were ranked in the top three information sources by respondents, 52% of patients indicated that their lymphoma or CLL doctor (or any member of the medical team) did not provide the contact details of a patient organisation, support group and/or provide information from a patient organisation to them. This leaves patients to find these additional avenues of support and information themselves.

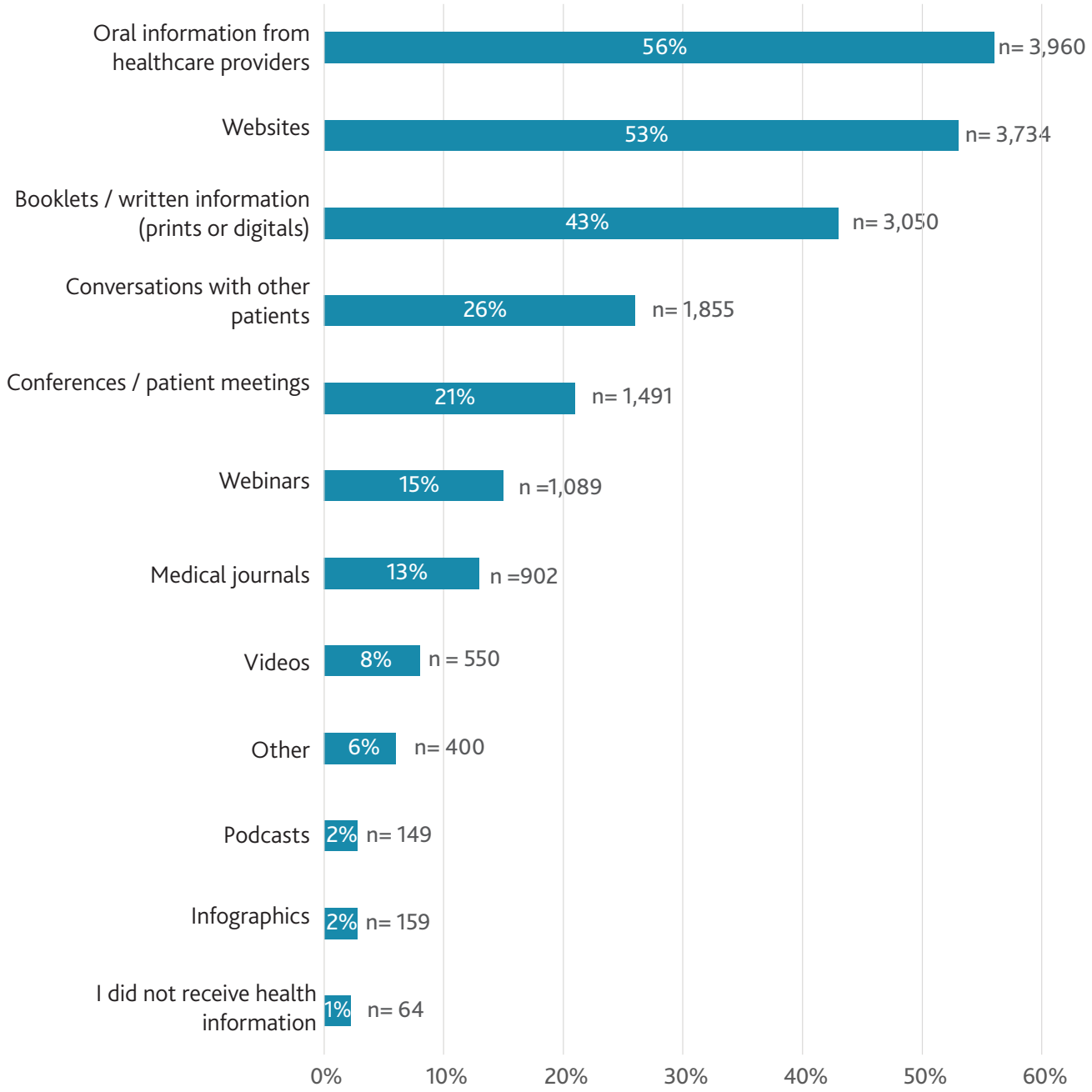
When asked to select up to five types of patient organisation information they used, 3,551 patient respondents ranked the top resources as follows:



The degree of patient satisfaction with the information provided by patient organisations was 81%, comparable to the satisfaction with information provided by healthcare professionals (74%).

In the LC 2022 GPS, participants were asked to pick their top three preferred methods of receiving information from any source. More than half of patients (56%) selected oral information from healthcare providers, 53% said websites and 43% noted booklets or sources of written information. This aligns with the learnings from similar questions.

Figure 15: What is your preferred method for obtaining or receiving health information about lymphoma or CLL?



For the patients who said they source lymphoma or CLL information from the internet, 70% indicated they usually look to search engines, such as Google or Bing, with 66% indicating they visit patient organisation websites for information.

As there is a mix of good and bad information on the internet, coupled with the complexity of lymphoma itself, it would help ensure patients are connecting to credible sources of information if they were provided with a list of reliable websites by their medical team.

The data shows a multitude of factors that influence health literacy in patients with lymphoma. It is vital physicians and other health professionals check with their patients about their interest level in knowing more, check their understanding of any information shared, encourage questions, help direct them to credible, understandable information sources, as well as other avenues for resources and support, along the entire care continuum.

Conclusions

Improving health literacy can improve health equity.

Many people across the world struggle to understand important information that may help them to manage their disease, care, and treatment. To support health literate environments that meet the needs of individuals, it is critical that health systems, policymakers, and healthcare professionals understand the key factors associated with population health literacy. It is also important that they understand how those factors impact patient experience and contribute to health inequities and disparities.

Increasingly, countries are adopting national health literacy policies and implementing strategies to support a systemic approach to improving health literacy within their respective populations while also moving to establish health literacy monitoring and evaluation measures and integrate national health literacy strategies in health agendas. Despite growing evidence and acknowledgement of the implications of low levels of health literacy in relation to health conditions, self-management of health, and health outcomes, interventions to measure and improve population health literacy remain inconsistent, varying between practices and policies across countries and within communities.

Health literacy is a strong predictor of health outcomes, with low health literacy associated with poorer health status. Healthcare organisations and health systems that are health literate play a major role in supporting people to navigate, understand, and use health resources. This can also include applying information to support decision-making, accessing healthcare services and improve health outcomes.

With progressively complex healthcare pathways, including care and treatment, the ability to understand medical information is essential as people strive to reach informed health-related decisions. The way in which information is shared or delivered by healthcare professionals to patients in a clinical setting is critically important. Healthcare professionals have an important role to play in providing information that, when done well, is more likely to increase patient confidence and support shared decision-making.

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Appendix: Background Information on the Global Patient Survey on Lymphomas & CLL [10]

Demographics

In 2022, the GPS was translated from English into 18 languages. There were 8637 respondents across 72 countries. Overall, there were 7,113 patient respondents and 1,524 caregivers. (Figure A1)

Figure A1: Overall number of survey respondents.

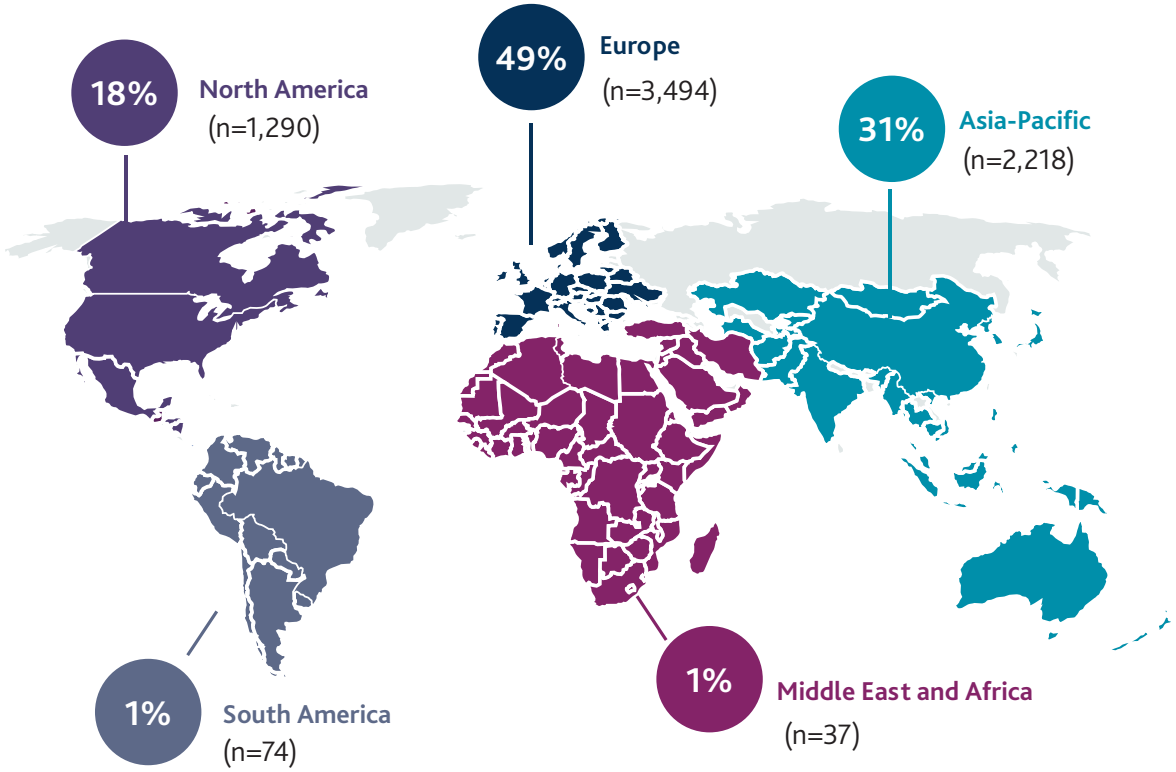
The overall cohort of patient respondents represented 58% female and 42% male. (Figure A2)

Figure A2: Sex of patient.

(n=2,951) (n= 4,154)

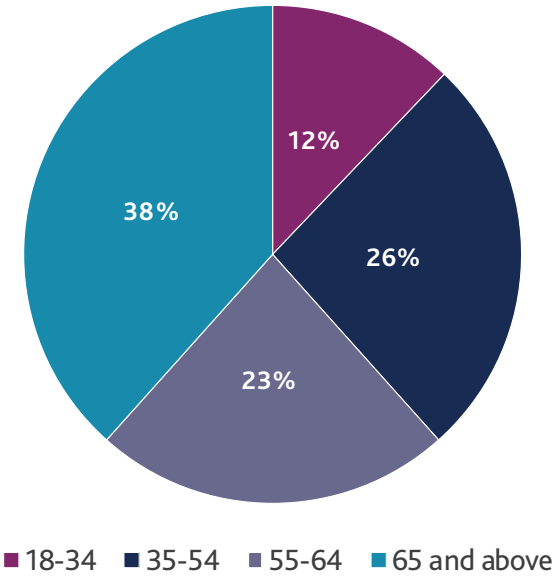
The top four country patient responses were: (1) France, 18% (2) China, 15% (3) United States of America, 13% (4) Italy, 7%. A total of 18 countries had over 100+ respondents to the GPS with the greatest global distribution in Europe (49%) followed by Asia-Pacific (31%), North America (18%) and South America and Middle East-Africa at 1% respectively. (Figure A3)

Figure A3: Global regional distribution of patient respondents.



Most responses were from patients over the age of 65 (38%), with the lowest survey respondents age group between 18 and 34 years old (12%). (Figure A4) This is similar to general lymphoma demographics.

Figure A4: Age range of patient respondents.



(n= 7,103)

Most GPS patient respondents (43%) reside in city/urban areas and nearly half of the overall respondents (49%) completed post-secondary education, with a high rate (21%) having completed postgraduate education such as a master's or Ph.D

Methodology

Data Collection

The 2022 GPS went live on 10 February 2022 and was hosted online for nine weeks. There were no time constraints to answer individual survey questions. Respondents could complete the survey at their own pace within the timeframe from the go-live date (10 February 2022) and the hosted end date (14 April 2022). LC created materials to help promote the survey. The engagement and promotion materials for the survey were shared on the LC website and social media properties such as Twitter, Instagram, and Facebook. Promotion materials were also shared with LC member organisation networks, healthcare professionals, and scientific and community partners across the globe.

LC ensured privacy and confidentiality measures were respected and ensured no participant identifiers were collected. Considerations were taken to ensure that respondents could be as honest as possible without fear of repercussions.

The 2022 GPS was scripted, thoroughly tested, and hosted on a third-party online survey portal, Qualtrics (Provo, UT). The English questions were translated into 18 languages by an approved language translation service using native speakers to translate and proofread. Native-speaking LC members also reviewed the final translations. The survey was published online in the following languages:

English	Dutch	German	Korean	Slovak
Arabic	Danish	Hindi	Lithuanian	Spanish
Bulgarian	Finnish	Italian	Portuguese	Swedish
Chinese	French	Japanese	Serbian	

Respondents could leave survey questions blank if they preferred not to answer.

Data Cleaning

The data cleaning process included the following steps: all partially completed surveys were kept if Q2=1 (respondents agreed to having their answers recorded) and if the survey had been completed at minimum up to Q47 (i.e., Q47 is completed). A review of surveys that were flagged by Qualtrics as potential bots was also completed prior to data being aggregated.

Data was categorised within Qualtrics before being exported to MS Excel and IBM Statistical Package for the Social Sciences (SPSS) v27 for visualisation into frequency tables and charts. Data were then exported into reports for researcher interpretation and commentary. No statistical analysis was performed; any reported differences cannot assume statistical significance.

Cross-tabulations were used to investigate patterns in care experiences between patient demographics, lymphoma subtype and countries and regions of residence. Cross tabulations were also used to examine patterns between caregiver experiences.

Results were only reported where there were 20 or more survey responses (per question). For any sub-group analyses (e.g., by lymphoma subtype, gender, or age group), data captured was not reported on groups lower than 20. Consideration was given to (i) the data can be misleading and unrepresentative from low numbers, and (ii) it risks individual respondents becoming identifiable.

Some questions were asked only to a subset of respondents and given that there was an option not to answer a particular question, the total number of respondents may fluctuate between questions.

Data Dissemination

LC dissemination and data preservation plan ensure best practices and ethical guidelines have been met. All critical data and documentation files produced during the data collection process are stored behind a security system, on the LC server a password protected server.

