调查概况
Overview

本次调查是由淋巴瘤之家、北京病痛挑战公益基金会和香港中文大学赛马会公共卫生及基层医疗学院共同发起，香港中文大学赛马会公共卫生及基层医疗学院董咚博士作为本次调查研究的负责人。针对淋巴瘤不同亚型的患者，对基本人口统计学特征、淋巴瘤患病与确诊过程、治疗周期与医疗负担、具体用药情况、生命质量等情况进行了调查。本次调查共回收有效问卷 4816 份，其中共有 2236 份患者自填版问卷，2580 份家属代填版问卷；家属代填问卷绝大多数为患者子女或患者父母代填。参与调查患者几乎覆盖全国所有省市、自治区、直辖市和特别行政区。

The survey was jointly initiated by House086,the Illness Challenge Foundation and the Jockey Club School of Public Health and Primary Care, Chinese University of Hong Kong (JCSPHPC, CUHK). Dr. DONG Dong from JCSPHPC, CUHK, took a leading role in the research. The survey was designed to be comprehensive in terms of focusing on multifaceted aspects of the life of patients with different subtypes of lymphomas, including the demographic characteristics, the experience from first onset to diagnosis, history of treatments and medications, the medical cost, specific medication situation and quality of life. A total of 4,816 valid responses were collected. 2,236 were completed by the patients and 2,580 were by their family members, most of whom were patients' children or parents. The survey covers patients from almost all provinces, autonomous regions and special administrative regions in China.

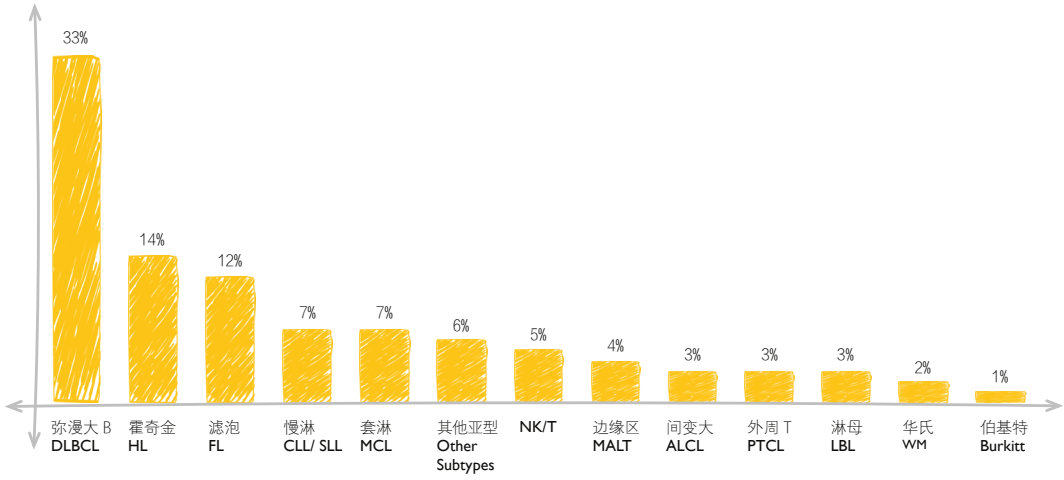
PART ONE

患者基础信息
Demographics

性别及亚型情况
Gender&Lymphoma Subtypes

参与调查的男性患者占比为 56%，女性患者占比为 44%，男性占比大于女性。
The proportion of male patients (56%) participating in the survey is a little higher than that of the female patients (44%).

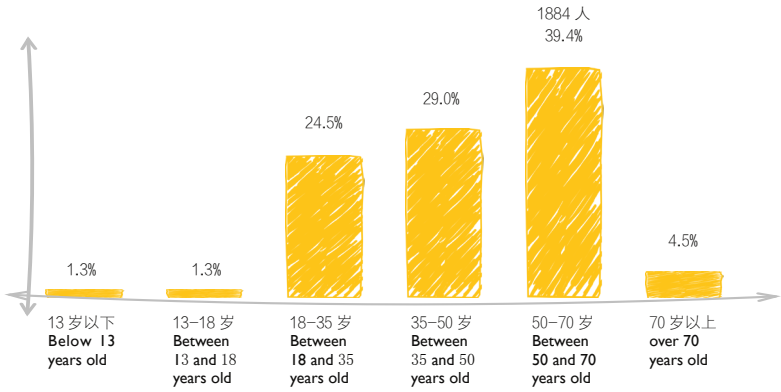
接受调查的患者病理亚型众多，占比最多的前三位亚型是弥漫大 B（33%）、霍奇金（14%）、滤泡（12%）。
Participants of the survey represent diverse subtypes of lymphomas, among which DLBCL , HL and FL are the most common ones, accounting for 33%, 14% and 12% of the total patients under survey.



PART ONE

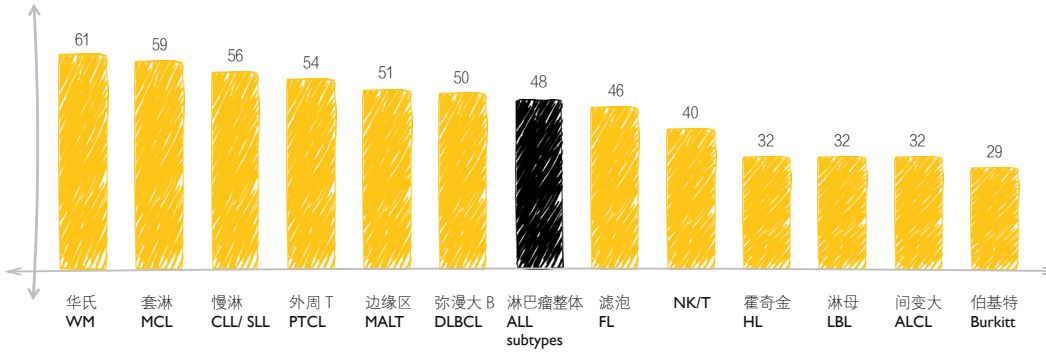
年龄
Age

接受调查的患者中位年龄为 48 岁，其中年龄最小者 2 岁，年龄最大者 95 岁。
The median of the patients' age is 48. The patients' ages range from 2 to 95.



患者年龄分布
Distribution of patients' ages

年龄最大的亚型是华氏，中位年龄为 61 岁；年龄最小的亚型是伯基特，中位年龄为 29 岁。
The median ages range from a high of 61 in patients with WM to 29 in patients with Burkitt.



各亚型患者中位年龄
Median age of patients with various subtypes

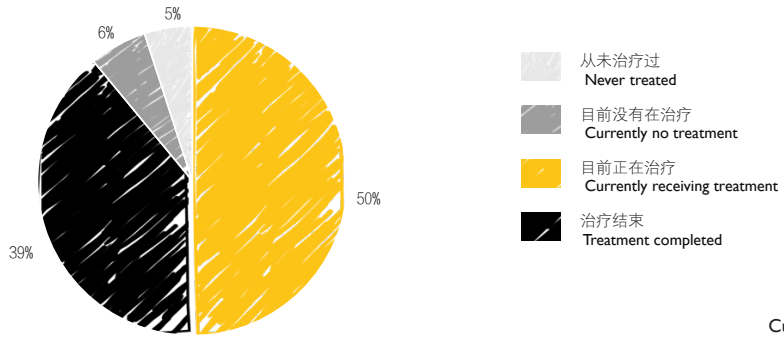
PART TWO 2

就诊与确诊
Medical visits and diagnosis

治疗情况及阶段
Treatment status and stage

接受调查的患者中，约有 50% 的患者目前正在接受治疗，治疗已经结束的患者占 39%，仅有 5% 的患者从未接受过治疗。

Among patients participating the survey, 50% are undergoing medical treatment, 39% have completed treatment, and only 5% have never received any treatment.

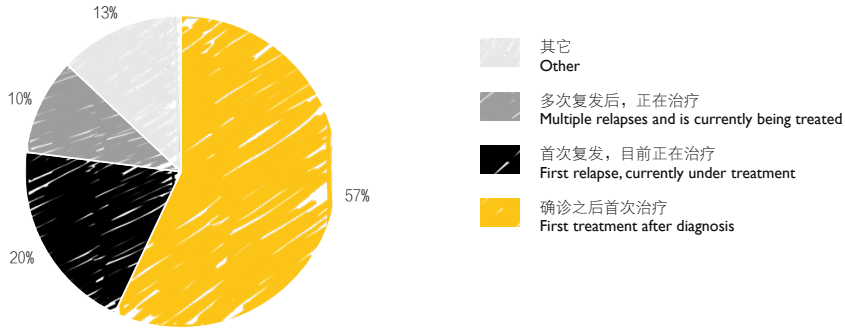


患者目前治疗
Current treatment status

PART TWO 2

正在接受治疗的患者中，57% 的患者是确诊之后的首次治疗；20% 的患者是首次复发后接受治疗；10% 的患者是多次复发后在接受治疗。

For patients who are currently under treatment, their specific treatment stages are further investigated. Among patients under medical treatment, about 57% are receiving first treatment after diagnosis, 20% are receiving treatment after first relapse, and 10% are treated after multiple relapses.

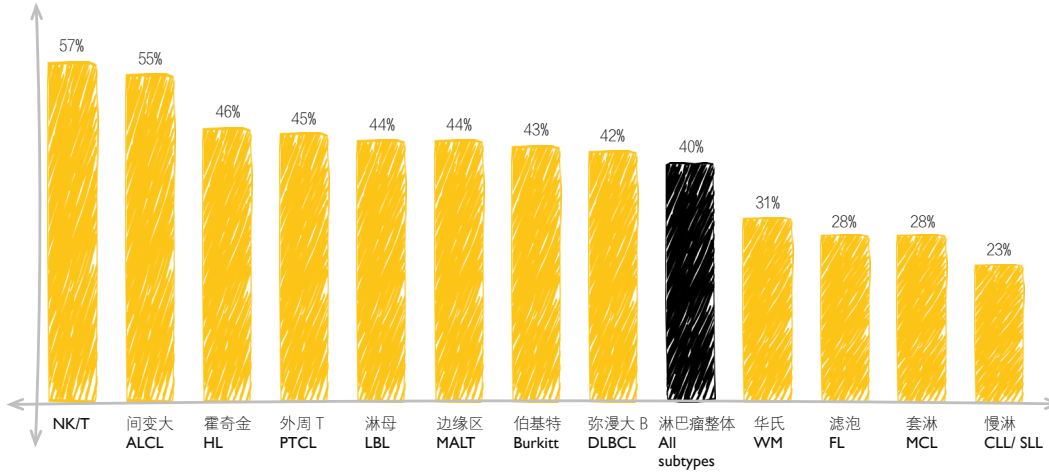


治疗中患者具体诊疗情况
Current specific treatment stage

误诊比例
Misdiagnosis Rate

在参与调查患者中， 2047 人有过误诊经历，占被调查者总数的 43% 。误诊分为两种情况：被误诊为非淋巴瘤疾病或淋巴瘤其他亚型。被误诊为非淋巴瘤疾病的比例为 40%，不同亚型淋巴瘤被误诊比例不同，最高为 57%，最低为 23%。

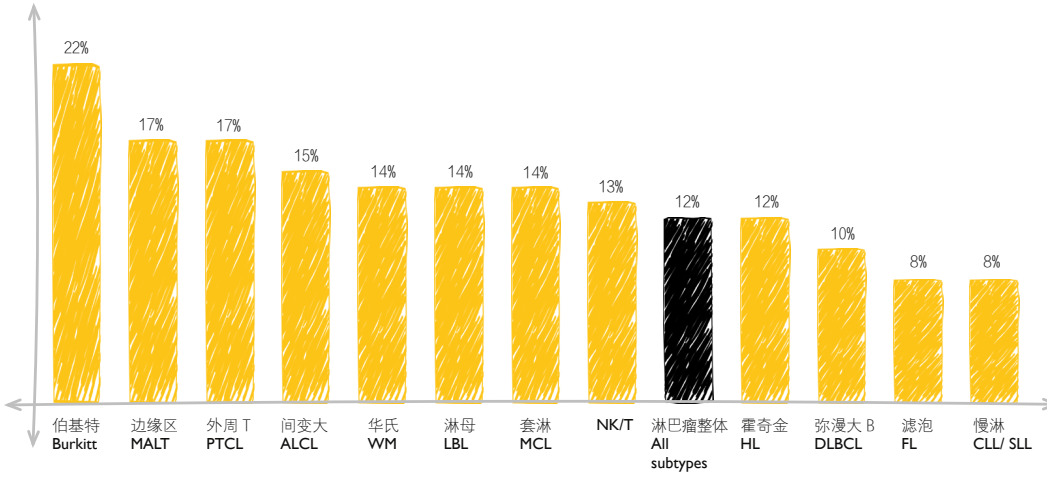
In this survey, 2,047 or 43% of the patients have been misdiagnosed. There are two kinds of misdiagnosis: patients with lymphoma were diagnosed with non-lymphoma diseases or misdiagnosed with other lymphoma subtypes.Among all misdiagnosed cases, 40% were misdiagnosed as non-lymphoma diseases.For different subtypes, the misdiagnosis percentage ranges from a high of 57% (NK/T) to 23% (CLL)



误诊为非淋巴瘤疾病的比例
Misdiagnosed with non-lymphoma diseases

被误诊为其他亚型的比例为 12%，不同亚型淋巴瘤被误诊比例不同，最高为 22%，最低为 8%。

Overall, 12% of the patients being misdiagnosed were diagnosed as other subtypes of lymphoma. For different subtypes, the percentages of being misdiagnosed with other subtypes range from a high of 22% (Burkitt) to 8% (CLL).



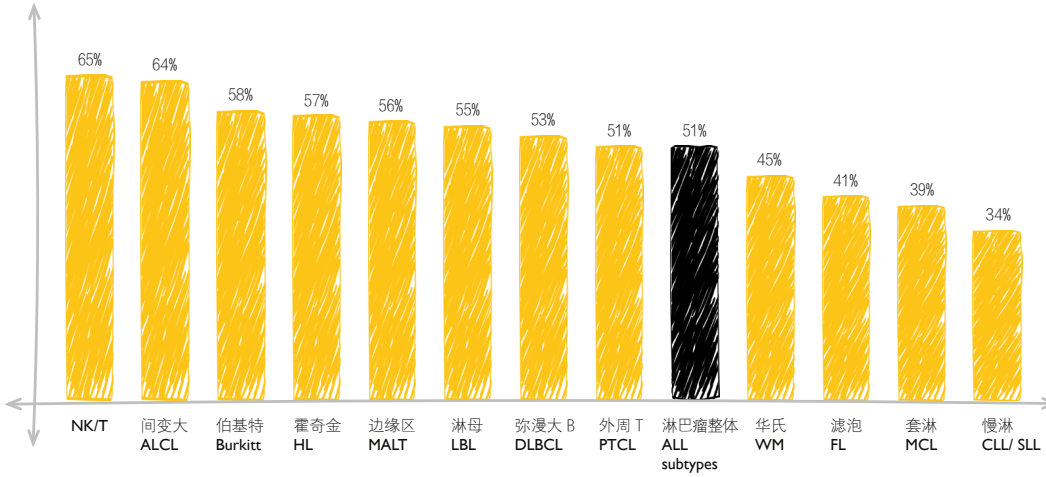
误诊为其他亚型的比例

Misdiagnosed with other subtypes of lymphoma

确诊时长
Diagnosis Lag Time

51% 的淋巴瘤患者经过多家医院才得以确诊，不同亚型情况有所不同，最高如 NK/T，65% 的患者要经过多家医院才得以确诊。

51% of lymphoma patients were only able to receive definitive diagnosis after visiting multiple hospitals. Among different subtypes, the percentage of multiple hospital visits for definitive diagnosis ranges from a high of 65% for NK/T to a low of 34% for ALCL.



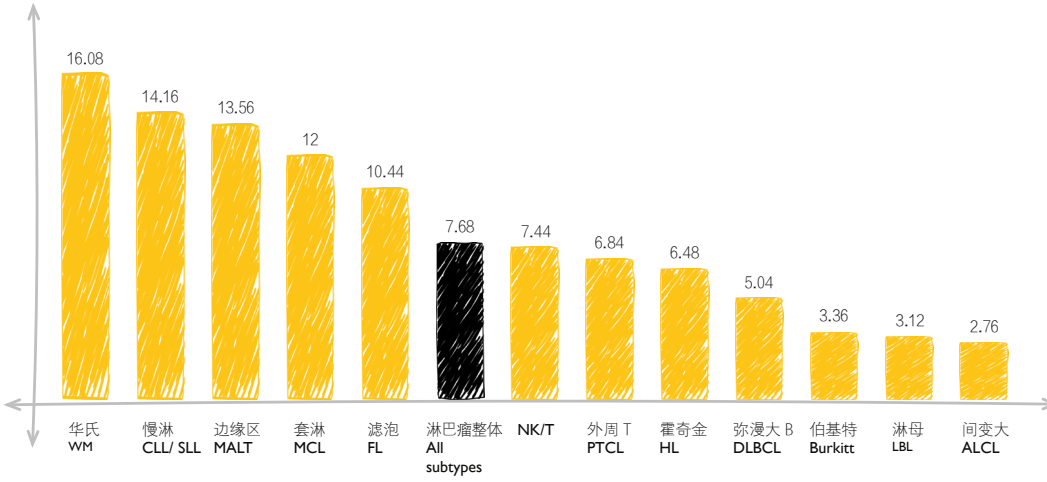
经多家医院才得以确诊亚型的比例

The percentage of patients receiving definitive diagnosis of subtypes after multiple hospital visits

PART TWO 2

淋巴瘤患者从发病到就诊平均需要 7.7 个月。

Lymphoma patients took an average of 7.7 months from onset to first medical encounter.

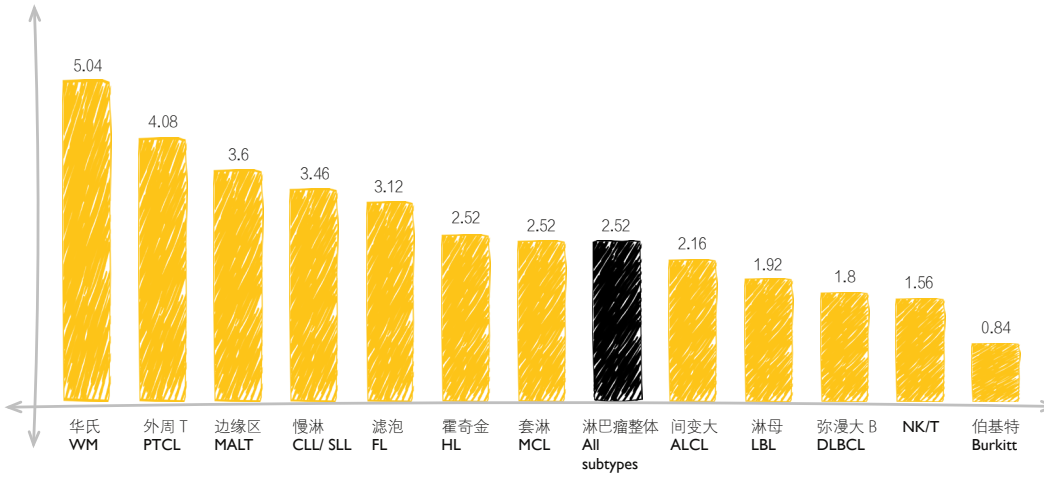


从发病到就诊平均时长（单位：月）

Average time from symptom onset to first medical encounter(unit: month)

淋巴瘤患者从初次就诊到最终确诊亚型平均需要 2.5 个月，其中华氏患者耗时最长，平均需要 5 个月。

Patients with lymphoma took an average of 2.5 months from first medical encounter to definitive diagnosis of specific subtype. Patients with WM took an average of 5 months, which is the longest among all subtypes.



从初诊到确诊亚型平均时长（单位：月）

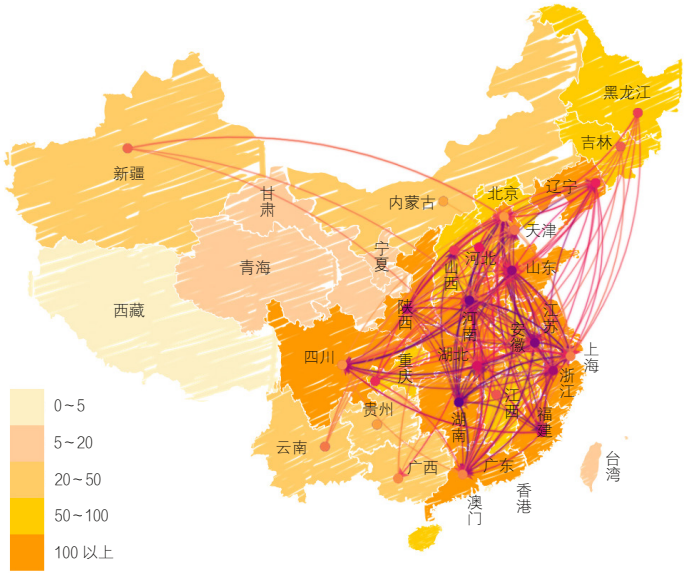
Average time from first medical encounter to definitive diagnosis(unit: month)

PART TWO 2

异地就诊
Trans-local diagnosis of lymphoma

无论是在确诊淋巴瘤还是进一步确诊亚型的过程中，大部分患者需要集中到北京、上海、广州等医疗资源比较集中的城市，或者省会地区，例如成都，才能获得确诊。

Most patients need to go to medical resources concentrated cities, such as Beijing, Shanghai and Guangzhou or provincial capitals such as Chengdu, to receive their first definitive diagnosis as lymphoma and further diagnosis of specific subtype.



患者人数
The number of patients

3 PART THREE

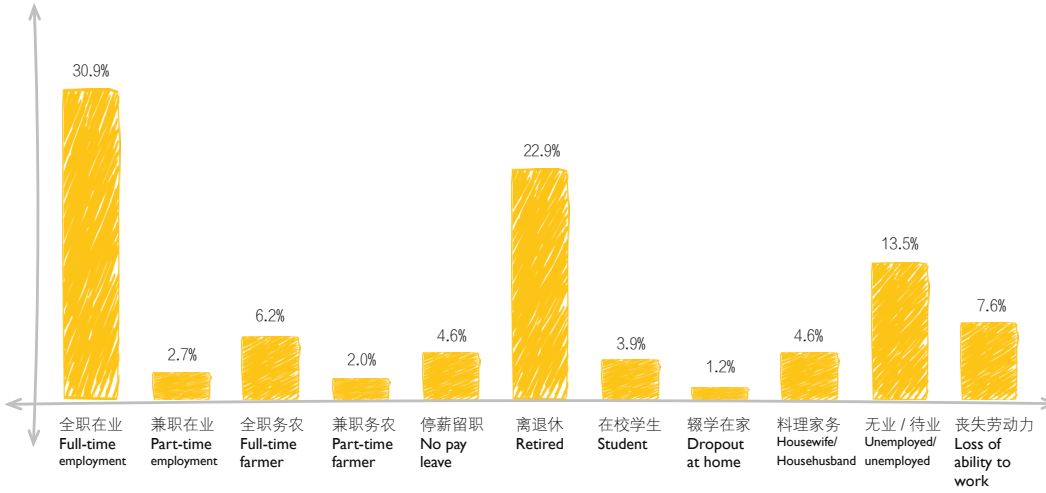
经济负担
Financial burden

PART THREE 3

患者就业情况
Employment status of patients

“全职在业”患者最多，占比30.9%，其中有半数以上患者治疗已结束或尚未开始治疗；其次为“离退休”，占总人数的22.9%；7.6%的患者已丧失劳动力。

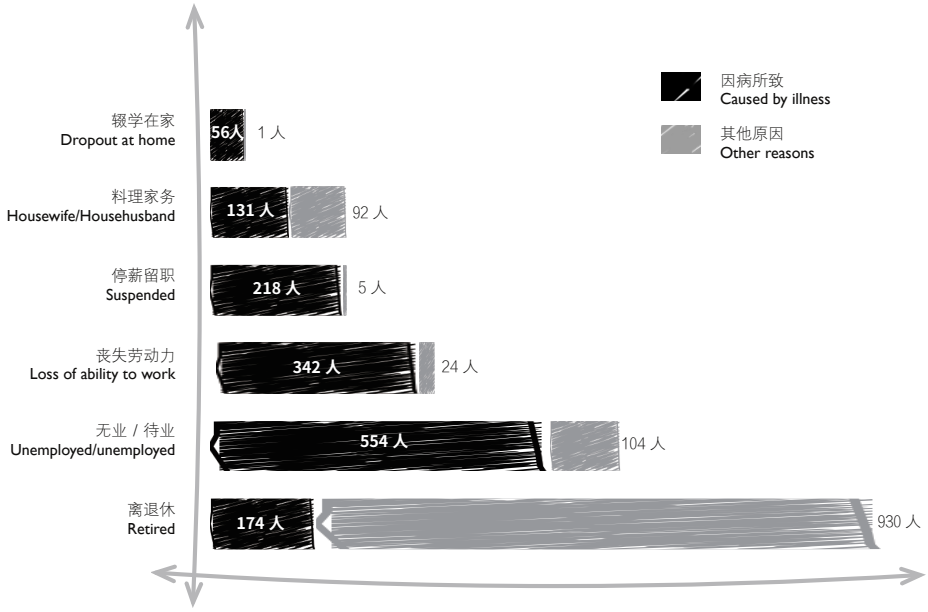
30% of the patients are "full-time employed", which is the highest among other employment status. More than half of the fully employed patients have completed their treatment or have not started medical treatment. "Retired" patients account for 22.9% of the total number. 7.6% of patients have lost their working capability.



失业原因
Reason for unemployment

停薪留职、辍学在家、丧失劳动力的患者中超过 90% 都是由于患病导致，绝大多数失业 / 待业或在家料理家务的患者也是因为患淋巴瘤而导致了目前的情况。

For the patients who took no pay leave, dropped out of school or lost their working capability, more than 90% is due to their illness. For the vast majority the unemployed patients and patients who became housewives or househusbands, their situations are caused by lymphoma as well.

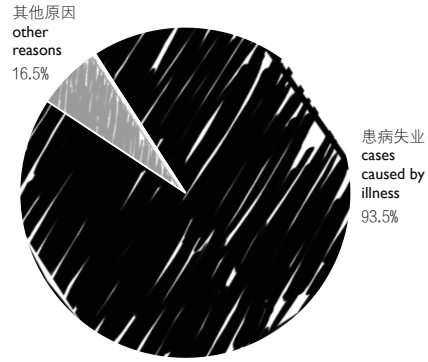


就业影响
The impact of illness on Employment

PART THREE 3

失业情况
Unemployment situation

18–35 岁的青年赋闲患者共计 568 人，其中有 93.5% 是因病失业或丧失读书机会。
Among the 568 unemployed young patients aged from18 to 35, 93.5% are unable to work or continue their study due to their illness.



18-35 岁青年患者失业情况
Unemployment situation of patients aged between 18 and 35

35–60 岁的中年赋闲患者共计 1125 人，其中有 70% 是由于患病而不能工作或不得不提前退休。

Of the 1,125 unemployed patients aged from 35 to 60, 70% are unable to work or take early retirement due to their illness.

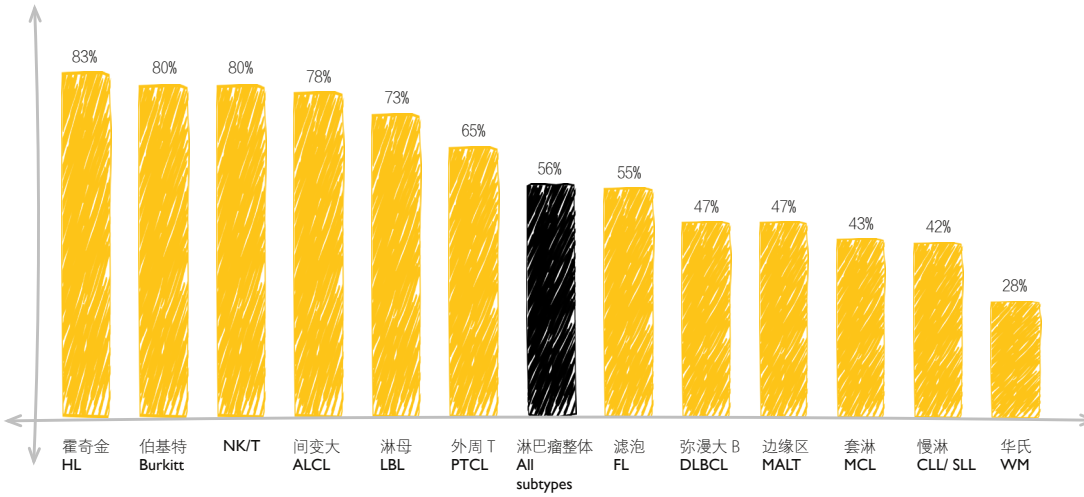
35-60 岁中年患者失业情况

Unemployment situation of patients aged between 35 and 60

PART THREE 3

霍奇金、伯基特、NK/T、间变大患者因病导致失业或辍学比例高于 75%。

More than 75% of the patients with HL, Burkitt, NK/T, and ALCL are unemployed or dropped out of school as a result of their illness

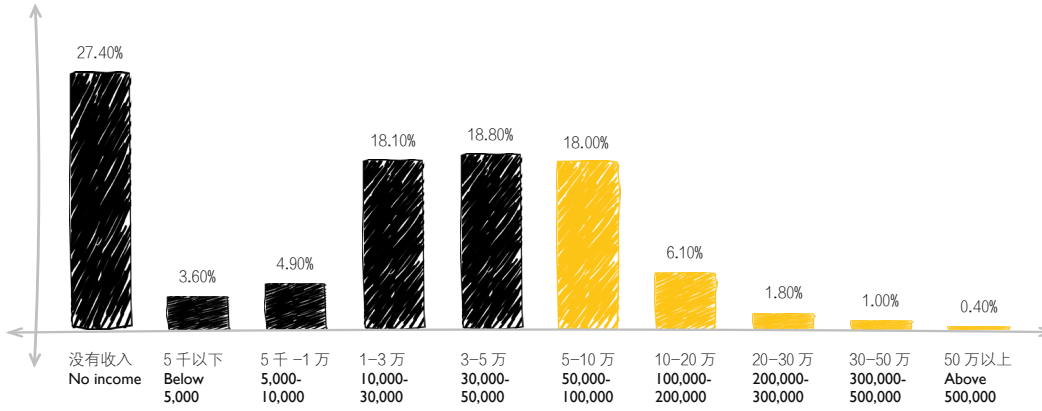


各亚型因病失业赋闲比例

The percentage of unemployed patients due to illness across different subtypes

2018 年度收入与医疗支出
Income and Medical Expenditure in 2018

27.4% 的患者没有任何收入，54% 的患者年收入在 3 万以下，72.8% 的患者年收入在 5 万以下。27.4% of the patients have no income. 54% have annual income of less than 30,000 yuan, and 72.8% have annual income of less than 50,000 yuan.



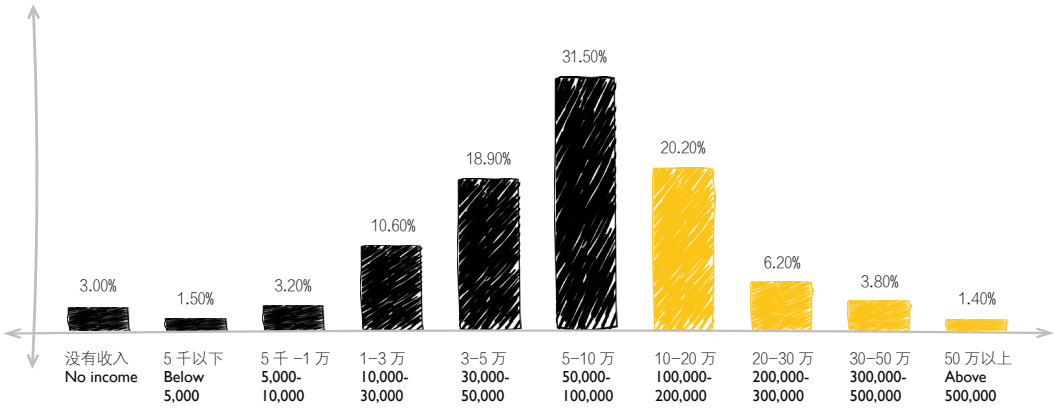
2018 年患者个人年收入情况

Total Individual Income of Patients in 2018

PART THREE 3

患者家庭年收入中位数为 8 万元，家庭年收入在 5–10 万范围内的患者最多，占 31.4%；家庭年收入在 3 万元以下的患者，占 18.3%。

The median annual family income of patients is 80,000 yuan. The annual family income of 50,000 to 100,000 yuan is the largest in number of patients, accounting for 31.4%. The annual family income of less than 30,000 yuan is of the smallest in number, accounting for 18.3%.

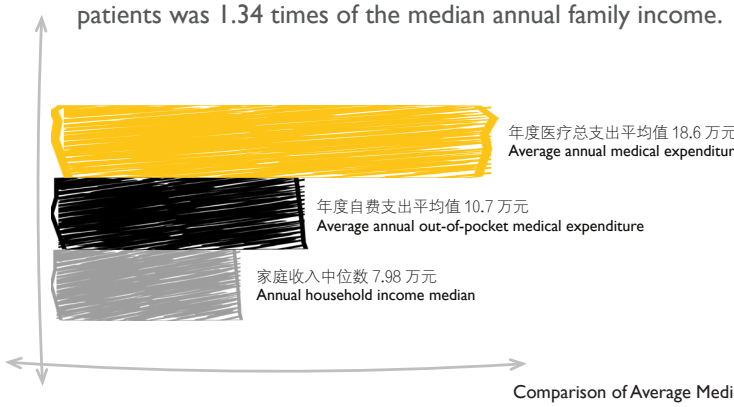


2018 年患者家庭年收入情况

Total Family Income of Patients in 2018

2018 年度，患者年度医疗总支出平均值约为家庭年收入中位数的 2.33 倍。患者年度自费支出平均值约为家庭年收入中位数的 1.34 倍。

In 2018,The average annual medical expenditure of patients in 2018 was 2.33 times of the median annual family income.The average annual out-of-pocket medical expenditure of patients was 1.34 times of the median annual family income.

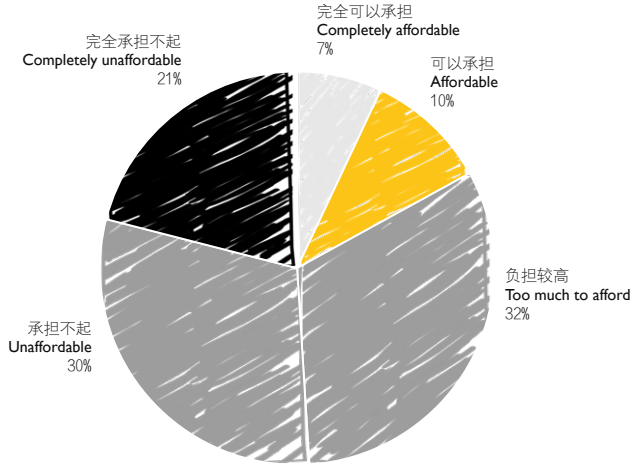


2018 年平均医疗支出及年收入

Comparison of Average Medical Expenditure and Annual Income in 2018

当患者被问及对医疗负担的主观感受时，只有17%的患者可以承受患病带来的医疗支出。

Only 17% of patients stated they could afford the medical expenses caused by the illness when asked about their subjective feelings about the medical burden.



医疗支出承受能力

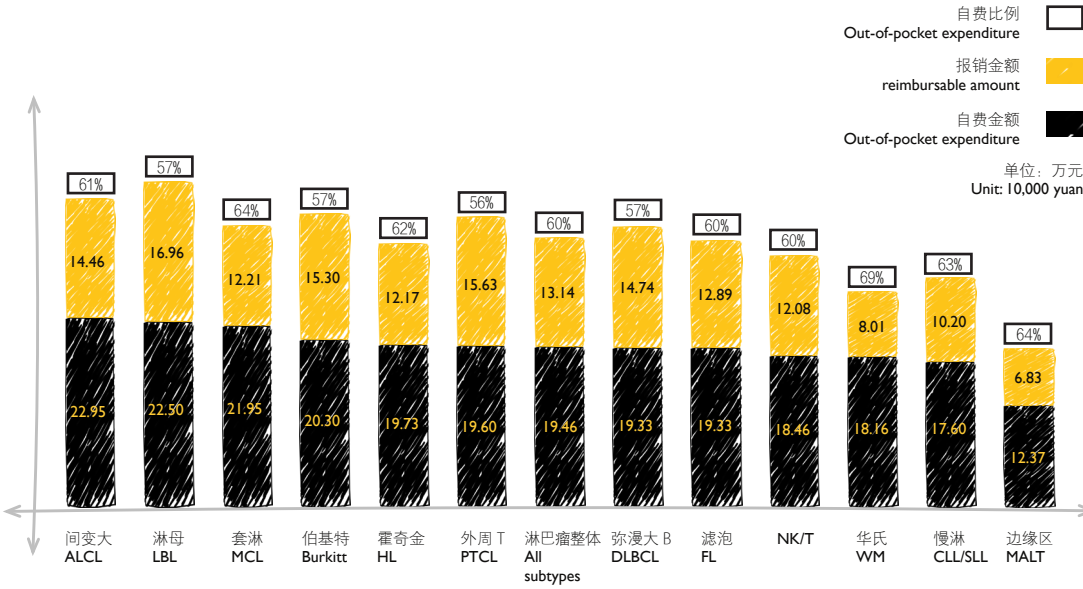
The affordability of medical treatment

PART THREE 3

治疗总体花费
Total cost of treatment

患者治疗总花费平均约为 32.6 万元，治疗自费比例为 60% 。

The total medical cost of lymphoma treatment is 326,000 yuan. The out-of-pocket expenditure reaches 60%.

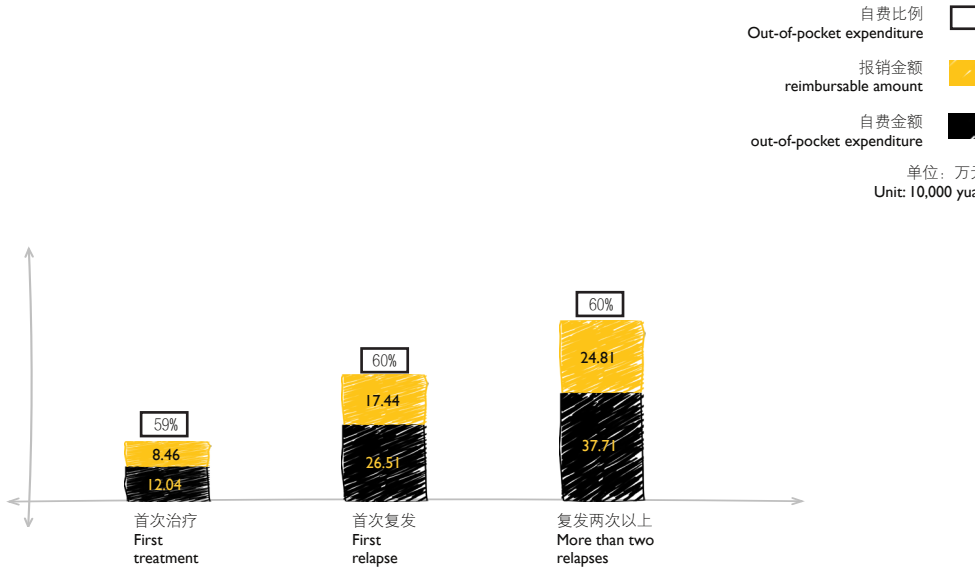


不同亚型治疗花费及自费比例

Expenses for different subtypes of lymphoma (in comparison of the reimbursable and out-of-pocket expenditures)

各治疗阶段的平均自费比例均为 60% 左右；非首次治疗平均花费比首次治疗平均花费高出 30 余万元。

The average proportion of out-of-pocket expenditure ratio of each treatment stage is about 60%. The average cost of non-first treatment is 300,000 yuan higher than that of first treatment.



不同治疗阶段平均花费与自费比例

The average cost and proportion of out-of-pocket expenditure at different treatment stages

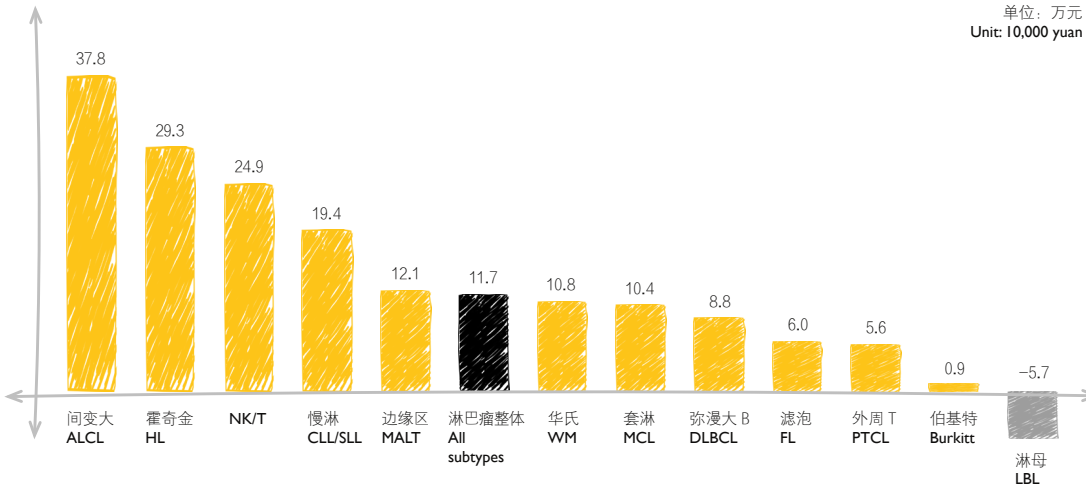
PART THREE 3

免疫 / 靶向药对总花费的影响

Impact of using immunotherapy/targeted therapy on total expenditure

间变大、霍奇金、NK/T、慢淋四种亚型，使用免疫 / 靶向药对于整体花费影响最大，会造成 19.4 万 –37.8 万元人民币的总体增量。

Using immunotherapy/targeted therapy in the treatment of ALCL, HL, NK/T and CLL/SLL had the greatest impact, resulting in an increase of 194,000 - 378,000 yuan to the overall medical cost.

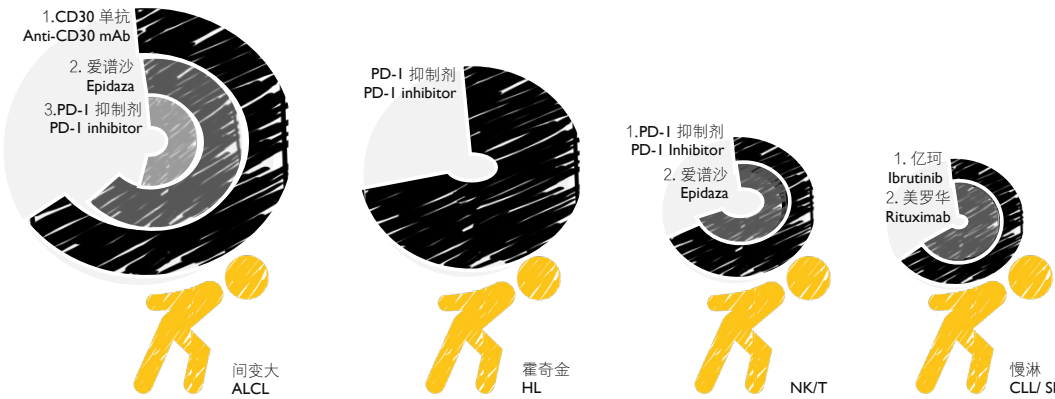


免疫 / 靶向药物带来的总花费增量

Incremental cost of immunotherapy/targeted therapy

免疫 / 靶向药负担最重的四种亚型及其主要用药如下。

Expenditure composition of immunotherapy/targeted therapy for the four most financially burdened subtypes of lymphoma.



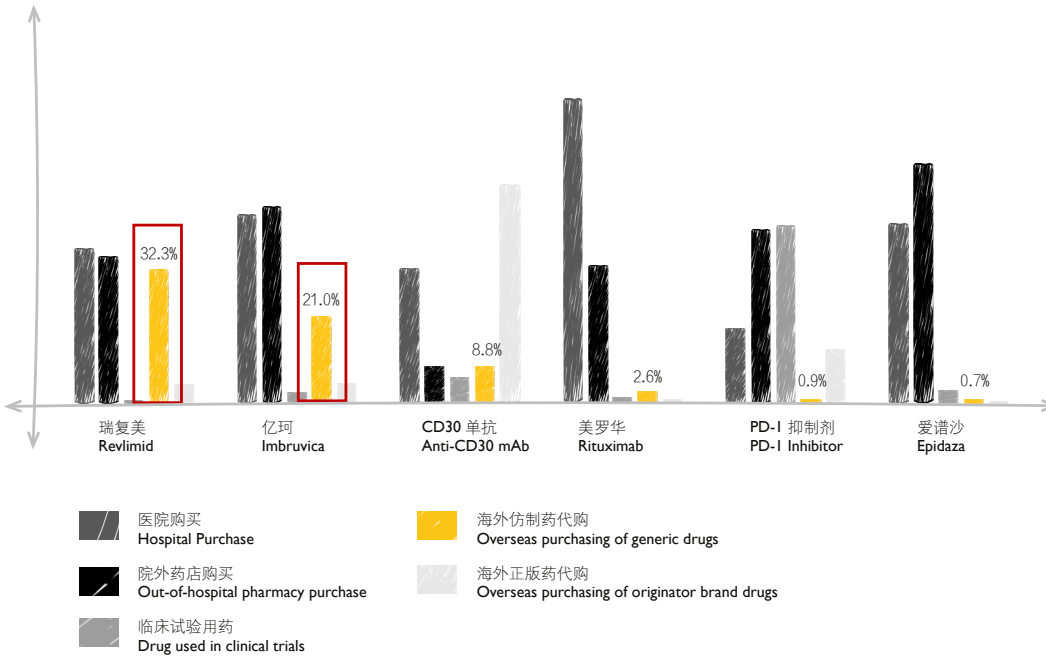
PART THREE 3

免疫 / 靶向药购药渠道

Purchasing Channels for immunotherapy/ targeted therapy

不同药物购买渠道差异较大，其中购买瑞复美和亿珂海外仿制药的患者占比高达 32.3% 和 21%。

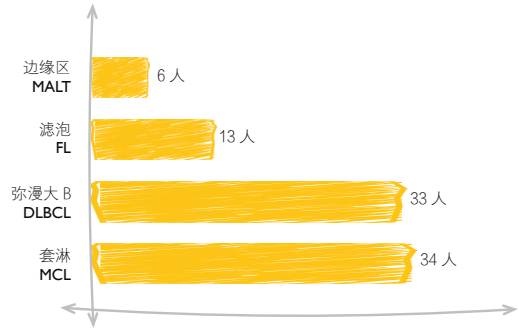
The purchasing channels for different drugs vary considerably. The purchasing rates of overseas generic drugs of Revlimid and Imbruvica are as high as 32.3% and 21%.



海外仿制药购买情况
Overseas purchasing of generic drugs

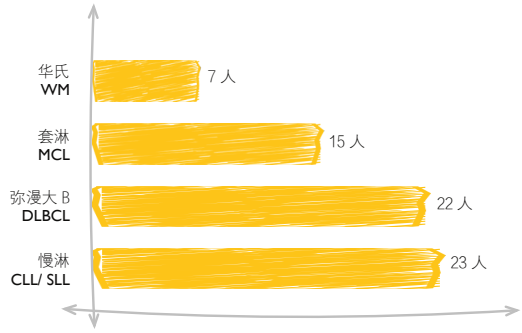
瑞复美海外仿制药购买主要集中在套淋、弥漫大 B 等亚型；亿珂海外仿制药购买主要集中在慢淋、弥漫大 B 等亚型。

The purchases of overseas generic drug of Revlimid are mainly concentrated in patients with MCL and DLBCL, while those of Imbruvica are mainly concentrated in patients with CLL/SLL and DLBCL.



购买瑞复美海外仿制药的主要亚型

Overseas purchasing of generic drug of Revlimid



购买亿珂海外仿制药的主要亚型

Overseas purchasing of generic drug of Imbruvica

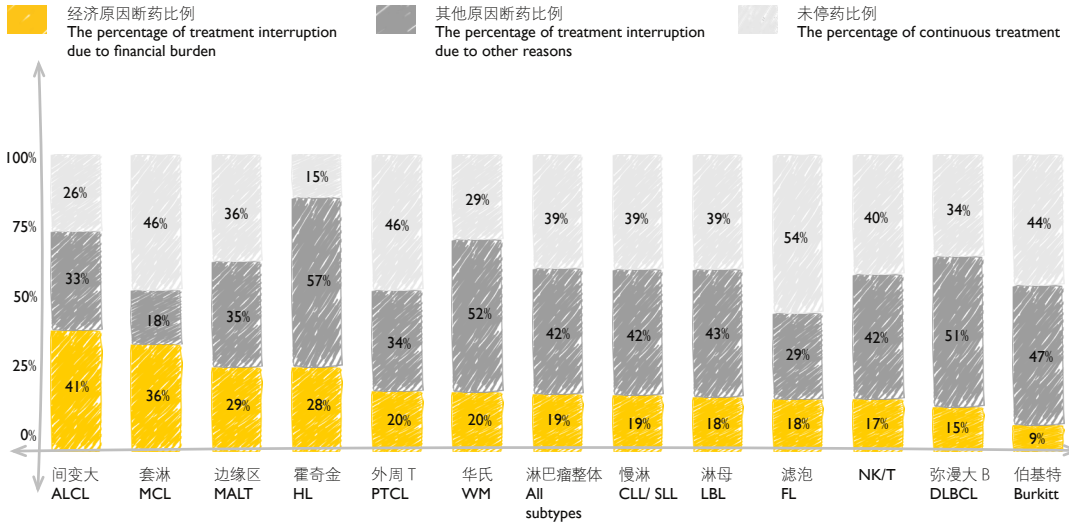
PART THREE 3

因经济原因而中断用药

Treatment Interruption due to Financial Difficulties

有 61% 的患者曾有过断药经历，其中有 19% 是因经济负担过重而断药。从所患淋巴瘤亚型来看，间变大、套淋这两种亚型因经济负担而断药的比例较高，分别为 41%，36%。

61% of the lymphoma patients have interrupted their medical treatment, of which 19% were due to enormous financial difficulties. In terms of lymphoma subtypes, patients with ALCL and MCL were of higher percentage of treatment interruption due to financial difficulties. The percentage are 41% and 36% respectively.

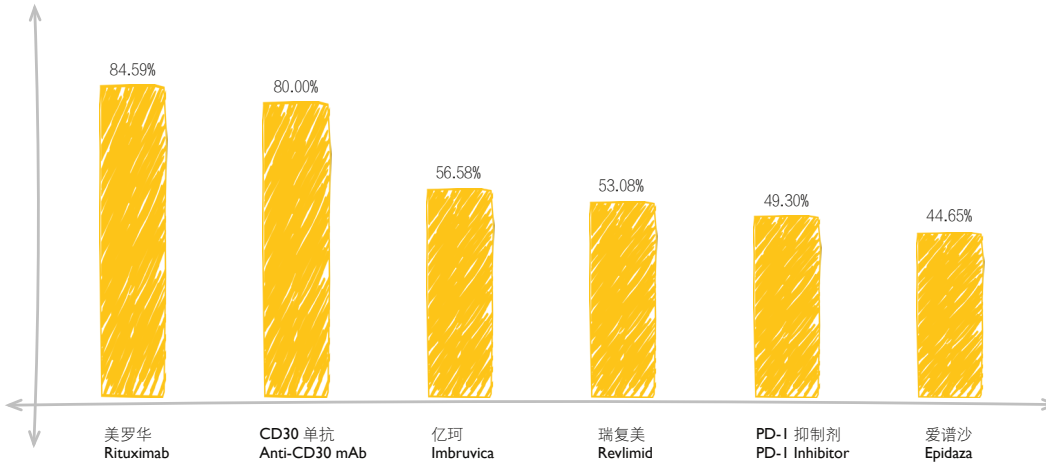


因经济原因停药情况

The situation of treatment interruption due to financial difficulties

患者中断免疫 / 靶向药的主要原因是经济负担过重。

The patients interrupted their medical treatment due to severe financial difficulties.



因经济原因中断免疫 / 靶向药情况

Interruption of immunotherapy/targeted therapy due to financial burden

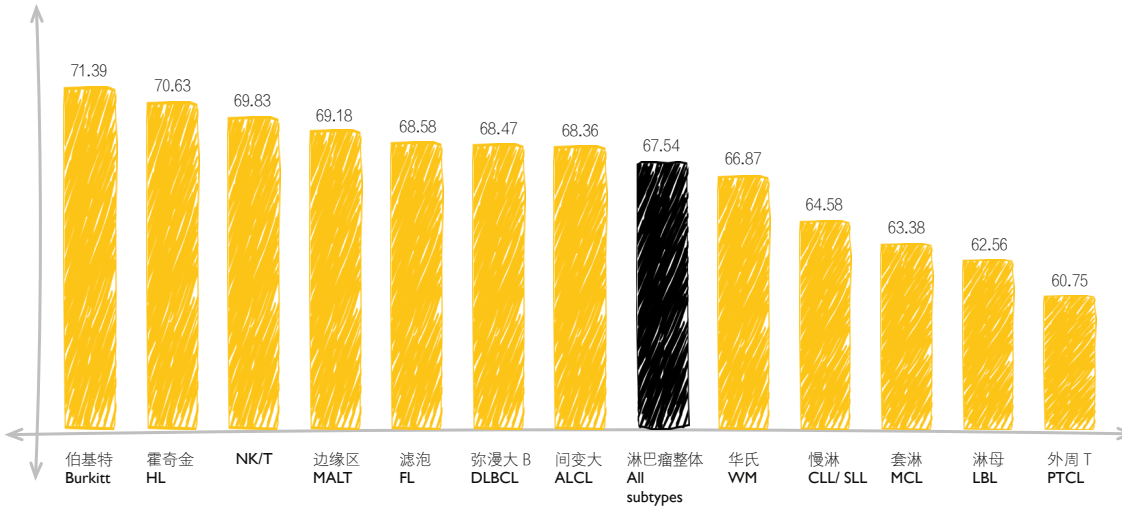
PART FOUR 4

生命质量
Quality of Life

生命质量自估
Self-evaluated Quality of Life

患者整体生命质量自估的平均值为 67.54，不同亚型之间略有区别，最低为 60.75，最高为 71.39。

The overall mean value of lymphoma patients on their quality of life was 67.54. There were slight differences among different subtypes. The lowest mean value was 60.75, and the highest mean value was 71.39.



生命质量自估平均值

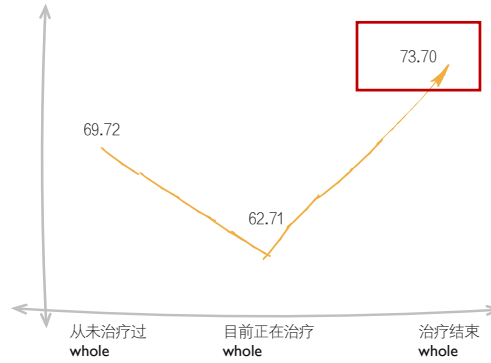
Average scores for Self-Evaluated Quality of Life

PART FOUR 4

治疗阶段与生命质量
Treatment Stages and Quality of Life

正在治疗的患者生命质量评分最低，但治疗结束后生命质量评分明显上升，且高于治疗之前，从侧面肯定了采取积极治疗的效果。

The score of quality of life of the patients under treatment was the lowest. The score increased significantly after the completion of treatment, which was higher than that before treatment. Such findings somewhat supported the positive outcome of active treatment.

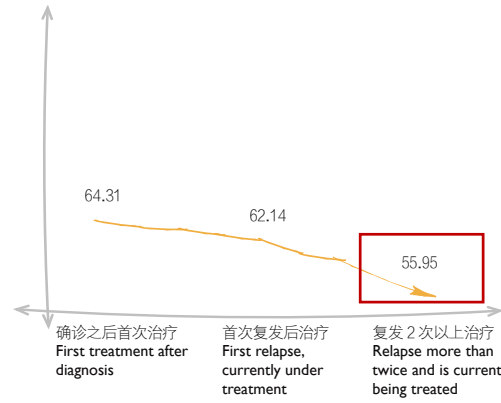


总体治疗阶段与生命质量

Overall treatment stage and quality of life

首次治疗期间，患者生命质量评分最高，而随着复发次数增加，病情加重，生命质量评分明显下降。

The quality of life score was the highest amony patients who were under first treatment after diagnosis, while the score decreased significantly with the increased number of relapses and aggravation of illness.

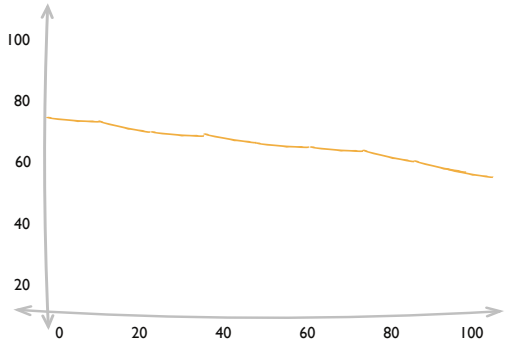


具体治疗阶段与生命质量

Specific treatment stages and quality of life

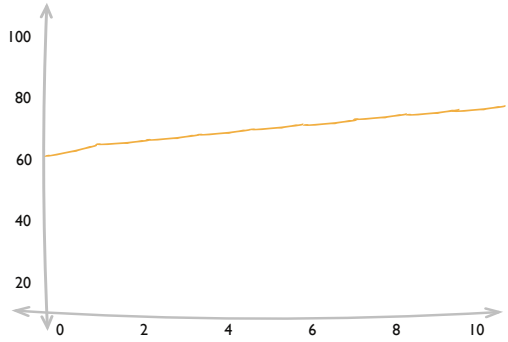
年龄和经济承受能力与生命质量
Age,Financial Capacity and Quality of Life

患者年龄越大，生命质量越低。
The quality of life score decreased with the age of the patients.



年龄对生命质量的影响
The association between age and quality of life

患者经济承受力越强，生命质量评分明显更高。
The more financially capable the patient, the higher the score of their quality of life.



经济承受能力对生命质量的影响
The association between financial capacity and quality of life

PART FOUR 4

症状对生命质量的影响
The Impact of Symptoms on Quality of Life

中位分值

Median score

注： 评分越高生命质量越差。

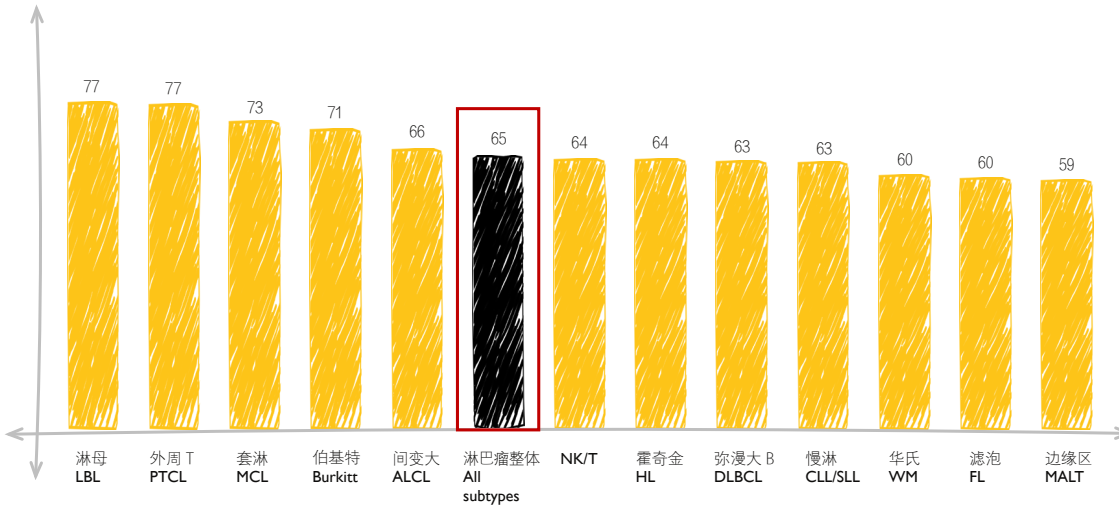
Note:The higher the score, the worse the quality of life.

经济困难与生命质量

The Impact of Financial Difficulties on Quality of Life

不论何种亚型，给患者生命质量带来最严重影响的不是各项身体症状，而是治疗带来的经济困难。

Regardless of subtypes of lymphoma, the most significant influence on quality of life is from the financial difficulties resulted from treatments rather than from the symptoms.



经济困难程度评分

The degree of financial difficulties

注： 评分越高生命质量越差。

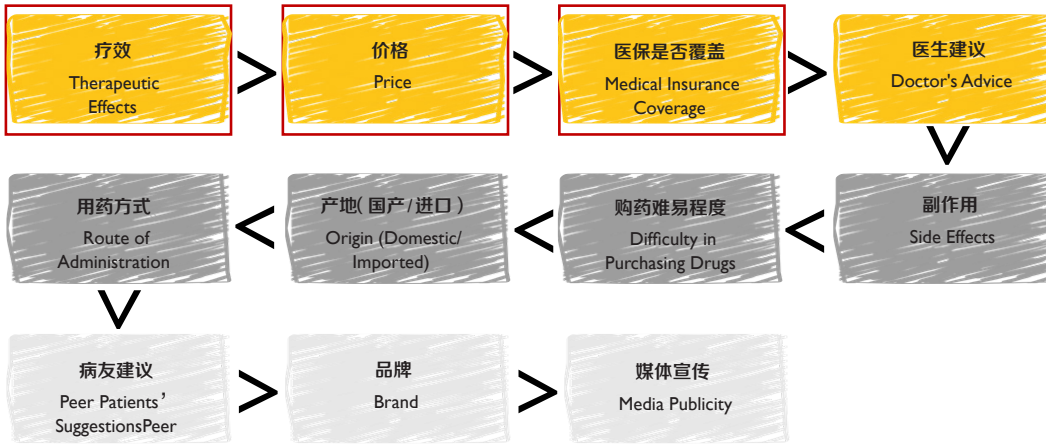
Note:The higher the score, the worse the quality of life.

PART FIVE 5

患者需求
Patient needs

决定用药的因素
Factors Affecting Patients' Choice of Medication

不同亚型患者在选择药品时，最看重的三个因素都是疗效、价格以及医保是否覆盖。
The three most important factors for patients with various subtypes to think about when they choose medications are: therapeutic effects, price and whether being covered by medical insurance.

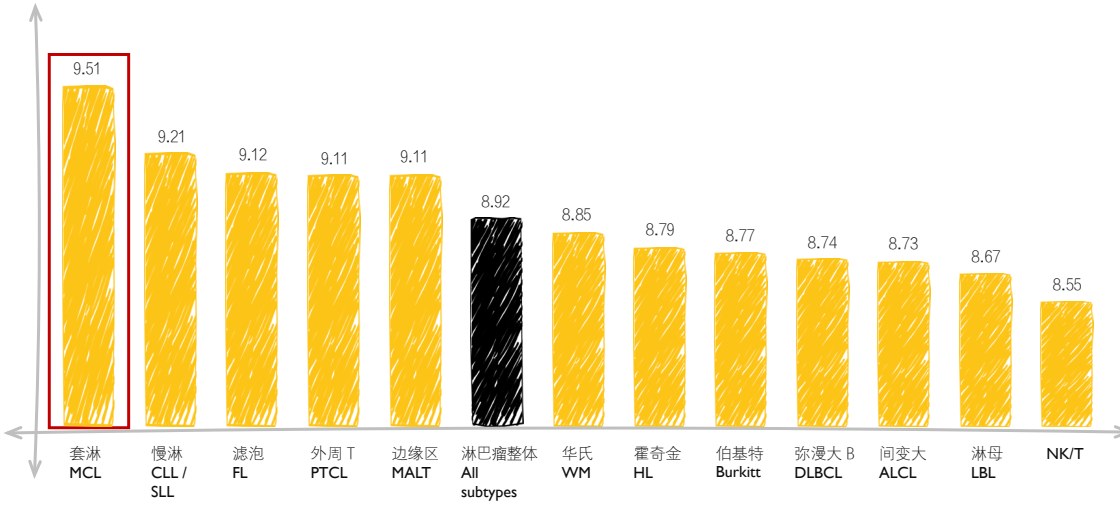


PART FIVE 5

新药期待
Desire for New Drugs

现有药物和疗法还不能满足患者的需要，患者迫切希望新的药物和疗法进入市场，且让他们有能力购买。

The existing drugs and treatments cannot meet the needs of patients. Patients are eager to have new and affordable drugs and treatments available in the market.



新药渴望程度

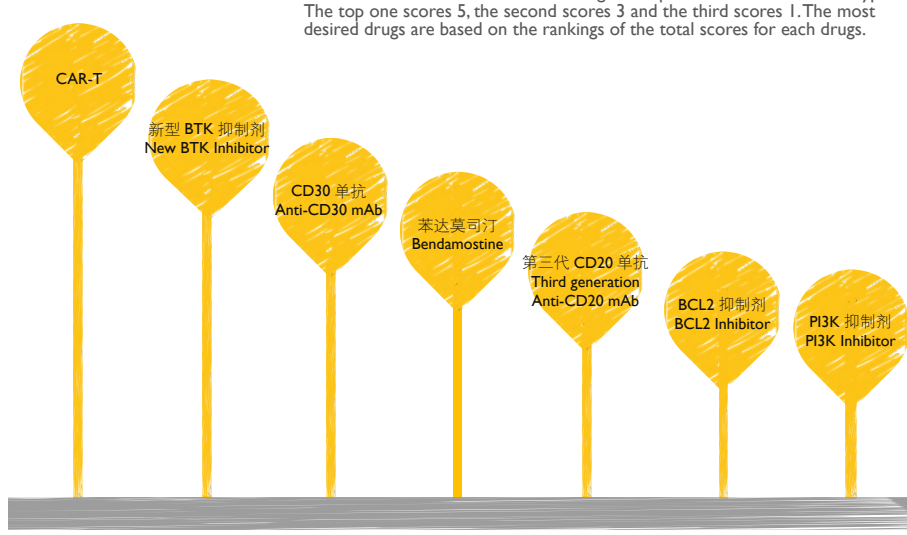
Degree of desire for new drugs

患者最期待上市的免疫／靶向药

The most desirable immunotherapy/targeted therapy by patients

统计方法：每个亚型患者最期望上市的3种药物，按第一名5分，第二名3分，第三名1分统计得出患者最期待的药物排名。

Statistical methods: 3 most desired drugs from patients with different subtypes. The top one scores 5, the second scores 3 and the third scores 1. The most desired drugs are based on the rankings of the total scores for each drugs.



弥漫大 B DLBCL	CAR-T
伯基特 Burkitt	CAR-T
淋母 LBL	CAR-T
NK/T	CAR-T
慢淋 CLL / SLL	新型 BTK 抑制剂（如 BGB-3111/ 泽布替尼） New BTK inhibitors (e.g. BGB-3111/Zanubrutinib)
华氏 WM	新型 BTK 抑制剂（如 BGB-3111/ 泽布替尼） New BTK inhibitors (e.g. BGB-3111/Zanubrutinib)
套淋 Mantle Cell	新型 BTK 抑制剂（如 BGB-3111/ 泽布替尼） New BTK inhibitors (e.g. BGB-3111/Zanubrutinib)

霍奇金 HL	CD30 单抗（如 SGN-35） Anti-CD30 mAb (e.g. SGN-35/ BV)
外周 T PTCL	CD30 单抗（如 SGN-35） Anti-CD30 mAb (e.g. SGN-35/ BV)
间变大 ALCL	CD30 单抗（如 SGN-35） Anti-CD30 mAb (e.g. SGN-35/ BV)
滤泡 FL	苯达莫司汀 Bendamostine
边缘区 MALT	苯达莫司汀 Bendamostine

PART SIX 6

主要发现
Key Findings

1 淋巴瘤发病症状不典型，常常容易被忽视。在本次调查中发现，如华氏、慢淋、MALT、套淋这些淋巴瘤亚型从发病到就诊平均时长甚至超过1年。而这四种亚型中，套淋甚至是侵袭性亚型。

The symptoms of lymphomas are atypical and often easy to be ignored. In this survey, we found that the average time lag from symptom onset to first medical encounter for some lymphoma subtypes, such as WM, CLL, MALT and MCL, was longer than one year. What's more, among the four subtypes, MCL was even an aggressive type.

2 本次调查报告也证实，淋巴瘤在诊断过程中，确实存在着很高的误诊比例。像NK/T、间变大都有超过半数的患者有过被误诊为其他疾病的经历。

The survey also confirms that there is a high misdiagnosis rate of lymphomas. More than half of the patients with subtypes of NK/T and ALCL have been misdiagnosed with other diseases.

3 从异地就诊分布图来看，绝大部分异地会诊的淋巴瘤患者集中在北京、上海、广州、成都四个城市得到确诊。

Based on the map of trans-local diagnosis of lymphoma, vast majority of the lymphoma patients receive their definitive diagnosis in Beijing, Shanghai, Guangzhou and Chengdu.

4 高达93.5%的青年赋闲患者，是由于患病导致不能工作或读书；70%的中年赋闲患者，是由于患病而不能工作或不得不提前退休。可见淋巴瘤对适龄劳动力有极强的消极影响，特别是对于青壮年劳动力。

Up to 93.5% of the young unemployed patients are unable to work or study because of the illness. 70% of the middle-aged unemployed patients are unable to work or retired in advance because of the illness. The data show that lymphoma has a strong negative impact on the working age labor force, especially on the young and middle-aged labor force.

5 免疫 / 靶向药在给淋巴瘤患者带来治疗获益的同时，也给患者及其家庭带来相当大的经济负担，在本次调查中，因免疫 / 靶向药带来总花费增量最多的四大亚型分别为：间变大为 37 万，霍奇金 29 万，NK/T 25 万，慢淋 19 万。

The immunotherapy and targeted therapy bring therapeutic benefits, together with considerable financial burden to lymphoma patients and their families. The survey results indicate that the four subtypes with the highest total cost increment due to immunotherapy/targeted therapy are ALCL(370,000 yuan), HL(290,000 yuan), NK/T (250,000 yuan), and CLL(190,000 yuan).

6 通过 EORTCQLQ-C30 生命质量量表对淋巴瘤患者进行评价发现，治疗过程中患者整体耐受性比较好，而且治疗结束后生命质量评分明显高于治疗之前，但是随着复发次数的增加，患者生命质量评分却明显降低。因此，降低复发可能性的确是淋巴瘤患者治疗非常需要关注的。

The EORTCQLQ-C30 quality of life scale was used to evaluate the patients with lymphoma. It is found that patients have a good tolerance on treatments, and their quality of life after treatments is significantly higher than that before the treatments. However, with the increase of relapse frequency, the patients' quality of life has significantly decreased. Therefore, reducing the likelihood of relapse is a key factor in the treatment of lymphoma patients.

7 各淋巴瘤亚型患者都表现出对于新的药物和治疗方法的需求，其中套淋、慢淋、滤泡、外周 T、MALT 患者的需求呼声都很迫切。

Patients with various lymphoma subtypes have shown the desire for new drugs and treatments, among which patients with MCL, CLL, PTCL, and MALT, have urgent needs.