

## 2014 GLOBAL PATIENT SURVEY







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## **DEMOGRAPHICS**



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#### **DEMOGRAPHICS: Who Responded**

Please describe your experience with lymphoma. (male vs female)

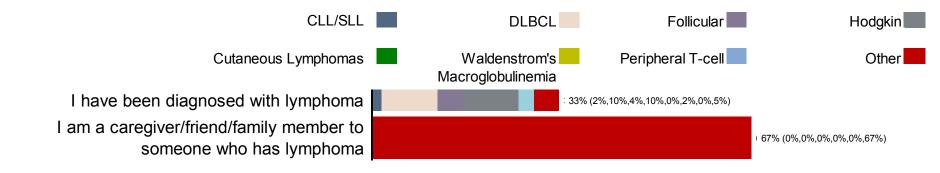
I have been diagnosed with lymphoma
I am a caregiver/friend/family member to someone who has lymphoma





#### **DEMOGRAPHICS: Who Responded**

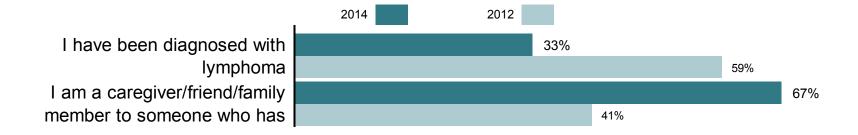
Please describe your experience with lymphoma. (by lymphoma sub-type)





#### **DEMOGRAPHICS: Who Responded**

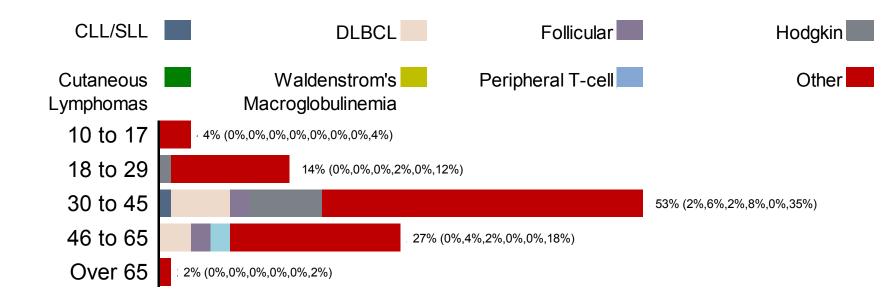
Please describe your experience with lymphoma. (2014 vs 2012)





#### **DEMOGRAPHICS:** Age of Respondents

What is this patient's age? (by lymphoma sub-type)





## **DEMOGRAPHICS:** Age and Gender of Respondents

What is this patient's age and gender?

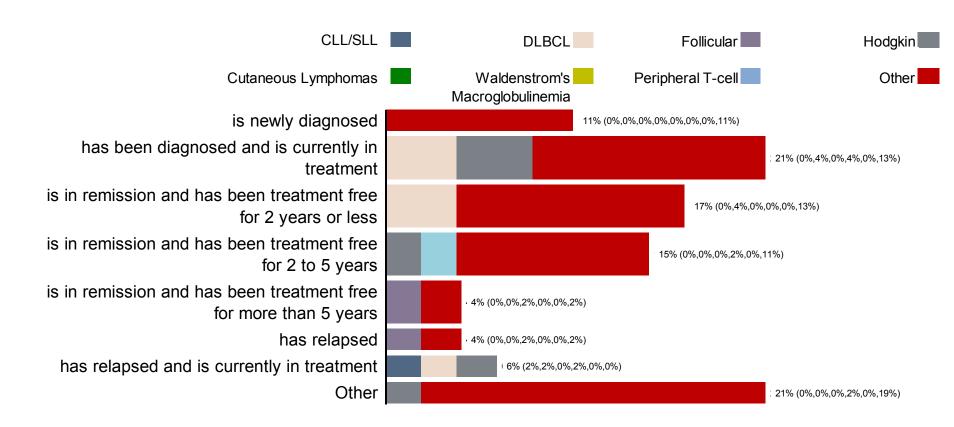
Response Rates			
	No. of	Portion of	
	Respondents	Responses	
Total	49	100%	
Male	23	47%	
Female	26	53%	
10 to 17	2	4%	
18 to 29	7	14%	
30 to 45	26	53%	
46 to 65	13	27%	
Over 65	1	2%	





## **DEMOGRAPHICS: Stage of Patient Journey**

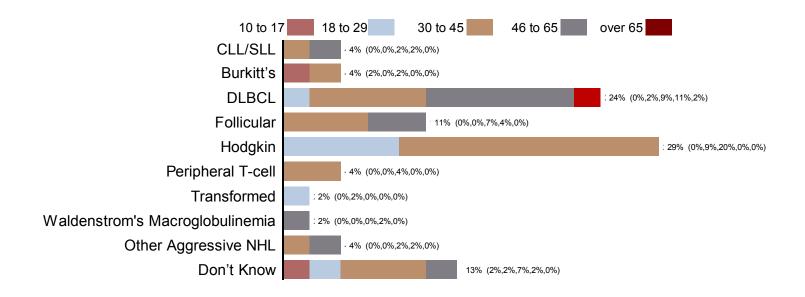
What stage best describes where the patient is in the lymphoma journey? (by lymphoma sub-type)





#### **DEMOGRAPHICS:** Lymphoma Sub-type

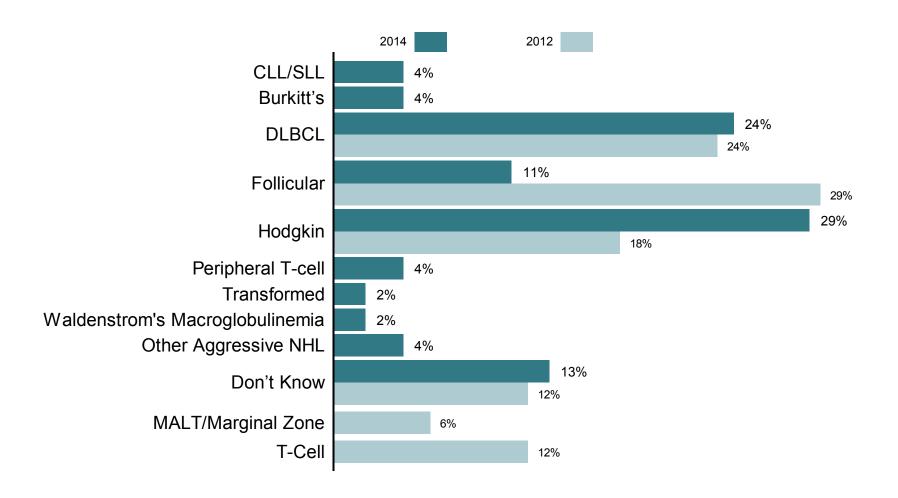
What sub-type of lymphoma does the patient have? (by age)





#### **DEMOGRAPHICS:** Lymphoma Sub-type

What sub-type of lymphoma does the patient have? (2014 vs 2012)







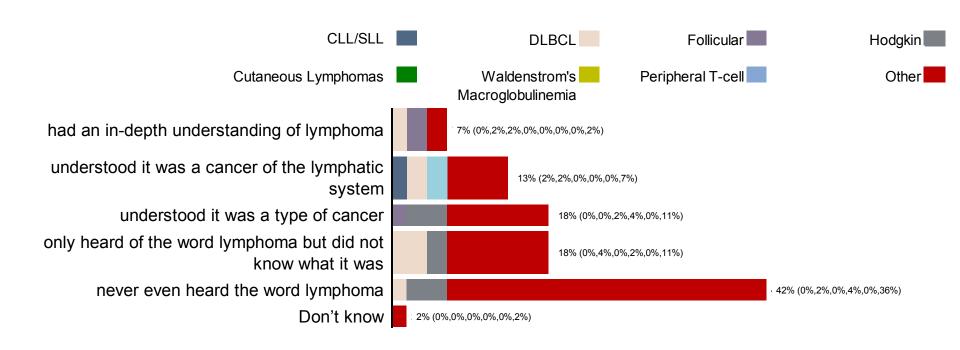
## PRE-DIAGNOSIS



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#### PRE-DIAGNOSIS: Understanding of Lymphoma

Please tell us how much the patient understood about lymphoma. (by lymphoma sub-type)

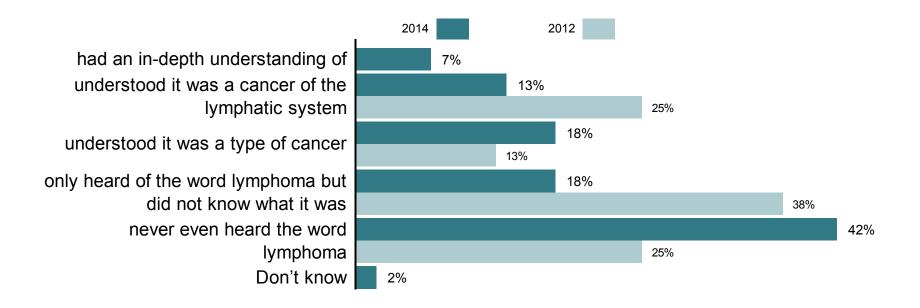






#### PRE-DIAGNOSIS: Understanding of Lymphoma

Please tell us how much the patient understood about lymphoma. (2014 vs 2012)







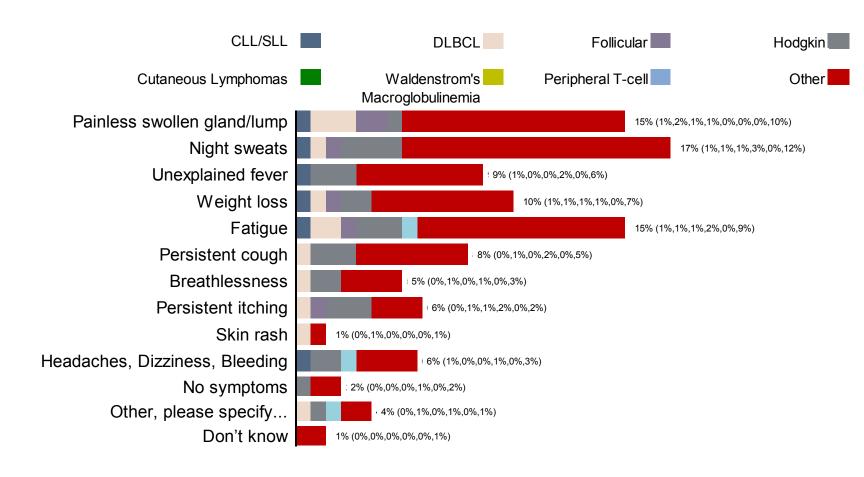
## BEING DIAGNOSED



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#### BEING DIAGNOSED: Initial Symptoms

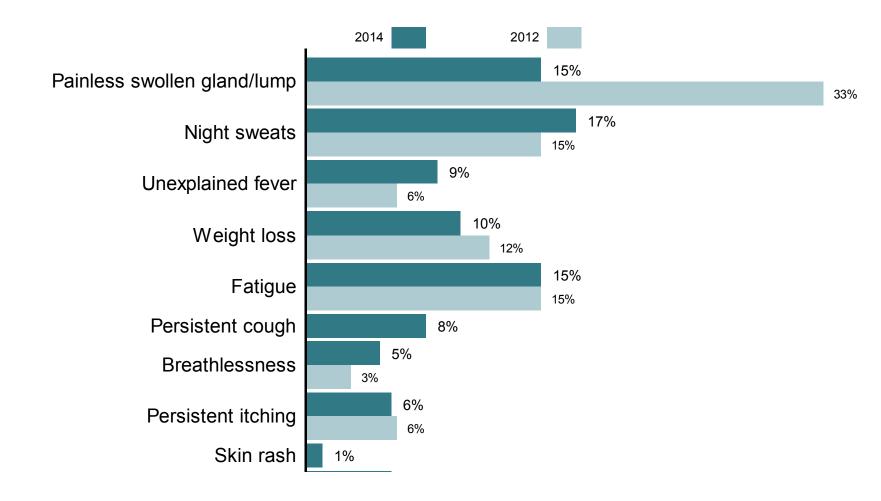
Looking back did the patient have any of the following symptoms? (by lymphoma sub-type)





## BEING DIAGNOSED: Initial Symptoms

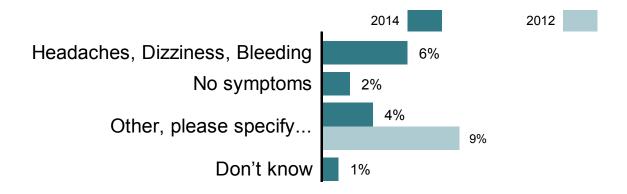
Looking back did the patient have any of the following symptoms? (2014 vs 2012)





## BEING DIAGNOSED: Initial Symptoms

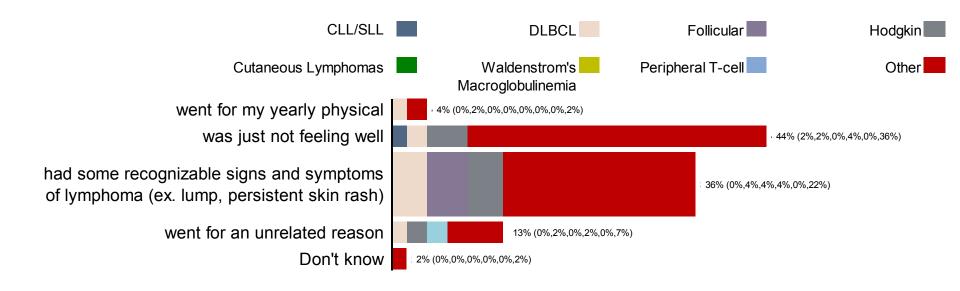
Looking back did the patient have any of the following symptoms? (2014 vs 2012)





#### BEING DIAGNOSED: Initial Prompt for Physician Visit

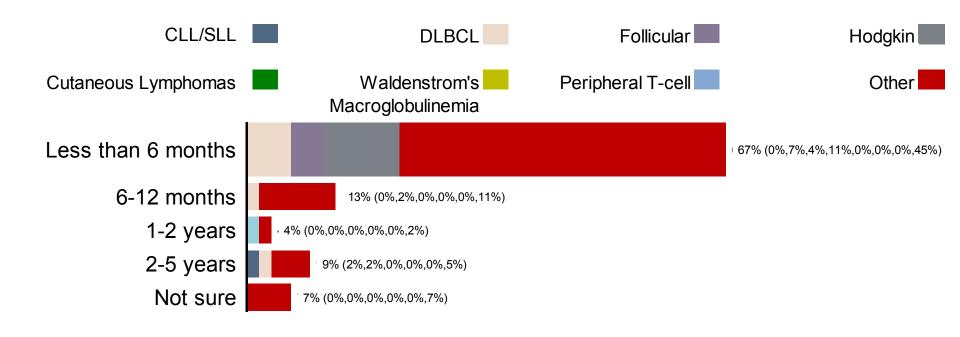
What initially prompted the patient to go to the doctor? (by lymphoma sub-type)





#### BEING DIAGNOSED: Time To First Visit to Physician

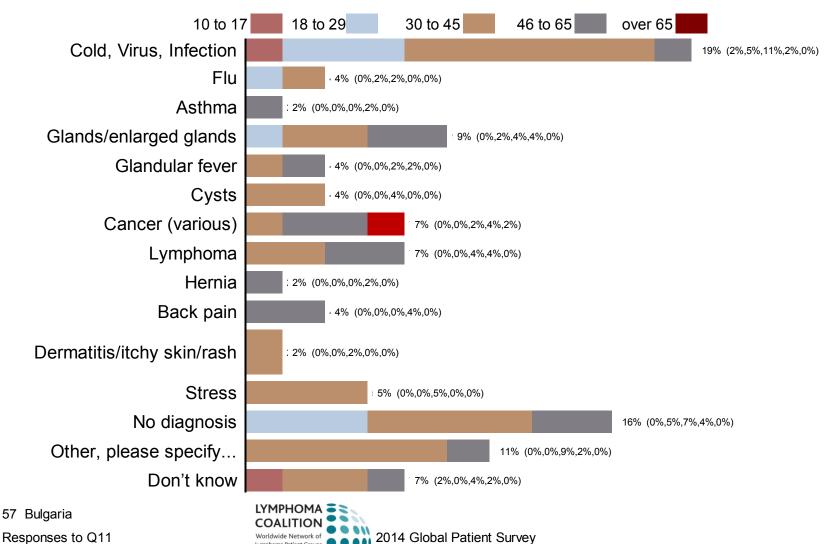
When you look back what do you estimate the time was between first experiencing any symptoms and the patient's first visit to see a doctor? (by lymphoma sub-type)





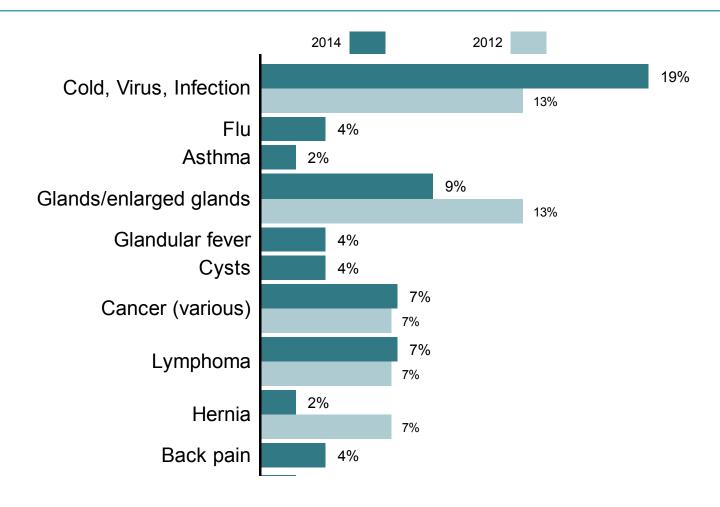
#### **BEING DIAGNOSED: Initial Diagnosis**

What was the doctor's diagnosis for the patient's INITIAL symptoms? (by age)



#### **BEING DIAGNOSED: Initial Diagnosis**

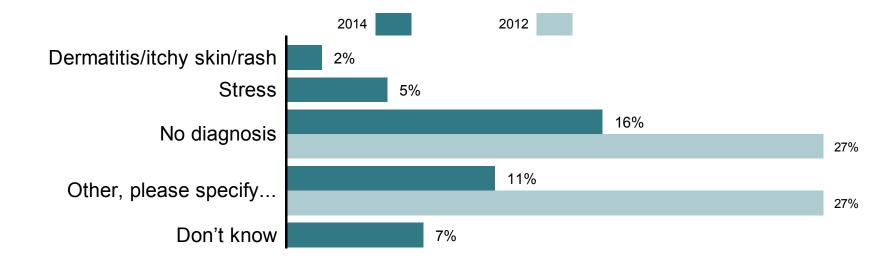
What was the doctor's diagnosis for the patient's INITIAL symptoms? (2014 vs 2012)





#### **BEING DIAGNOSED: Initial Diagnosis**

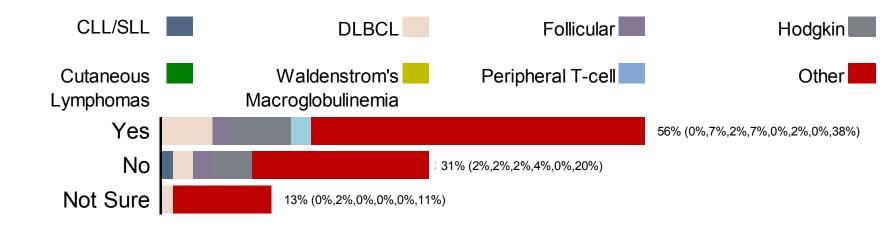
What was the doctor's diagnosis for the patient's INITIAL symptoms? (2014 vs 2012)





#### BEING DIAGNOSED: Prescription for 1st Diagnosis

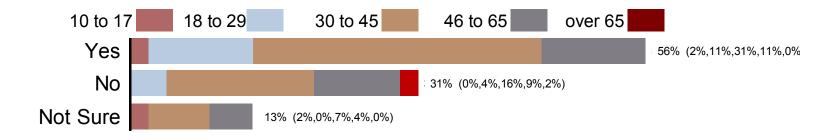
Was the patient given any medication for their initial diagnosis? (by lymphoma sub-type)





## BEING DIAGNOSED: Prescription for 1st Diagnosis

Was the patient given any medication for their initial diagnosis? (by age)

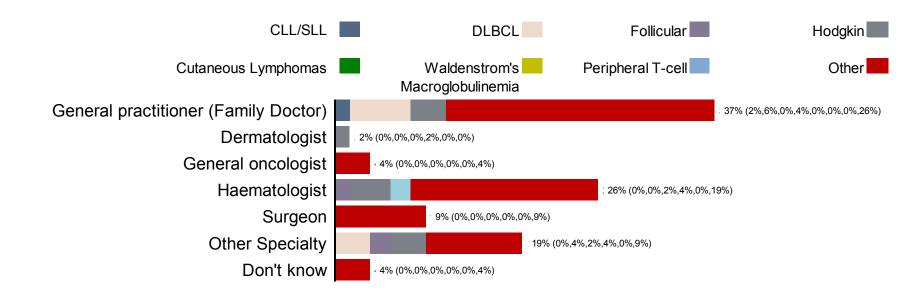






#### BEING DIAGNOSED: Type of Physician at Initial Diagnosis

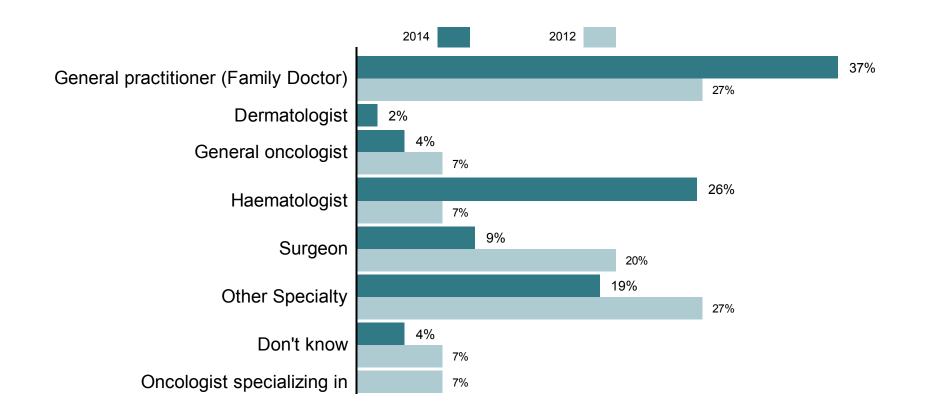
What type of doctor was the patient in the care of at initial diagnosis? (by lymphoma sub-type)





#### BEING DIAGNOSED: Type of Physician at Initial Diagnosis

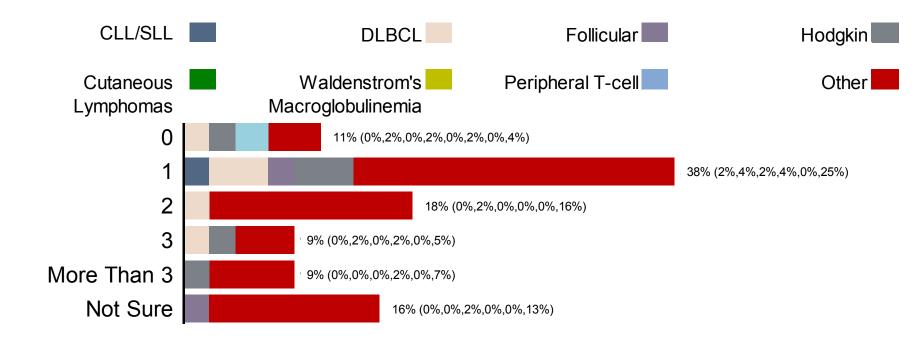
What type of doctor was the patient in the care of at initial diagnosis? (2014 vs 2012)





#### BEING DIAGNOSED: Number of Diagnoses Received

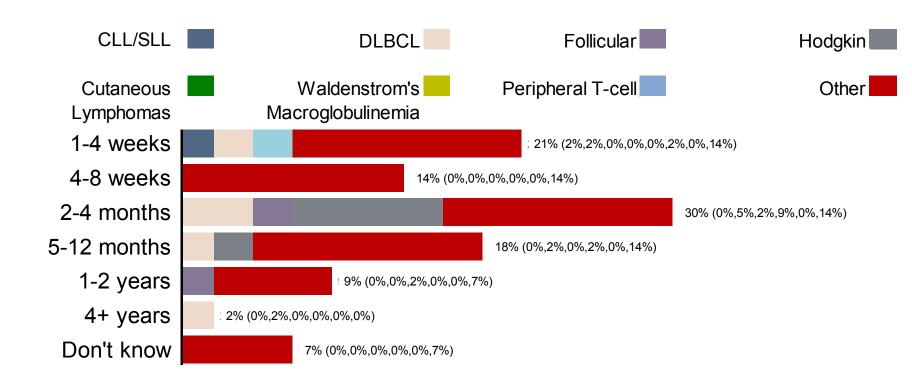
How many diagnoses did the patient receive before being officially diagnosed with lymphoma? (by lymphoma sub-type)





## BEING DIAGNOSED: Timing of Accurate Diagnosis

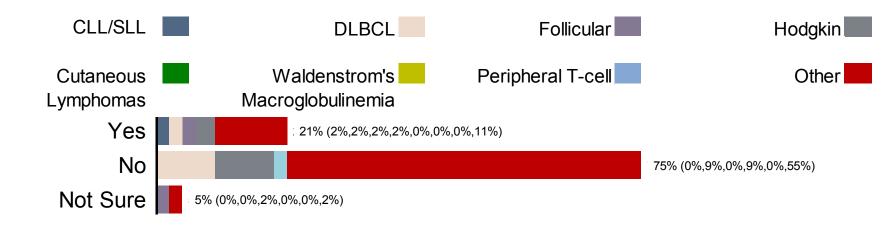
How long did it take for the patient to be ACCURATELY diagnosed with lymphoma? (by lymphoma subtype)





## BEING DIAGNOSED: Suspicion of Lymphoma

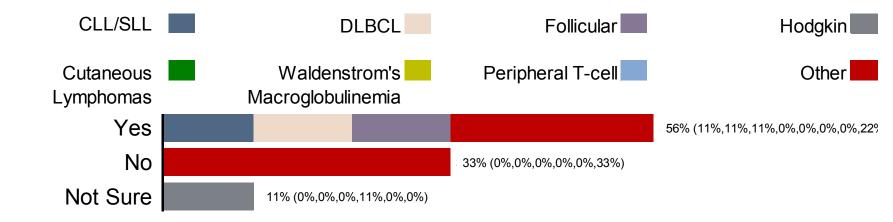
Did you or anyone in your support community EVER suspect the patient might have lymphoma prior to their official diagnosis? (by lymphoma sub-type)





#### BEING DIAGNOSED: Suspicion Discussed with Physician

Was this suspicion ever discussed with the doctor? (by lymphoma sub-type)







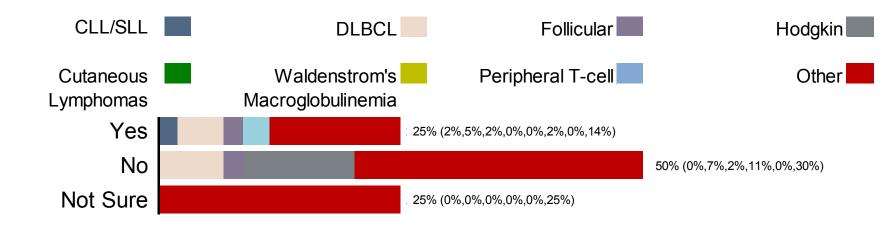
# CLINICAL TRIALS



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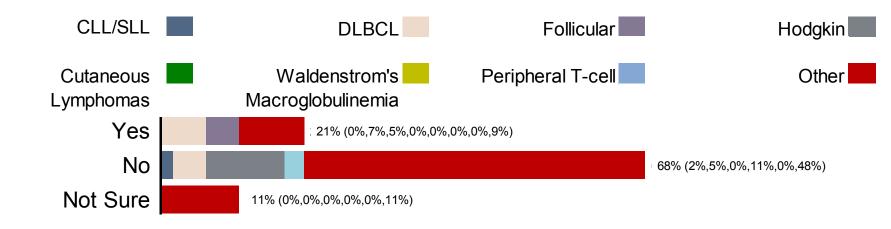
## CLINICAL TRIALS: Knowledge at Diagnosis

At the time of diagnosis did the patient know what a clinical trial was? (by lymphoma sub-type)



## CLINICAL TRIALS: Offering as Treatment Option

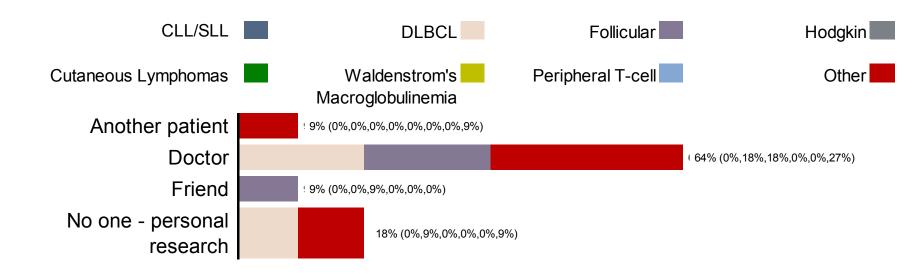
Has the patient ever been approached to participate in a clinical trial as an option to treatment? (by lymphoma sub-type)





## CLINICAL TRIALS: Who Discussed Option With Patient

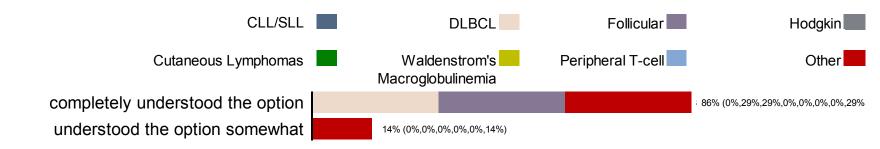
Who discussed this option of treatment with the patient? (by lymphoma sub-type)





#### **CLINICAL TRIALS: Understanding Options**

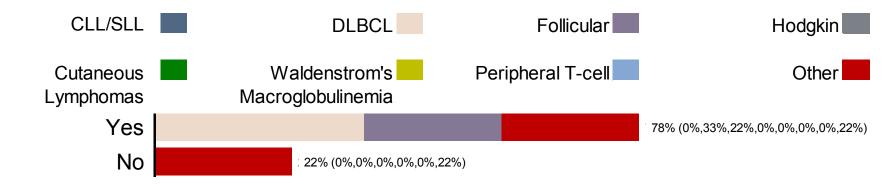
How well did the patient understand their option of undergoing a clinical trial? (by lymphoma sub-type)





# **CLINICAL TRIALS: Agreed to Participate**

Of those that were asked did the patient participate? (by lymphoma sub-type)





#### CLINICAL TRIALS: If Asked, Would Patient Participate

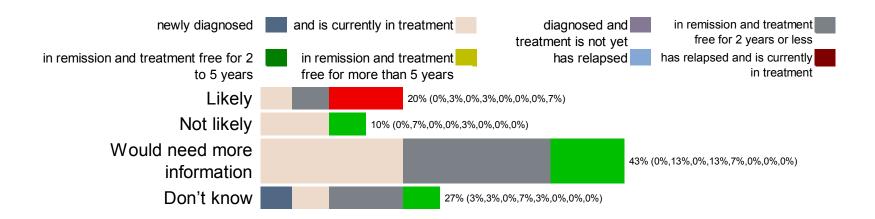
What were the patient's reasons for not wanting to participate? (by lymphoma sub-type)





#### **CLINICAL TRIALS: Reasons for Not Participating**

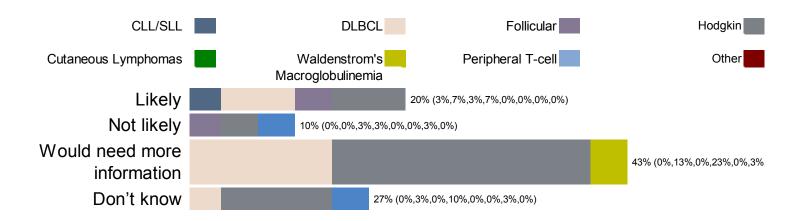
Of those that were not asked how likely is it that the patient would agree to participate in a clinical trial if asked? (by journey stage)





#### **CLINICAL TRIALS: Reasons for Not Participating**

Of those that were not asked how likely is it that the patient would agree to participate in a clinical trial if asked? (by lymphoma sub-type)







# QUALITY OF LIFE



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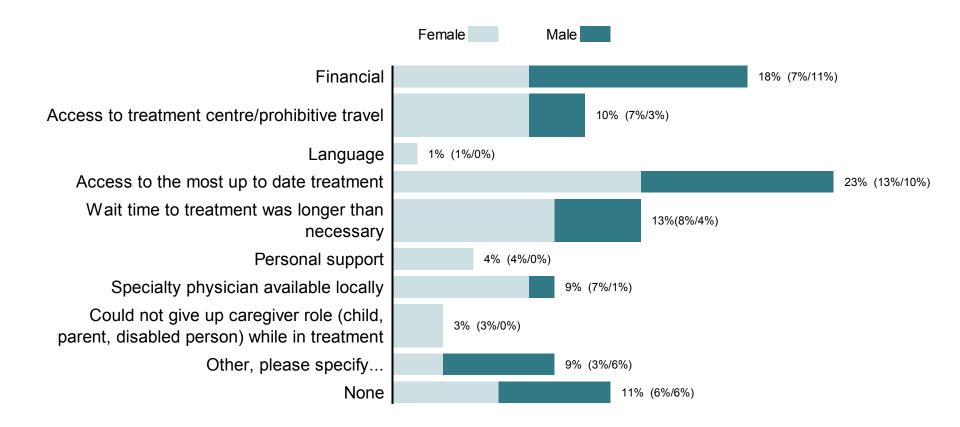
# QoL: Barriers to ReceivingTreatment



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#### QUALITY OF LIFE: Barriers to Receiving Treatment

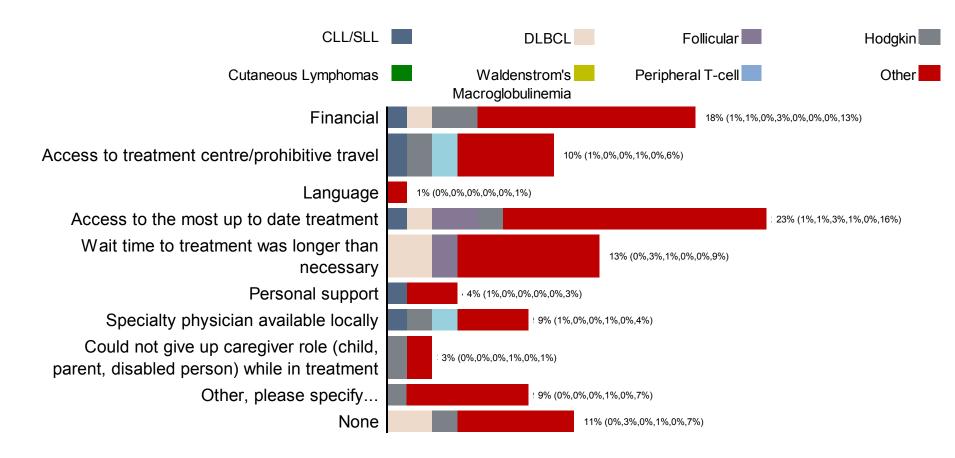
What barriers has the patient experienced in receiving adequate lymphoma treatment? (male vs female)





#### QUALITY OF LIFE: Barriers to Receiving Treatment

What barriers has the patient experienced in receiving adequate lymphoma treatment? (by lymphoma sub-type)

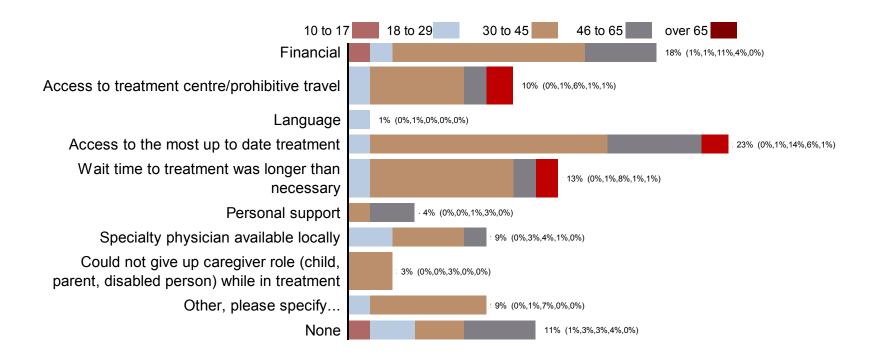






#### QUALITY OF LIFE: Barriers to Receiving Treatment

What barriers has the patient experienced in receiving adequate lymphoma treatment? (by age)





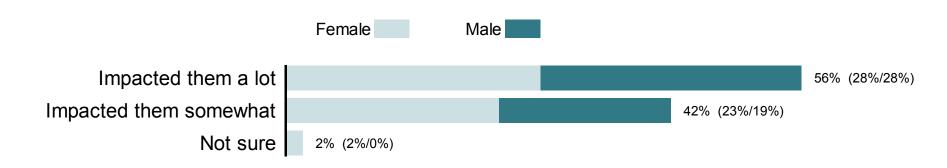


# QoL: Impact on Sense of Well Being



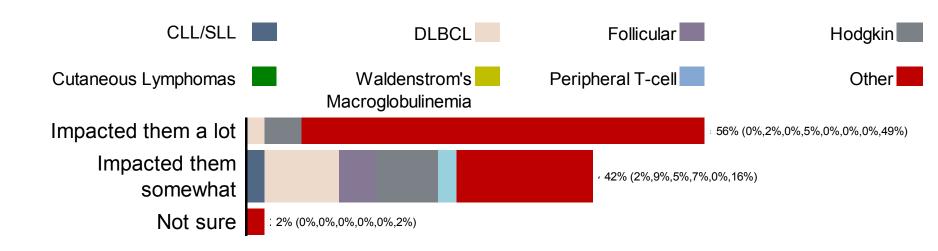
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Fatigue (male vs female)



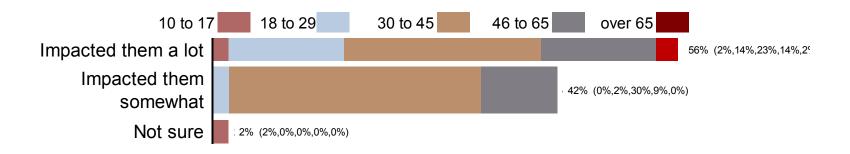


Fatigue (by lymphoma sub-type)



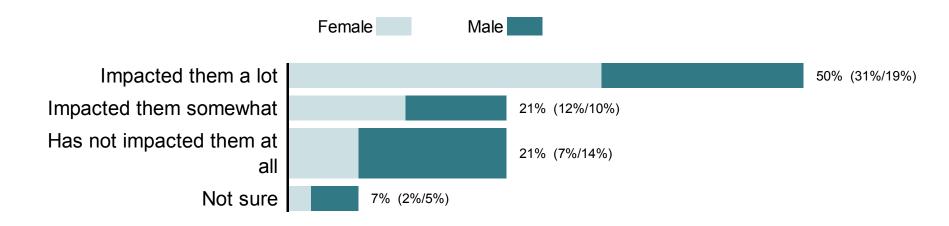


Fatigue (by age)



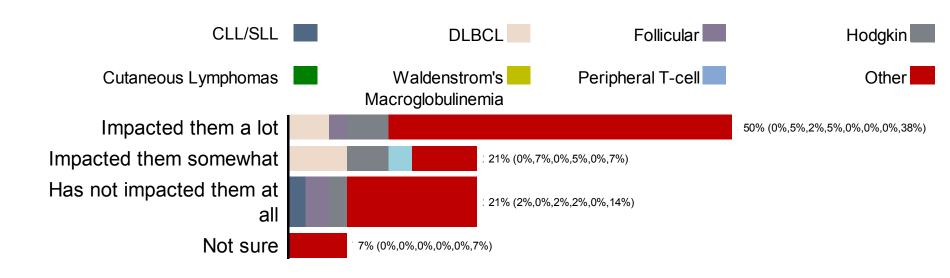


Hair loss (male vs female)



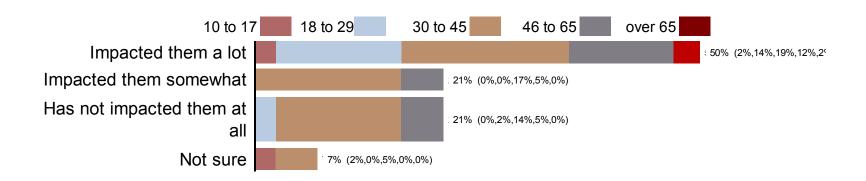


Hair loss (by lymphoma sub-type)



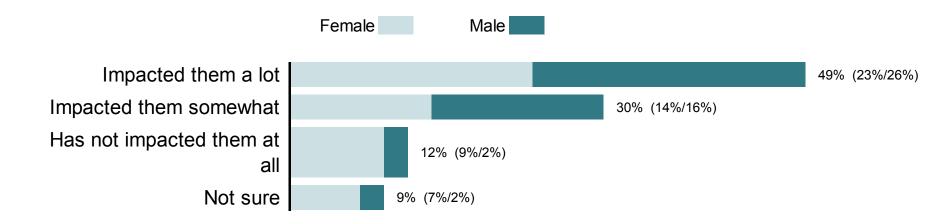


Hair loss (by age)



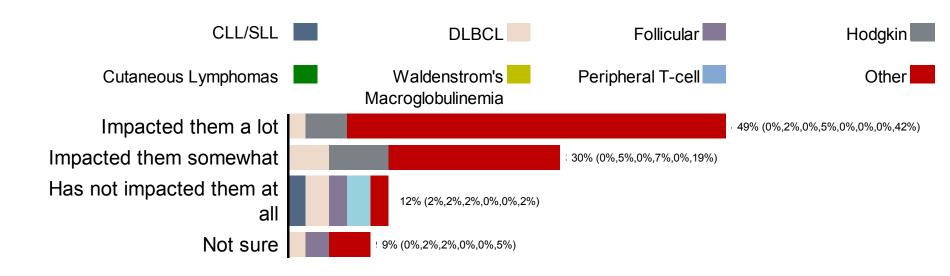


Muscle weakness (male vs female)



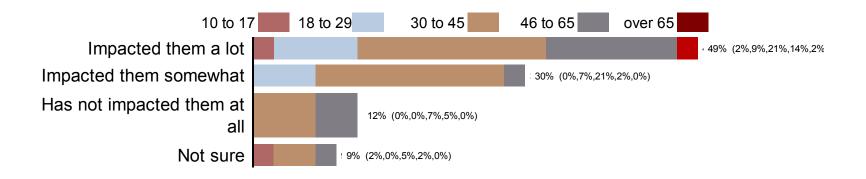


Muscle weakness (by lymphoma sub-type)





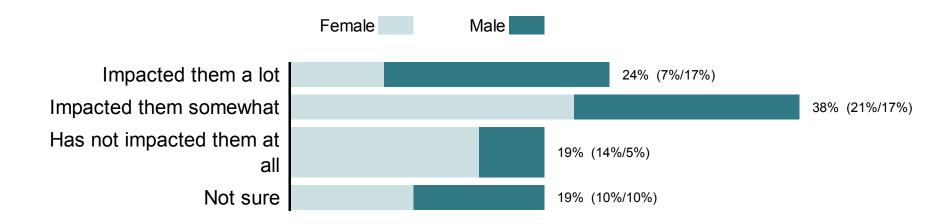
Muscle weakness (by age)







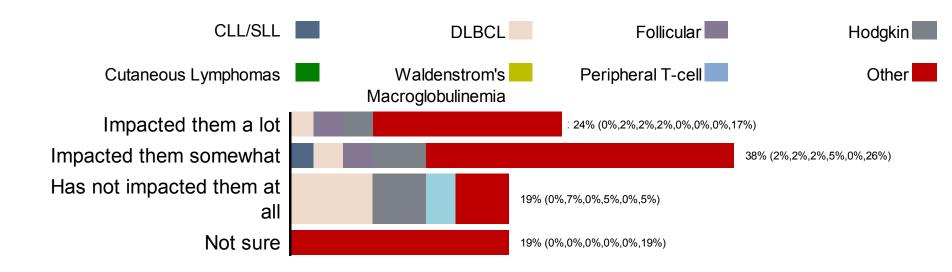
Trouble concentrating (male vs female)





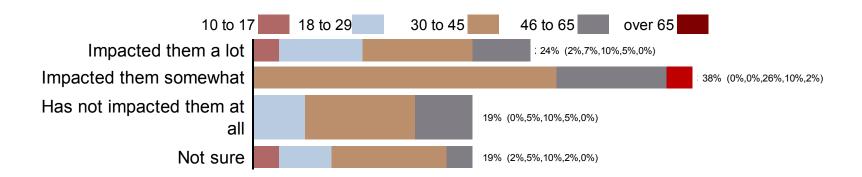


Trouble concentrating (by lymphoma sub-type)



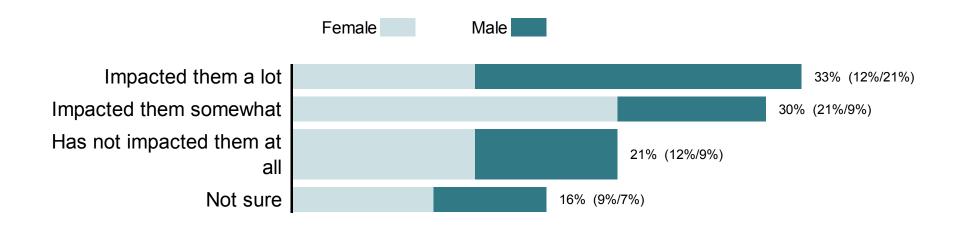


Trouble concentrating (by age)



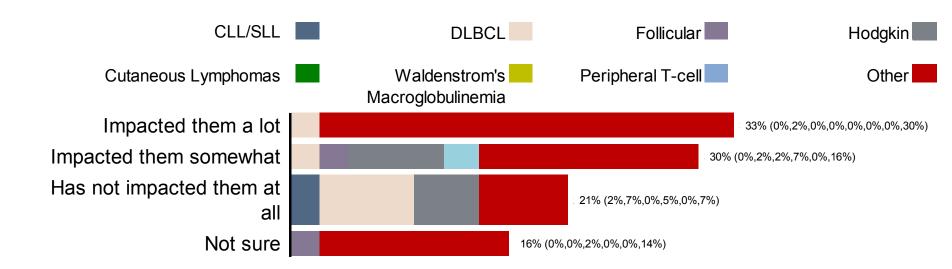


Sleeplessness (male vs female)



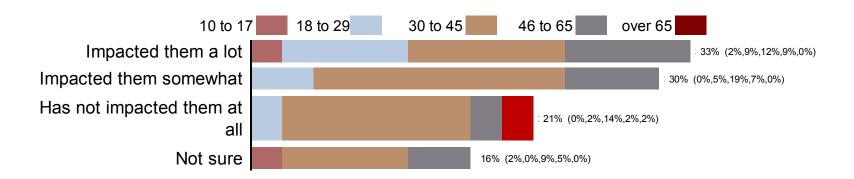


Sleeplessness (by lymphoma sub-type)



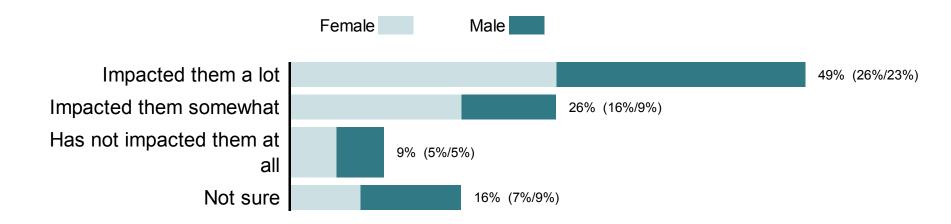


Sleeplessness (by age)



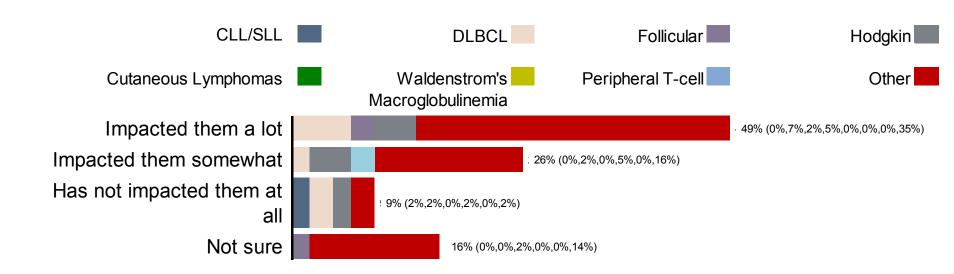


Changes in taste and smell (male vs female)



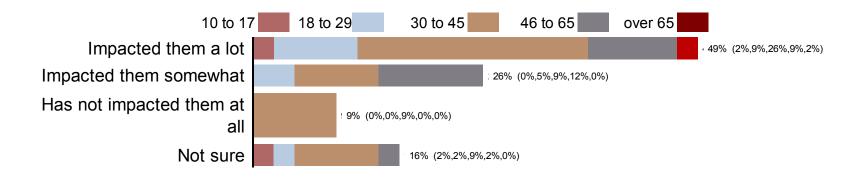


Changes in taste and smell (by lymphoma sub-type)



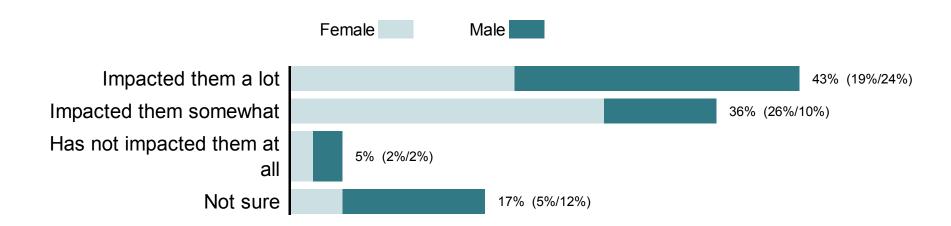


Changes in taste and smell (by age)





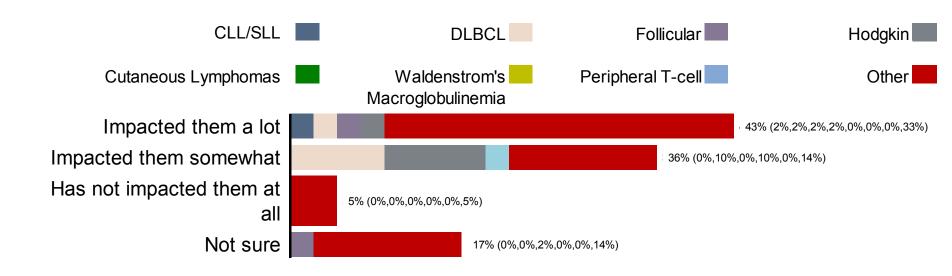
Bowel changes (male vs female)





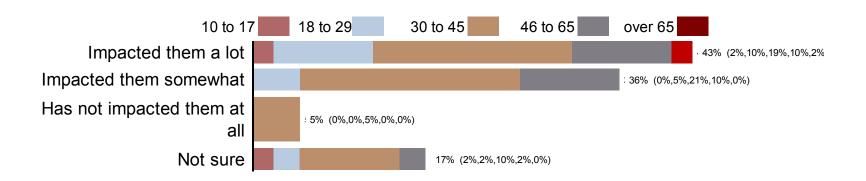


Bowel changes (by lymphoma sub-type)



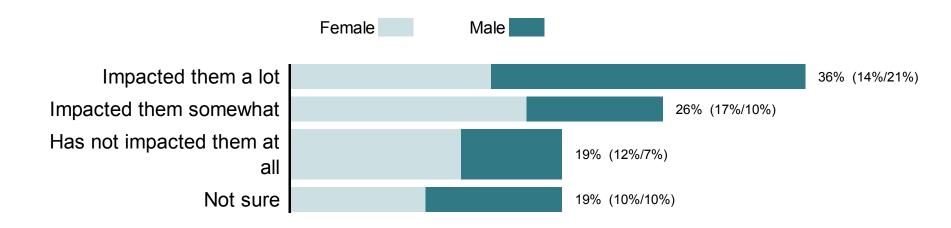


Bowel changes (by age)



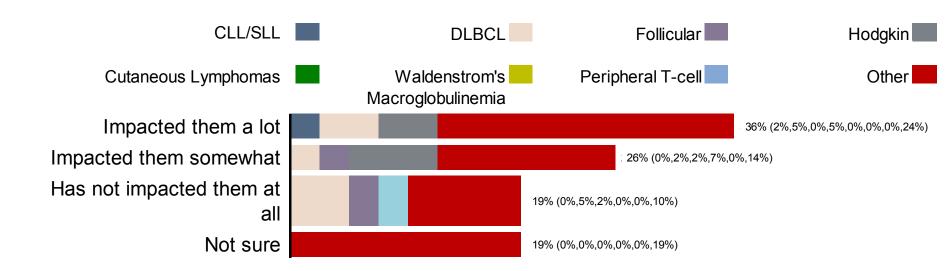


Aching joints (male vs female)



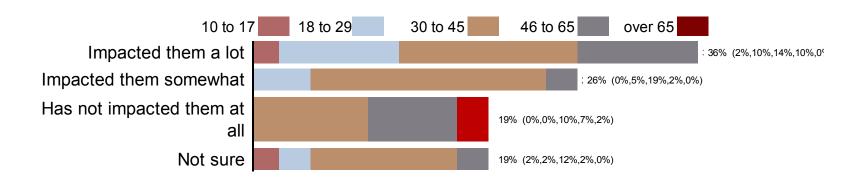


Aching joints (by lymphoma sub-type)



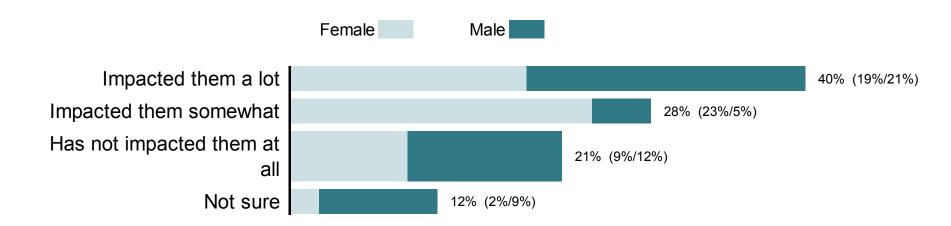


Aching joints (by age)



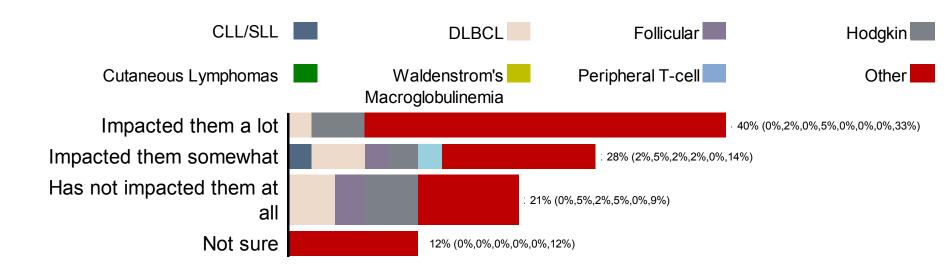


Nausea and vomiting (male vs female)



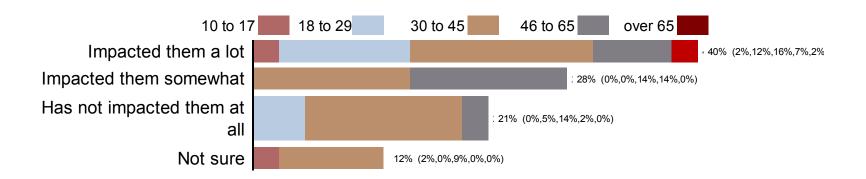


Nausea and vomiting (by lymphoma sub-type)



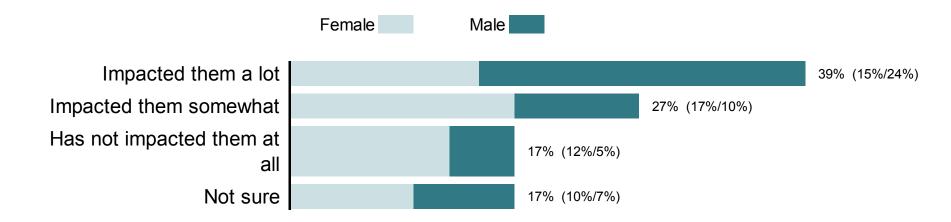


Nausea and vomiting (by age)



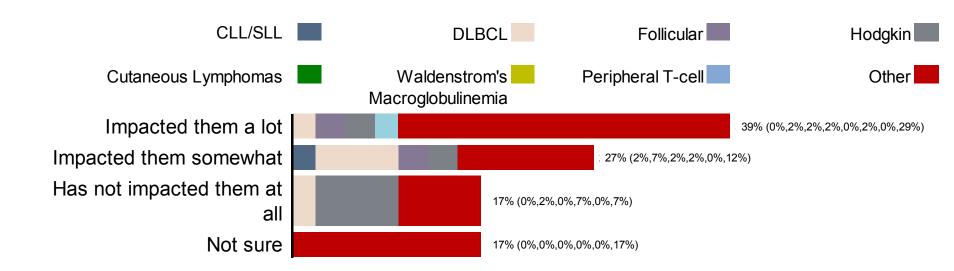


Problems fighting infections (male vs female)



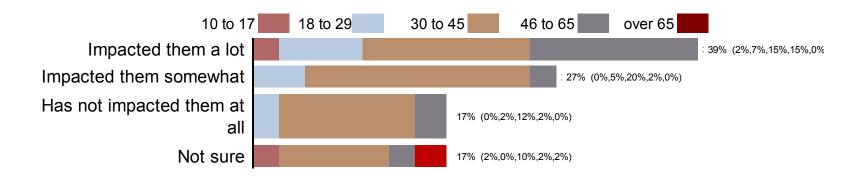


Problems fighting infections (by lymphoma sub-type)





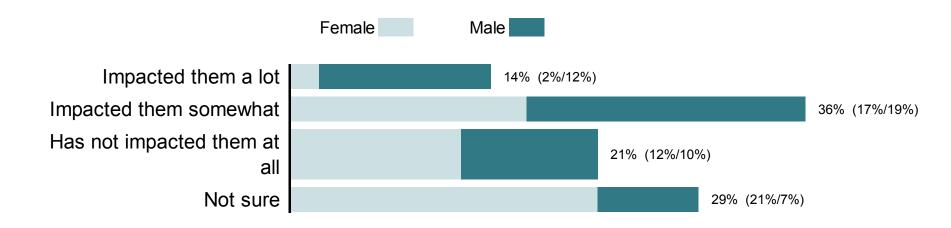
Problems fighting infections (by age)





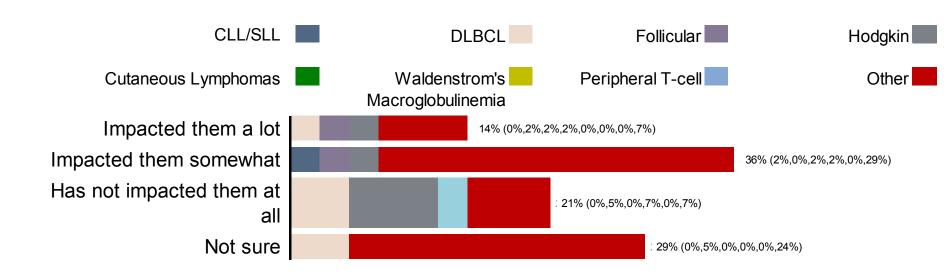


Memory loss (male vs female)



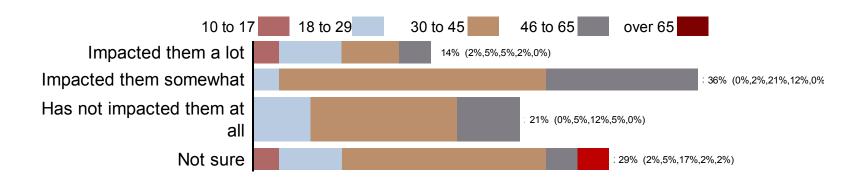


Memory loss (by lymphoma sub-type)





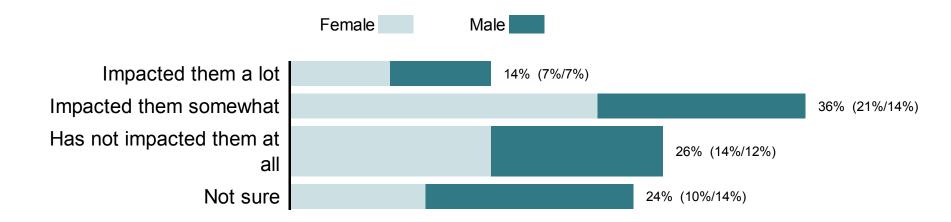
Memory loss (by age)





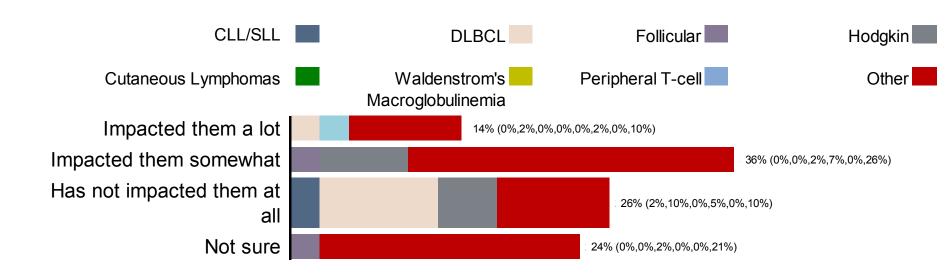


Skin reactions (male vs female)



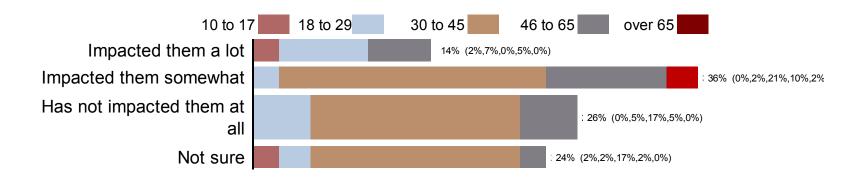


Skin reactions (by lymphoma sub-type)





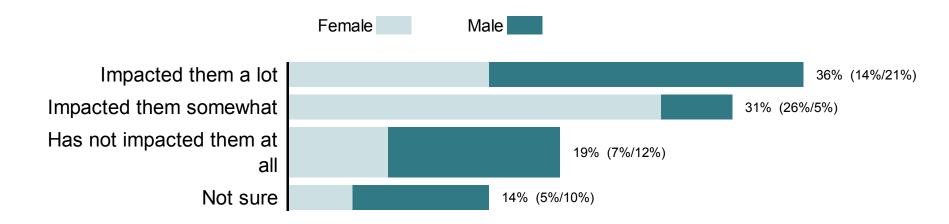
Skin reactions (by age)





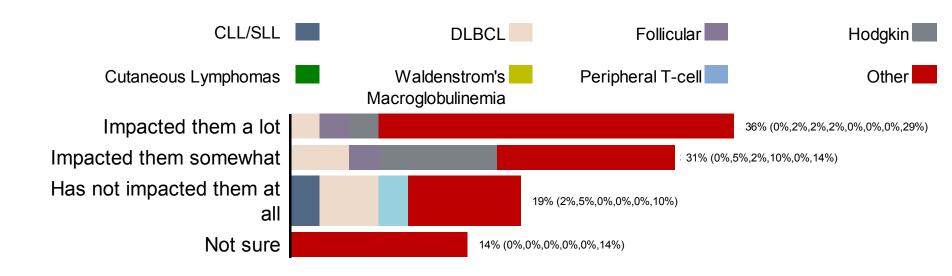


Mucositis/mouth ulcers (male vs female)



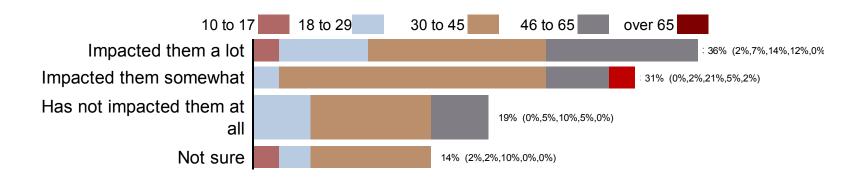


Mucositis/mouth ulcers (by lymphoma sub-type)



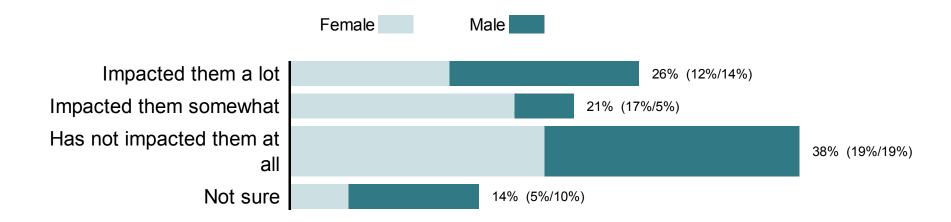


Mucositis/mouth ulcers (by age)





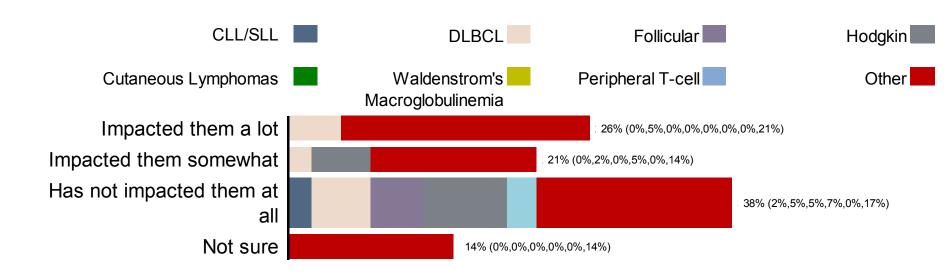
Loss of appetite (male vs female)





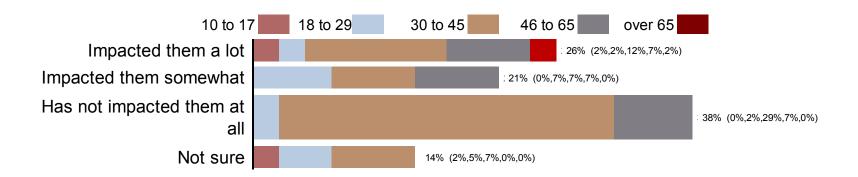


Loss of appetite (by lymphoma sub-type)



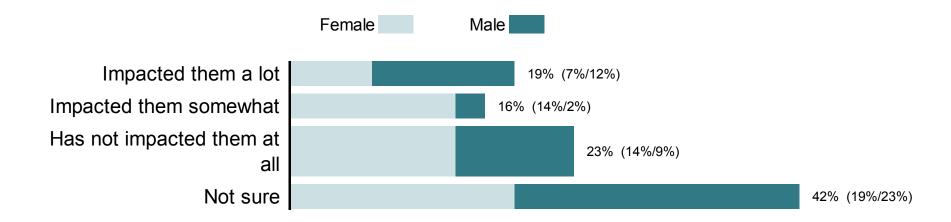


Loss of appetite (by age)



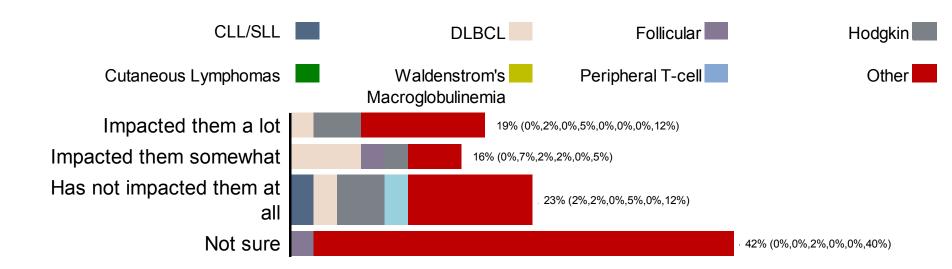


Change in sexual function (male vs female)



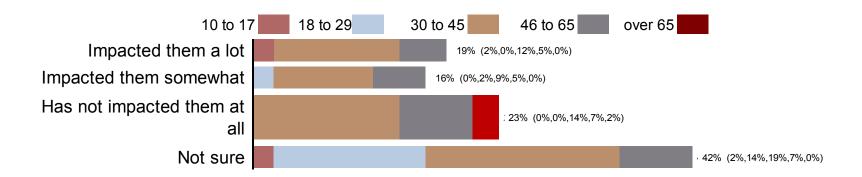


Change in sexual function (by lymphoma sub-type)



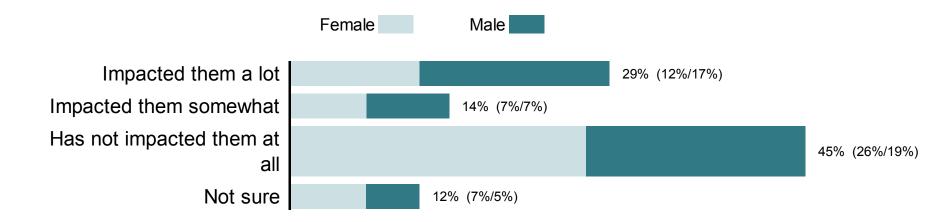


Change in sexual function (by age)





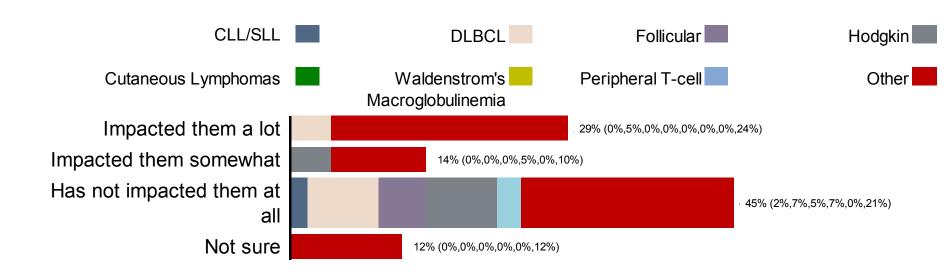
Weight loss (male vs female)





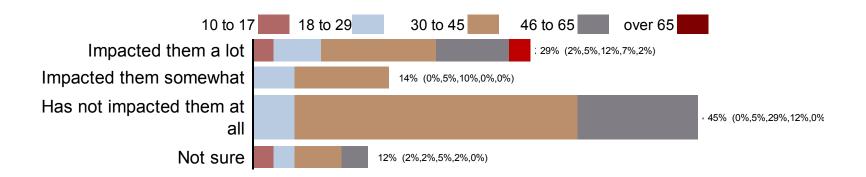


Weight loss (by lymphoma sub-type)



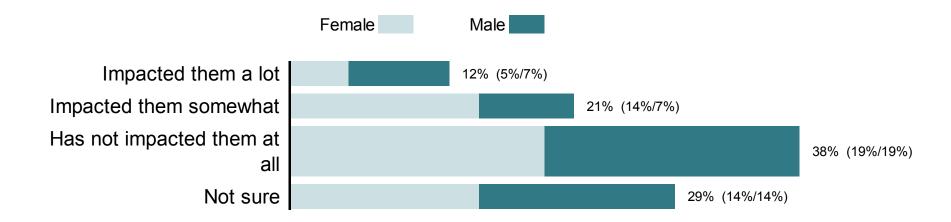


Weight loss (by age)





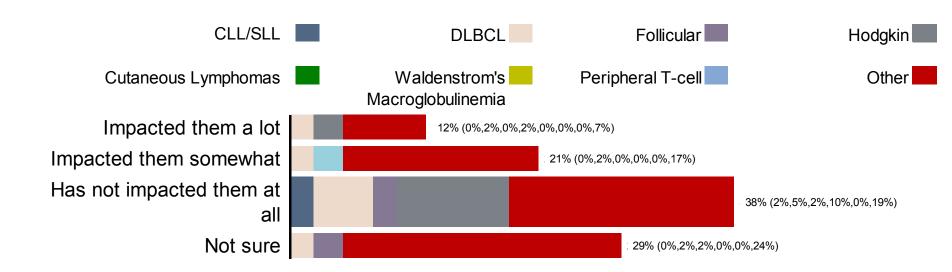
Fluid retention (male vs female)





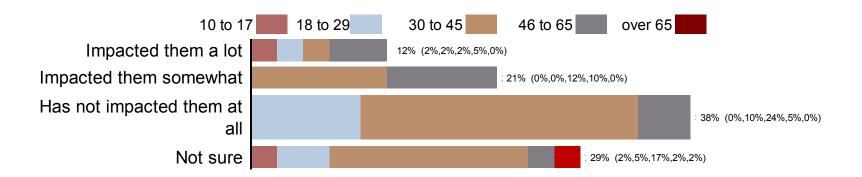


Fluid retention (by lymphoma sub-type)





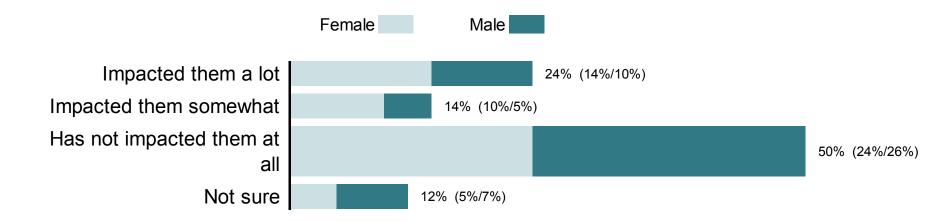
Fluid retention (by age)







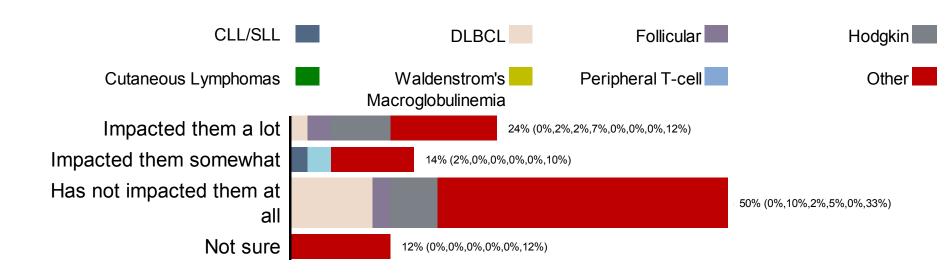
Weight gain (male vs female)





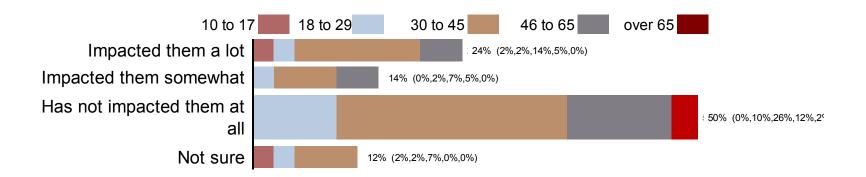


Weight gain (by lymphoma sub-type)





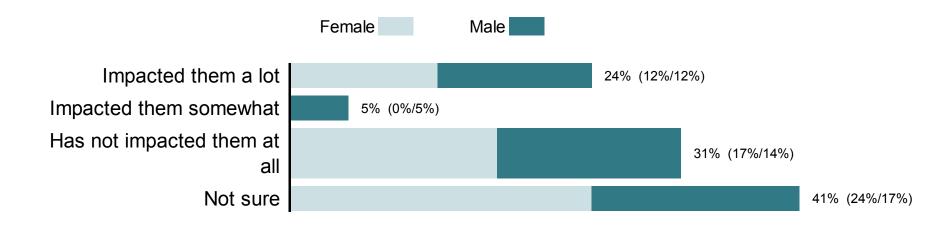
Weight gain (by age)







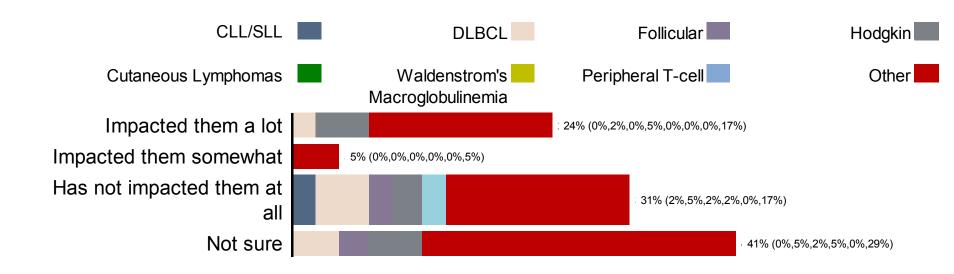
Loss of fertility (male vs female)





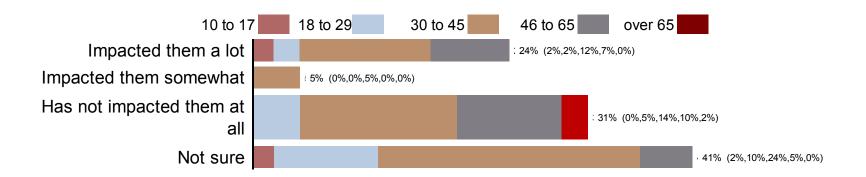


Loss of fertility (by lymphoma sub-type)





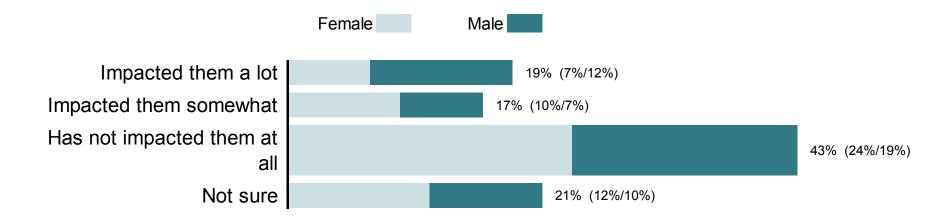
Loss of fertility (by age)





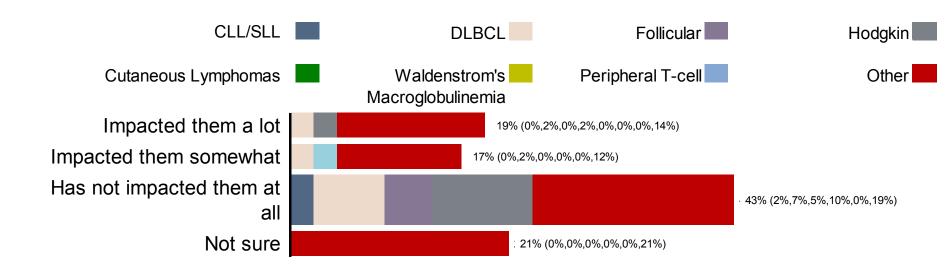


Swelling of arms and legs (male vs female)



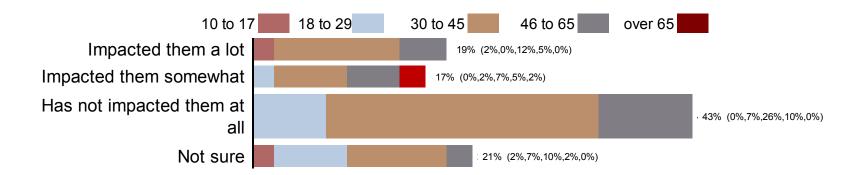


Swelling of arms and legs (by lymphoma sub-type)



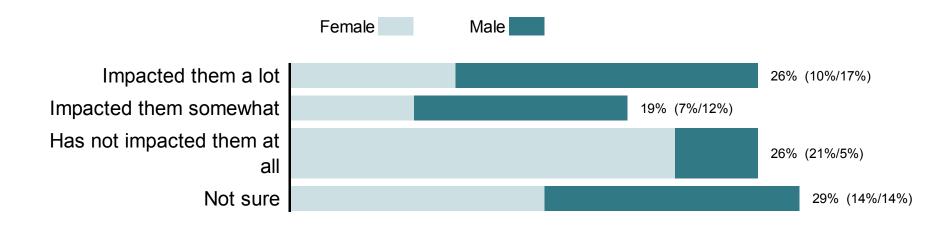


Swelling of arms and legs (by age)





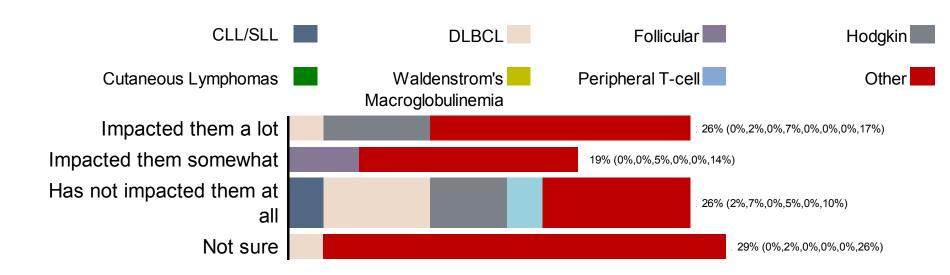
Itching (male vs female)





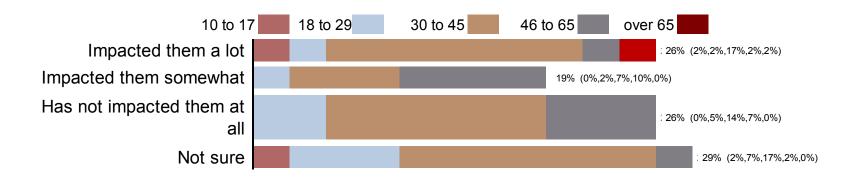


Itching (by lymphoma sub-type)





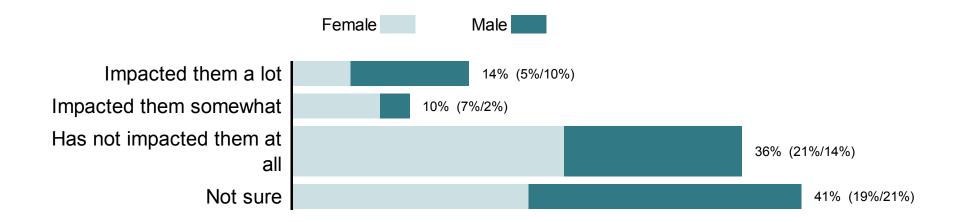
Itching (by age)





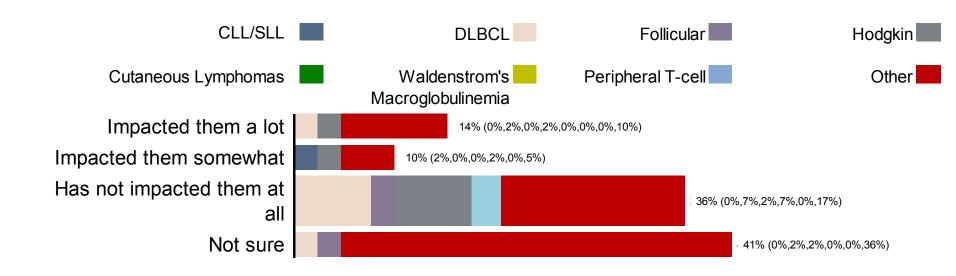


Burning (male vs female)



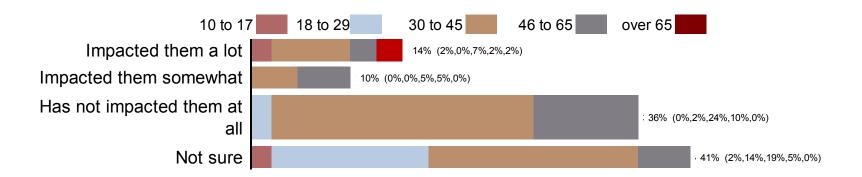


Burning (by lymphoma sub-type)





Burning (by age)









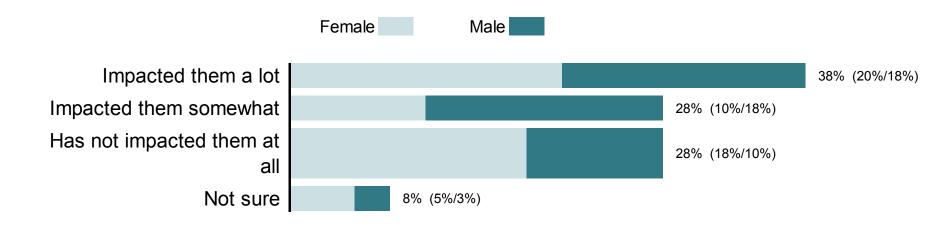
# QoL: Patient Experience Since Diagnosis



LYMPHOMA

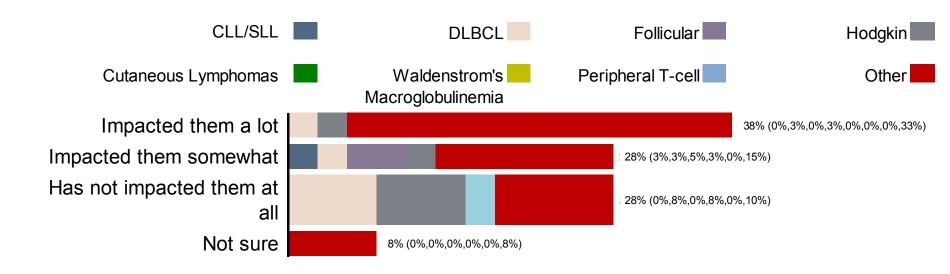
COALITION Worldwide Network of Lymphoma Patient Groups

Changes in relationships with loved ones, friends or co-workers/social life (male vs female)





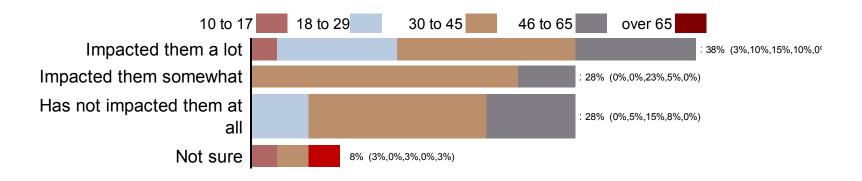
Changes in relationships with loved ones, friends or co-workers/social life (by lymphoma sub-type)







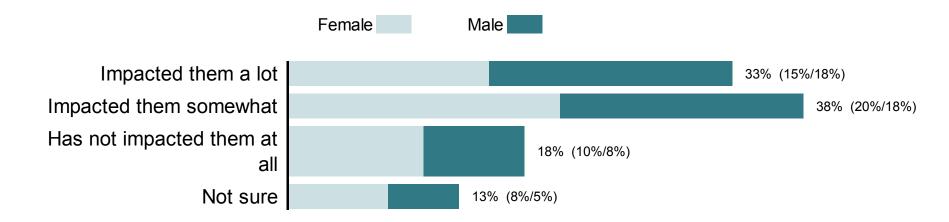
Changes in relationships with loved ones, friends or co-workers/social life (by age)





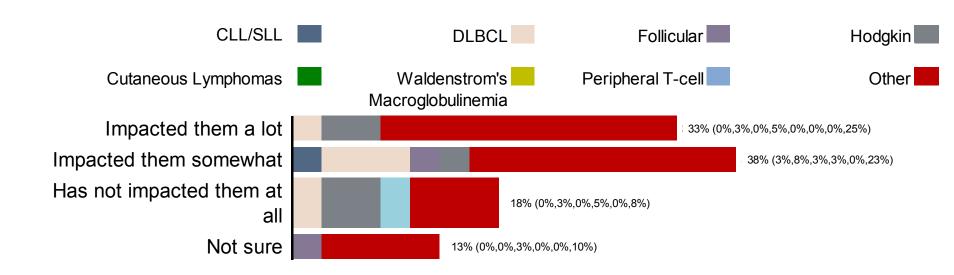


Stress related to financial issues (male vs female)



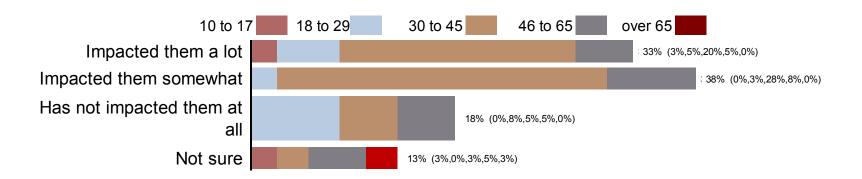


Stress related to financial issues (by lymphoma sub-type)



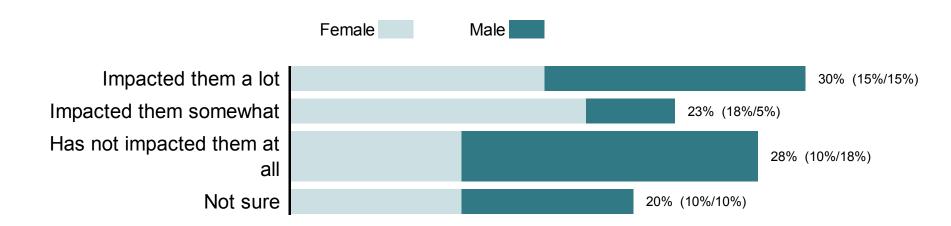


Stress related to financial issues (by age)





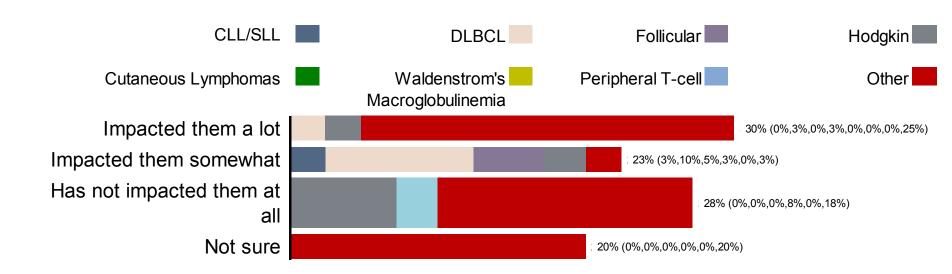
Loss of self-esteem (male vs female)





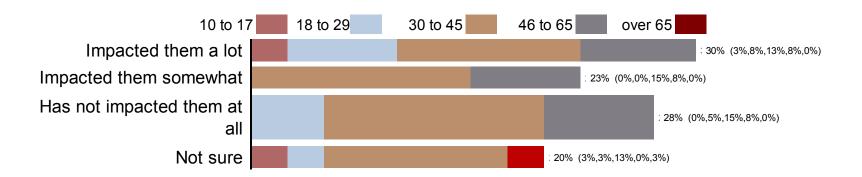


Loss of self-esteem (by lymphoma sub-type)





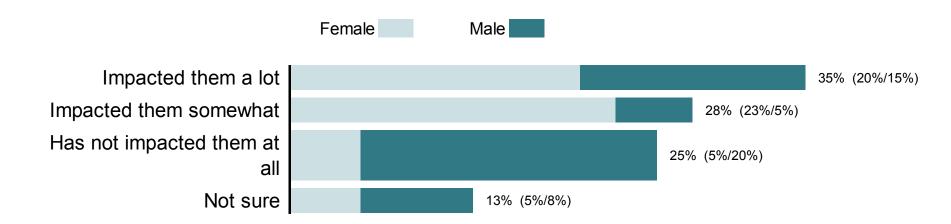
Loss of self-esteem (by age)







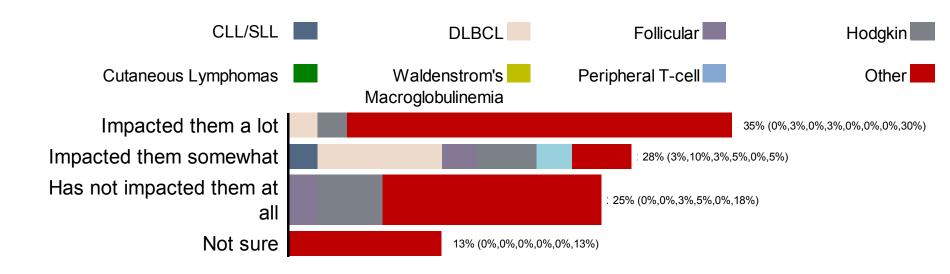
Concerns about body image/physical appearance changes (male vs female)





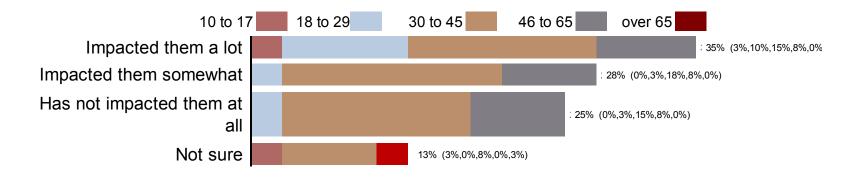


Concerns about body image/physical appearance changes (by lymphoma sub-type)



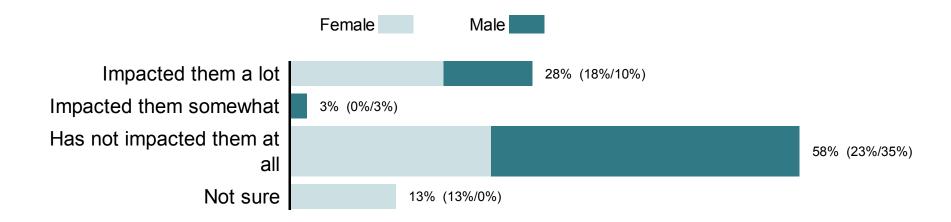


Concerns about body image/physical appearance changes (by age)





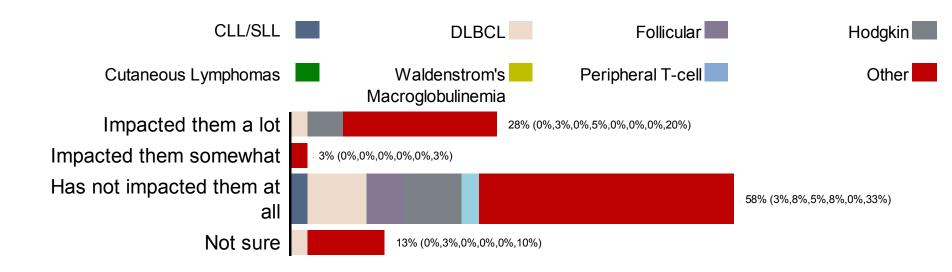
Loss of employment/reduced employment (male vs female)





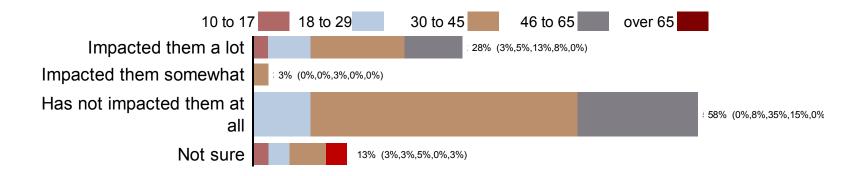


Loss of employment/reduced employment (by lymphoma sub-type)





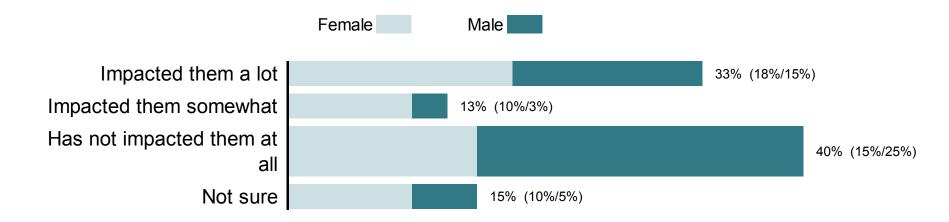
Loss of employment/reduced employment (by age)





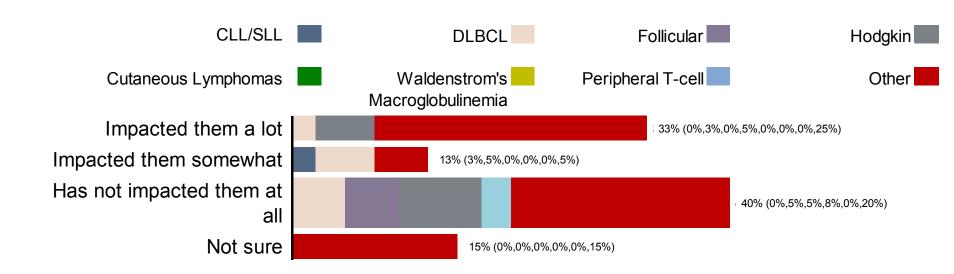


Isolation (male vs female)



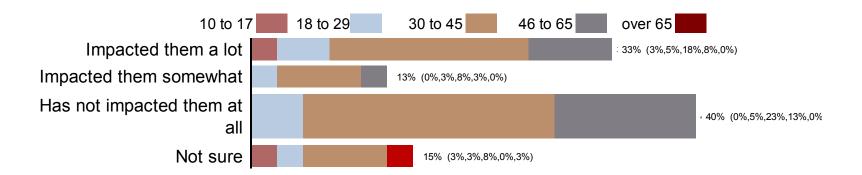


Isolation (by lymphoma sub-type)



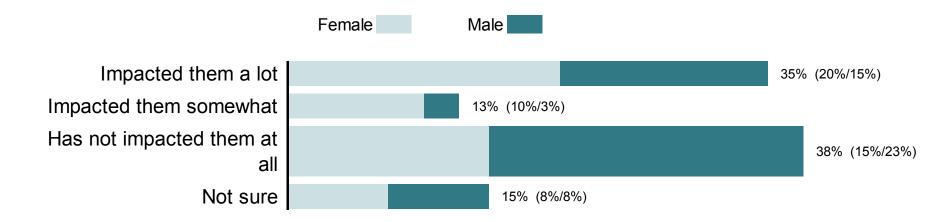


Isolation (by age)



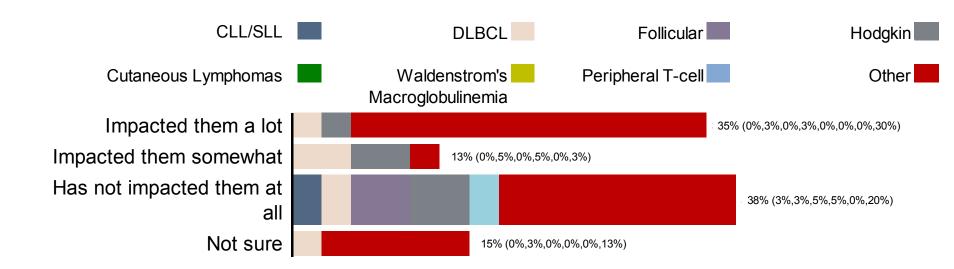


Depression (male vs female)



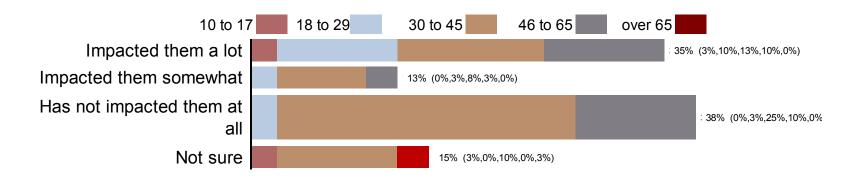


Depression (by lymphoma sub-type)





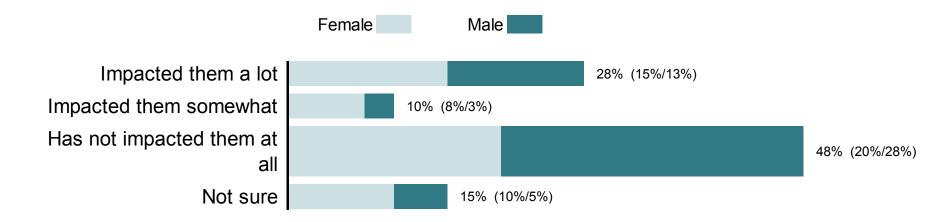
Depression (by age)







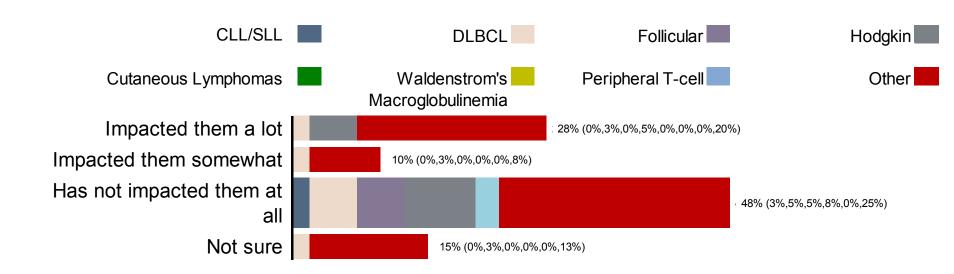
Difficulty on the job or in school (male vs female)





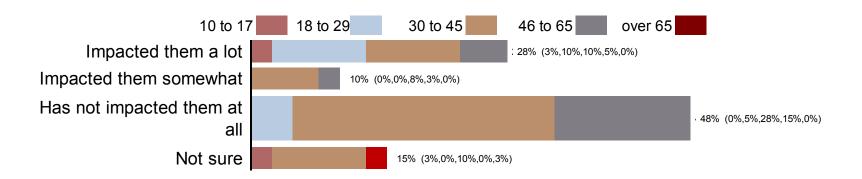


Difficulty on the job or in school (by lymphoma sub-type)



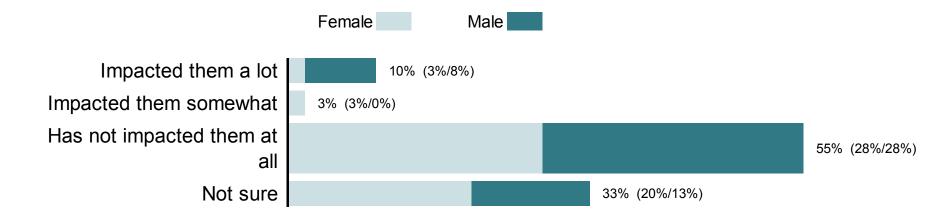


Difficulty on the job or in school (by age)





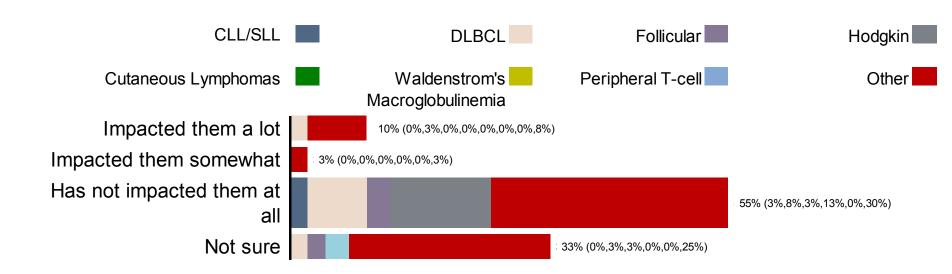
Problems getting health or life insurance coverage (male vs female)





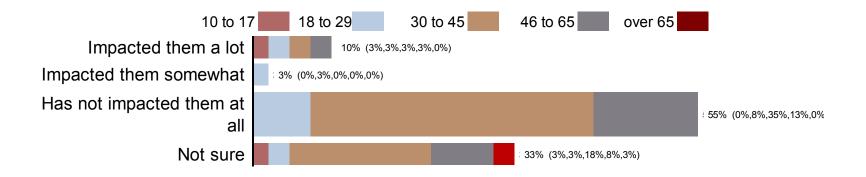


Problems getting health or life insurance coverage (by lymphoma sub-type)





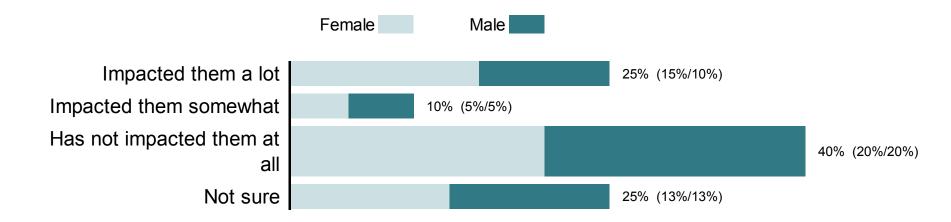
Problems getting health or life insurance coverage (by age)







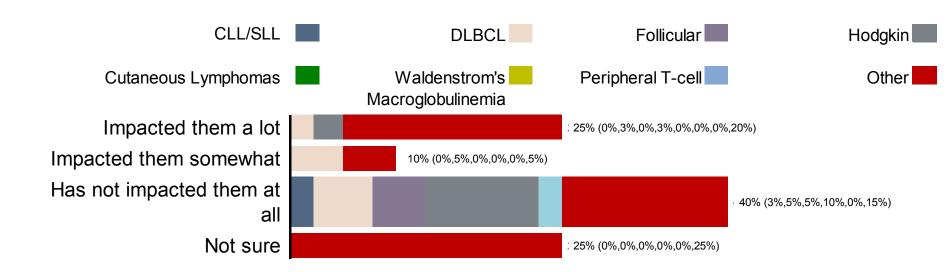
Not understanding their options (male vs female)





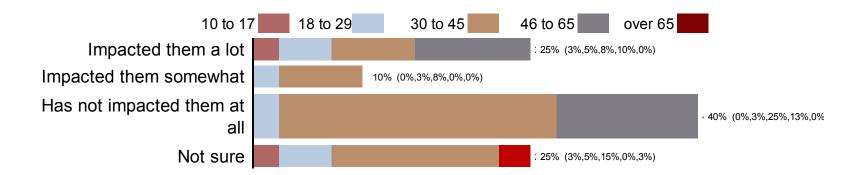


Not understanding their options (by lymphoma sub-type)



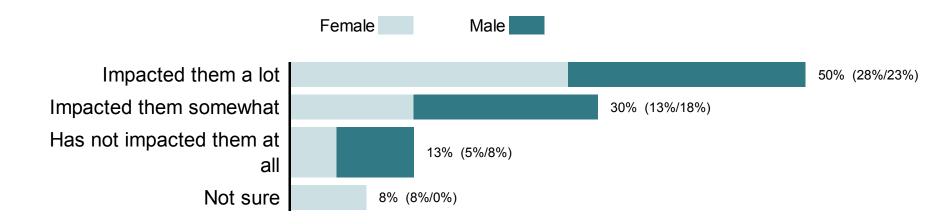


Not understanding their options (by age)





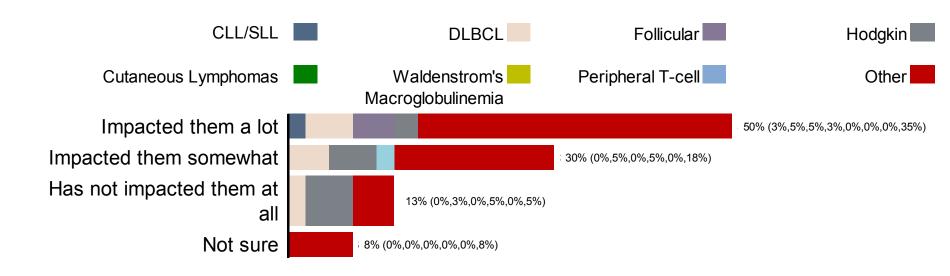
Difficulty working through the healthcare system effectively (male vs female)





# QUALITY OF LIFE: Patient Experience Since Diagnosis

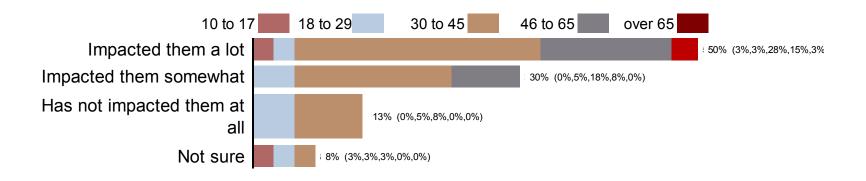
Difficulty working through the healthcare system effectively (by lymphoma sub-type)





# QUALITY OF LIFE: Patient Experience Since Diagnosis

Difficulty working through the healthcare system effectively (by age)









# QoL: Communication With Doctor



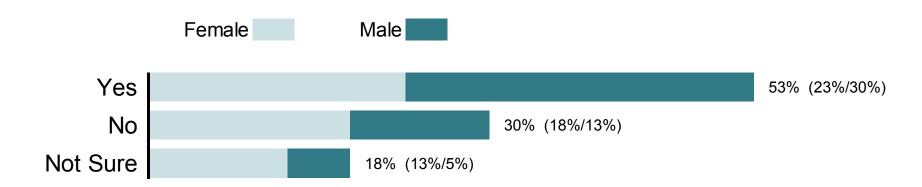
LYMPHOMA 3

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Lymphoma Patient Groups

#### **QUALITY OF LIFE: Communication With Doctor**

Has the patient communicated any of this with the doctor? (male vs female)

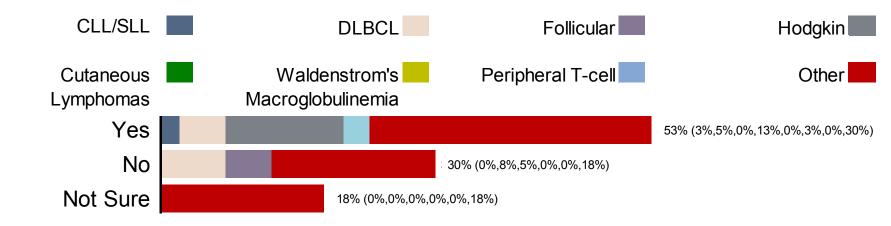






#### **QUALITY OF LIFE: Communication With Doctor**

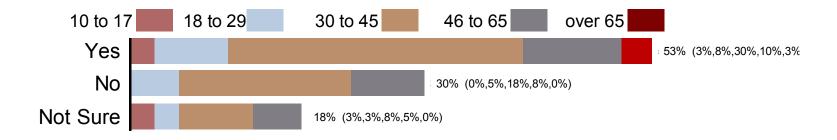
Has the patient communicated any of this with the doctor? (by lymphoma sub-type)





#### **QUALITY OF LIFE: Communication With Doctor**

Has the patient communicated any of this with the doctor? (by age)









# QoL: Helpfulness of Doctor



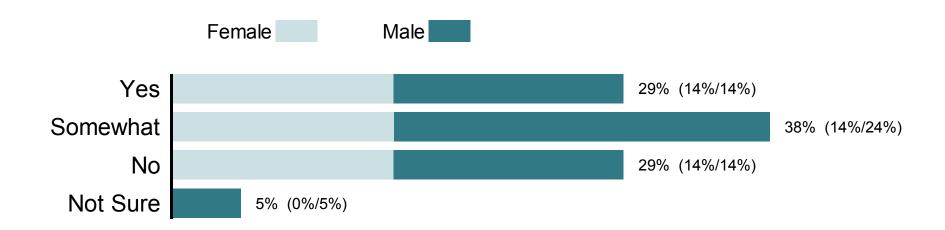
LYMPHOMA = 3

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Lymphoma Patient Groups

# QUALITY OF LIFE: Helpfulness of Doctor

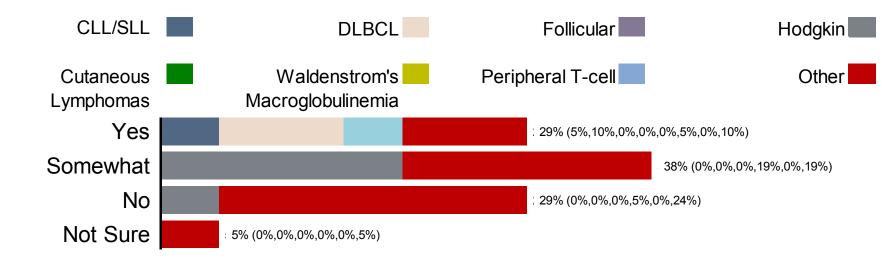
Was the doctor able to help? (male vs female)





### QUALITY OF LIFE: Helpfulness of Doctor

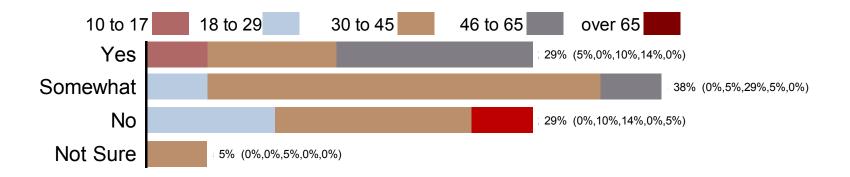
Was the doctor able to help? (by lymphoma sub-type)





### QUALITY OF LIFE: Helpfulness of Doctor

Was the doctor able to help? (by age)







# QoL: Effectiveness of Support

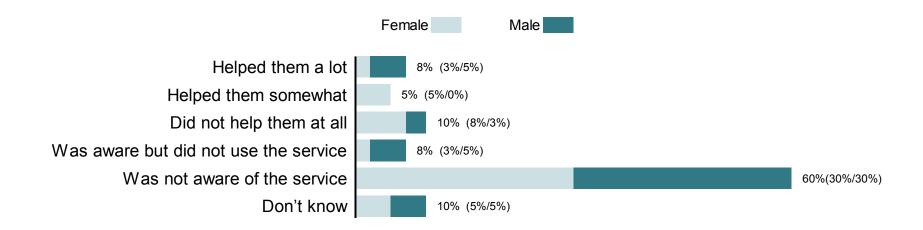


LYMPHOMA 3

COALITION

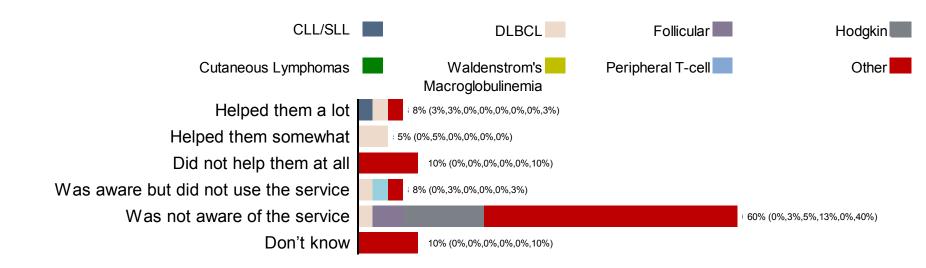
Worldwide Network of
Lymphoma Patient Groups

Social worker (male vs female)





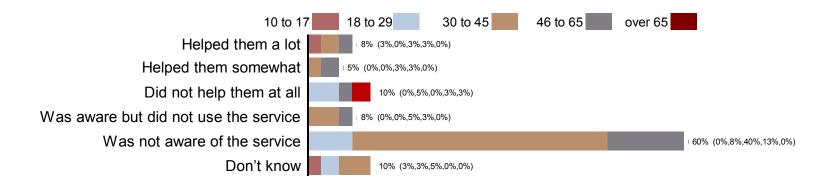
Social worker (by lymphoma sub-type)





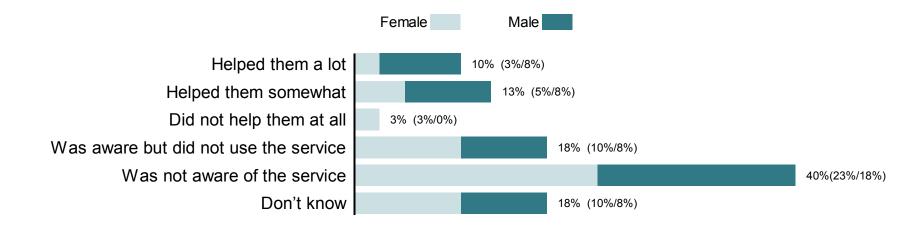


Social worker (by age)



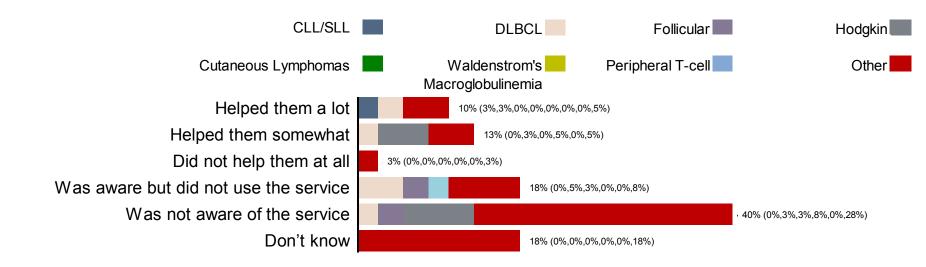


Referral to external support group e.g. patient support group, hospital support group (male vs female)



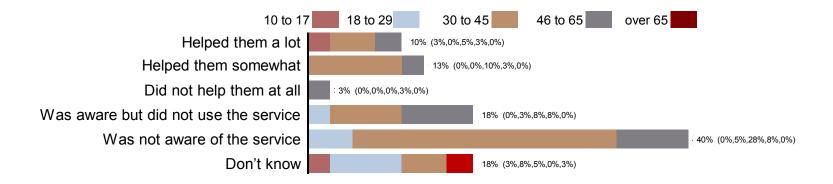


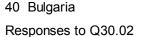
Referral to external support group e.g. patient support group, hospital support group (by lymphoma subtype)





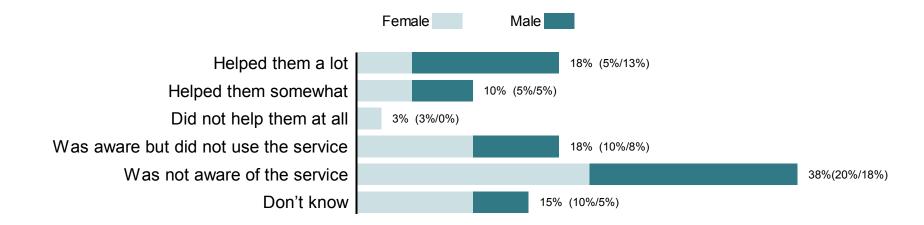
Referral to external support group e.g. patient support group, hospital support group (by age)







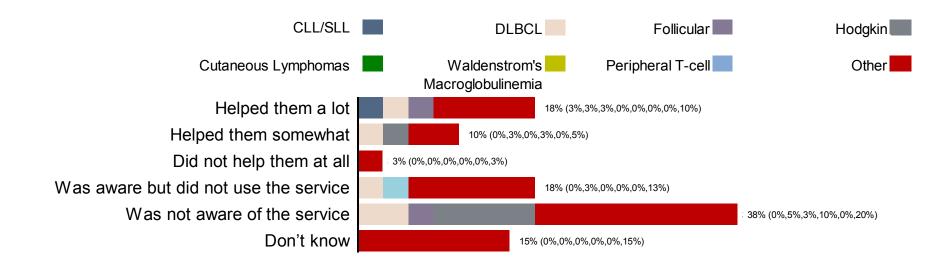
Patient organisation (male vs female)





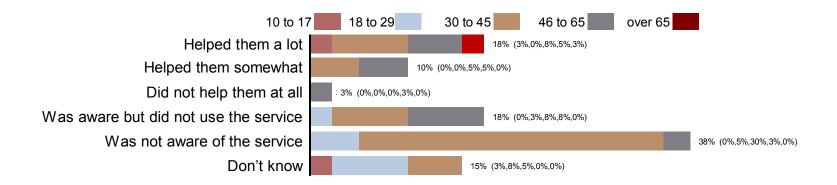


Patient organisation (by lymphoma sub-type)



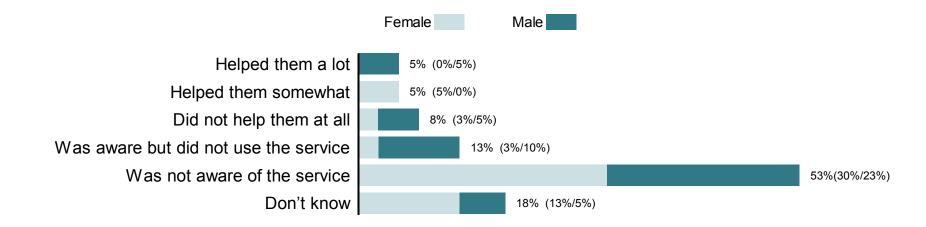


Patient organisation (by age)



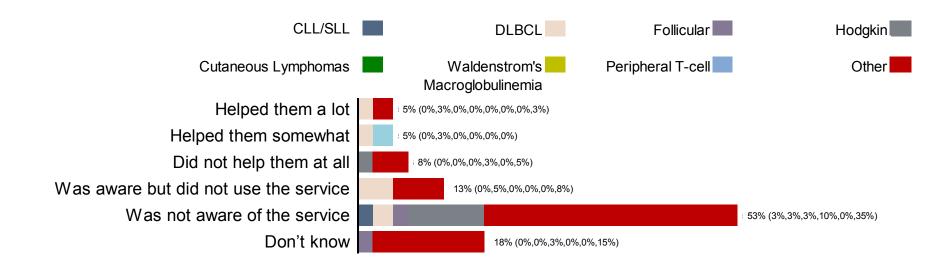


Dietician/nutritionist (male vs female)



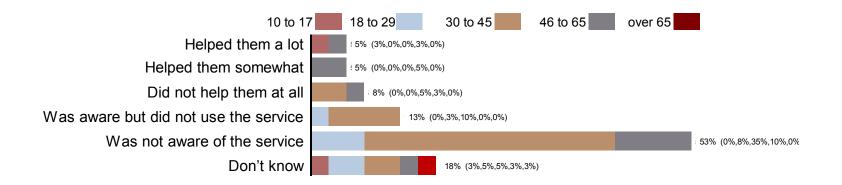


Dietician/nutritionist (by lymphoma sub-type)



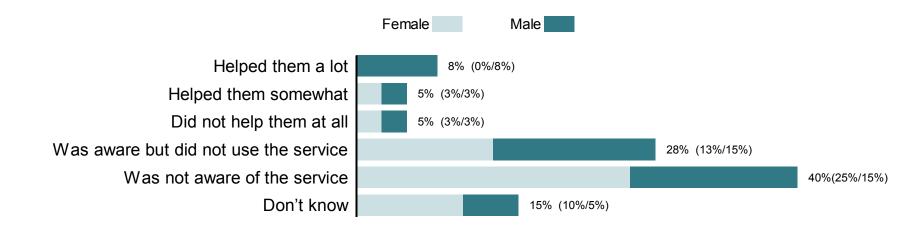


#### Dietician/nutritionist (by age)





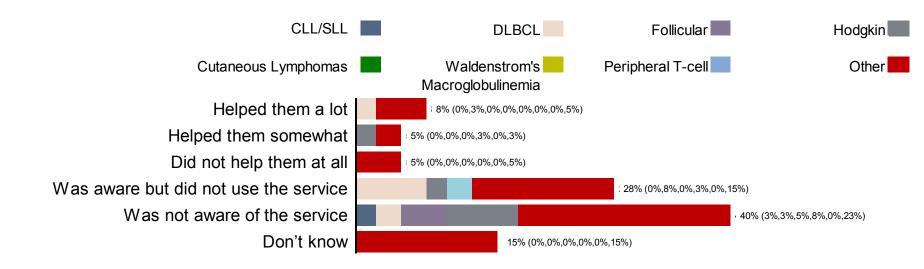
Counsellor/psychologist (male vs female)





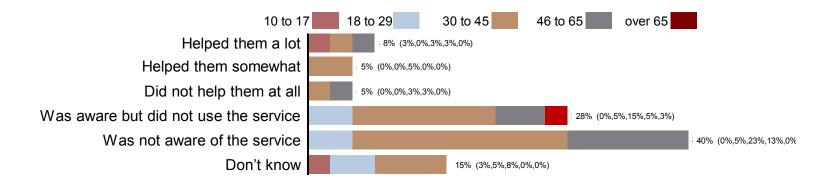


Counsellor/psychologist (by lymphoma sub-type)



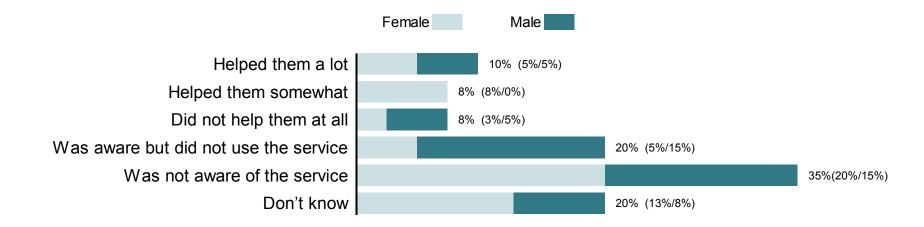


#### Counsellor/psychologist (by age)





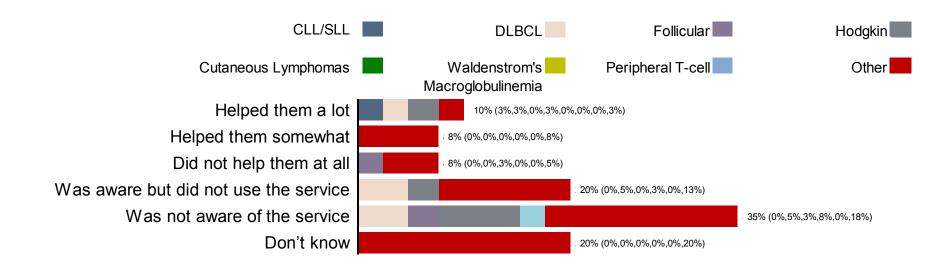
Chaplain, church group (male vs female)





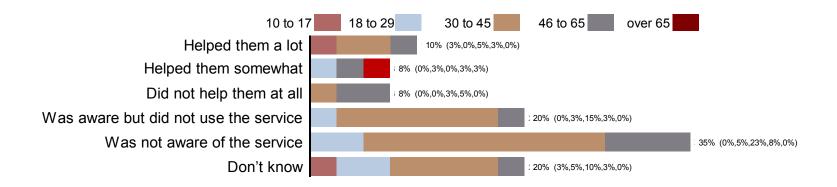


Chaplain, church group (by lymphoma sub-type)



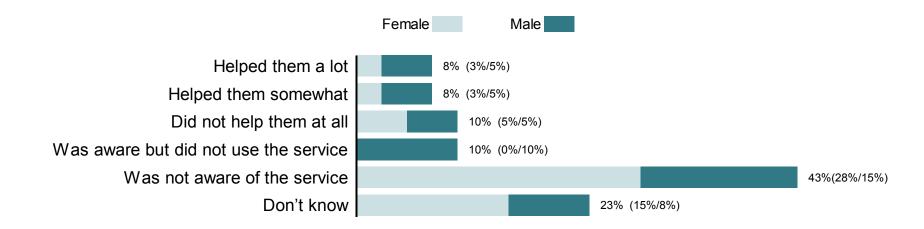


Chaplain, church group (by age)





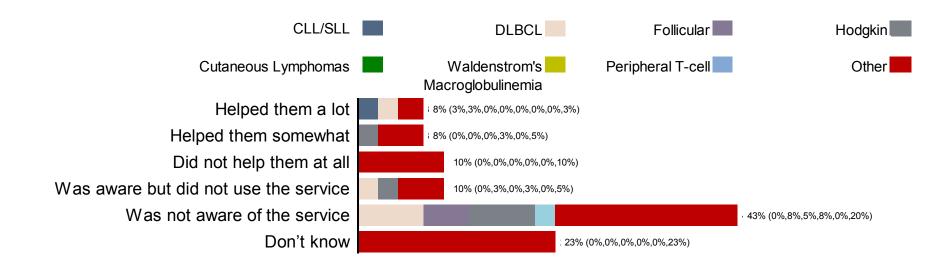
Physical therapy (male vs female)





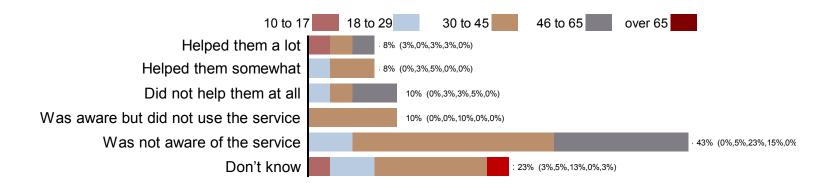


Physical therapy (by lymphoma sub-type)



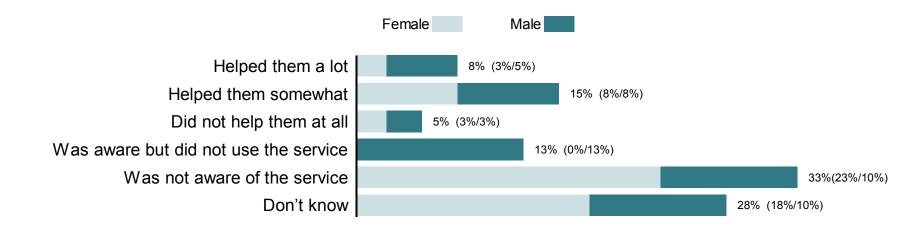


Physical therapy (by age)





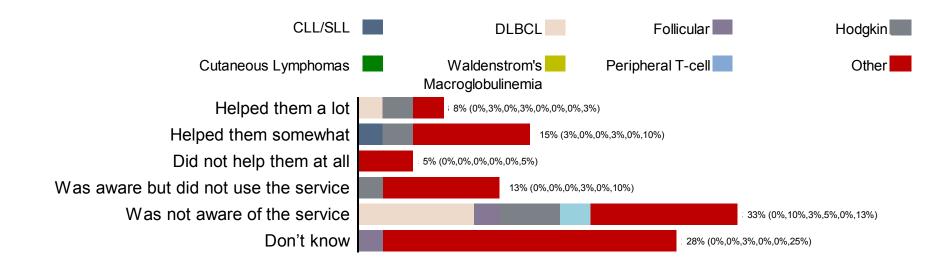
Pain management (male vs female)





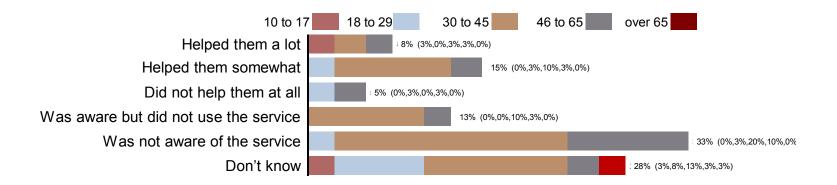


Pain management (by lymphoma sub-type)



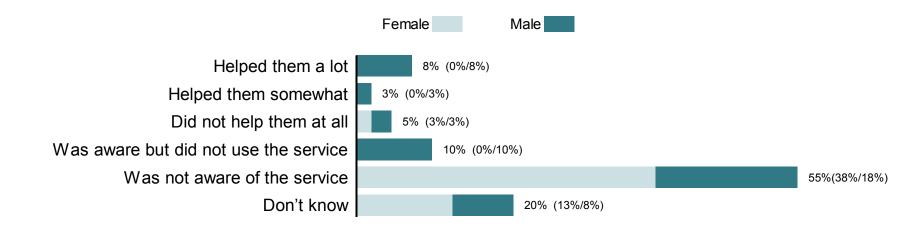


Pain management (by age)





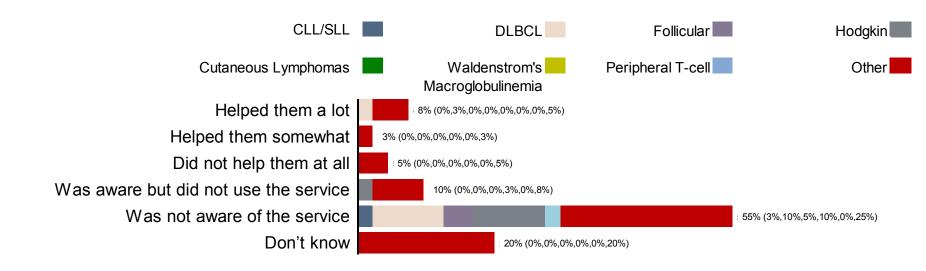
Complementary therapist (male vs female)





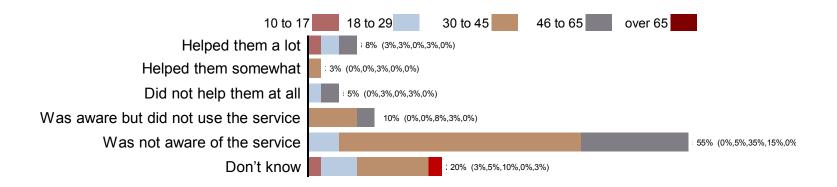


Complementary therapist (by lymphoma sub-type)





#### Complementary therapist (by age)







# **QoL: Information Sources**

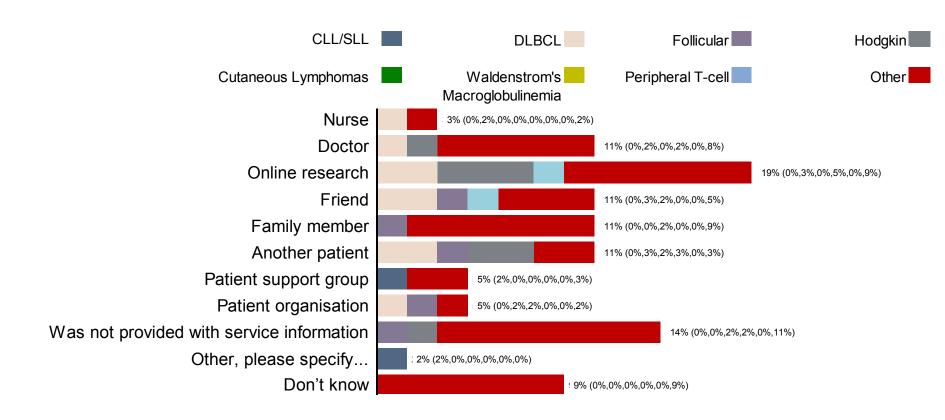


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#### **QUALITY OF LIFE: Information Sources**

Who provided this service information to the patient? (by lymphoma sub-type)









# PATIENT ORGANISATIONS

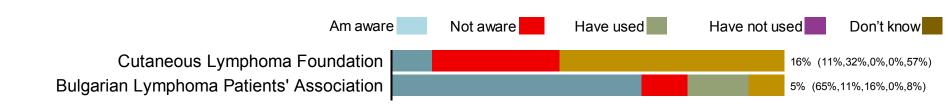


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LYMPHOMA ?

#### **PATIENT ORGANISATIONS: Awareness**

Please tell us which patient organisations the patient is aware of or have used in any way.





#### PATIENT ORGANISATIONS: Effectiveness

How helpful has Bulgarian Lymphoma Patients' Association been for each of the following services?

