BHS

Belgian Hematology Society

38th General Annual Meeting of the Belgian Hematology Society

February 3-4, 2023

Face to face Meeting

www.bhs.be

—
‘**Best** care
for **every** patient
with a **blood disorder**
in Belgium’
—

Lymphoma survey: results for Belgium, what to do with them?

Marijke Quaghebeur

- Clinical nurse specialist UZ Gent
- Board member BHS nurse committee
- Member BHS patient committee

Elke Stienissen

- Chair Lymfklierkanker Vereniging Vlaanderen vzw
- Chair BHS patient committee
- Chair patient advisory board for scientific research UZ Gent

Lymphoma survey

- **Organiser: Lymphoma coalition (LC)**

= a world-wide network of lymphoma patient groups

More than 80 members

From 52 countries (incl. LVV and Hodgkin en non-Hodgkin vzw)

- **Survey Research Centre - University of Waterloo, Ontario, Canada**

Enquête sur les lymphomes et les LLC

Pour qui ?
Pour les patients atteints de lymphome, de la maladie de Waldenström ou de la LLC et/ou leurs proches.

Pourquoi ?
Afin de mieux comprendre le vécu des patients adultes et des aidants.

Quand ?
Jusqu'au 31 mars.

Durée ?
Environ 25 minutes.

Comment participer ?
Par le code QR ou www.alwb.be.

Plus d'info ?
Action Lymphome Wallonie-Bruxelles asbl (www.alwb.be).

Lymfklierkanker Vereniging Vlaanderen asbl, Stekkestraat 70, 2235 Houtvenne
N° entreprise 0656.940.121, RPM Anvers (Malines)
www.lymfklierkanker.be - info.lymfklierkanker@gmail.com

- **Endorsed by the Belgian lymphoma PO:**

- Action Lymphome Wallonie Bruxelles asbl (lymphoma)
- CMP Vlaanderen vzw (waldenström)
- Hodgkin en non-Hodgkin vzw (lymphoma)
- Lymfklierkanker Vereniging Vlaanderen vzw (lymphoma)
- Wildgroei vzw (hematological malignancies)

Enquête lymfeklierkanker en CLL

Voor wie?
(ex-)Patiënten met lymfeklierkanker (lymfomen), de ziekte van Waldenström of CLL en/of hun mantelzorgers.

Waarom?
Om ervaringen van patiënten en mantelzorgers te kennen en de ondersteuning te verbeteren.

Wanneer?
Vanaf nu tot en met 31 maart.

Duur?
Ongeveer 25 minuten

Deelnemen?
Via de QR-code of www.lymfklierkanker.be

Meer info?
info.lymfklierkanker@gmail.com

Lymfklierkanker Vereniging Vlaanderen vzw, Stekkestraat 70, 2235 Houtvenne.
Ondernemingsnummer 0656.940.121. RPR Antwerpen, afdeling Mechelen.

- **BHS lymphoma committee (LPD)**

Hoeveel Belgen krijgen jaarlijks een lymfoom?
Combien de Belges sont atteints d'un lymphome chaque année ?

a. +- 2.500

b. +- 4.500 ✓

c. +- 6.500

Lymphoma diagnosis in 2020: Belgium

Hodgkin: 337

NH: 4159

Bron: Stichting Kankerregister, Brussel, 2022

Source: Fondation Registre du Cancer, Bruxelles, 2022

Methodology

- Patients with lymphoma (including CLL and waldenström) and caregivers
- Online survey
- Open from February 10 – April 14, 2022 (9 weeks)
- Survey was available in 19 languages (incl. French, Dutch and German)
- Country specific report: > 100 respondents
- Questions were the same for every country

+ 5 specific country questions (survey 2020: > 100 respondents)

Methodology

- Results were only reported when 20+ responses per question
- Some questions were asked only to a subset of respondents to ensure only applicable questions were presented
- Respondents had the ability to leave questions blank if they preferred not to answers

➔ total number of respondents may fluctuate between questions

Respondents

- Overall number of completed responses was 267, made up of

238 patients

29 caregivers

⬄ 2020 survey: 165 respondents (147 patients and 18 caregivers)

KEY FINDINGS FROM 238 PATIENTS

PATIENT CHARACTERISTICS

- Aged 65+: 40%
- 55-64 years old: 33%
- 35-54 years old: 20%
- 18-34 years old: 7%

(n=238)

- Caucasian/white: 81%
- Another race: 17%
- Prefer not to say: 2%

(n=236)

- Female: 51%
- Male: 49%

(n=238)

- Retired: 45%
- Full time employment: 18%
- Part time employment: 17%
- Self employment: 8%
- Unable to work: 3%
- Student: 1%
- Homemaker: 1%
- Other: 6%

(n=238)

- Bachelor degree: 49%
- High-school: 32%
- Master’s degree/ Ph.D: 18%

(n=237)

DIAGNOSTIC DEMOGRAPHICS

Time of diagnosis
- 2-5 years ago: 29%
- 5-10 years ago: 23%
- >10 years ago: 16%
- 1-2 years ago: 14%
- <6 months ago: 9%
- 6 months-1 year ago: 8%

(n=238)

- No relapse: 64% of treated patients
- More than 1 relapse: 16%
- 1 relapse: 20%

(n=192)

Remission: 32%
- Receiving treatment: 24%
- Maintenance therapy: 13%
- Treatment not yet needed (W&W): 11%

(n=238)

Subtype of lymphoma
- CLL: 23%
- DLBCL: 16%
- Follicular: 13%
- Hodgkin: 13% (nlphl: 1%)
- Mantle cell: 7%
- Waldenström: 5%
- Don’t know: 5%

(n=238)

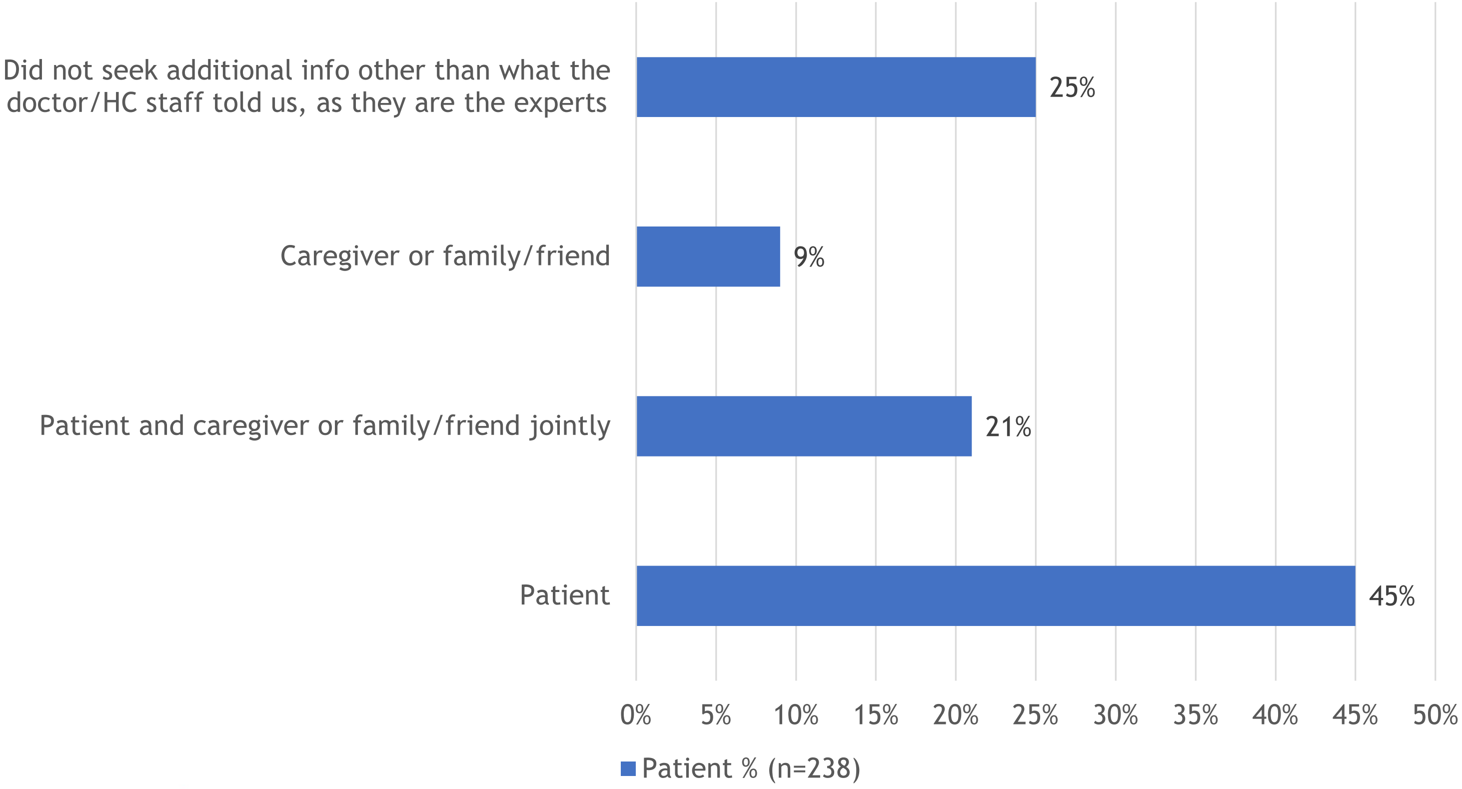
Time between symptoms and diagnosis
- <3 months: 70%
- 3-6 months: 11%
- >12 months: 8%
- 6-12 months: 7%
- Don’t know: 3%

(n=238)

INFORMATION, GUIDANCE AND SUPPORT

Seeker of information

Following the lymphoma diagnosis, who was seeking out info and details about the disease and potential treatments?

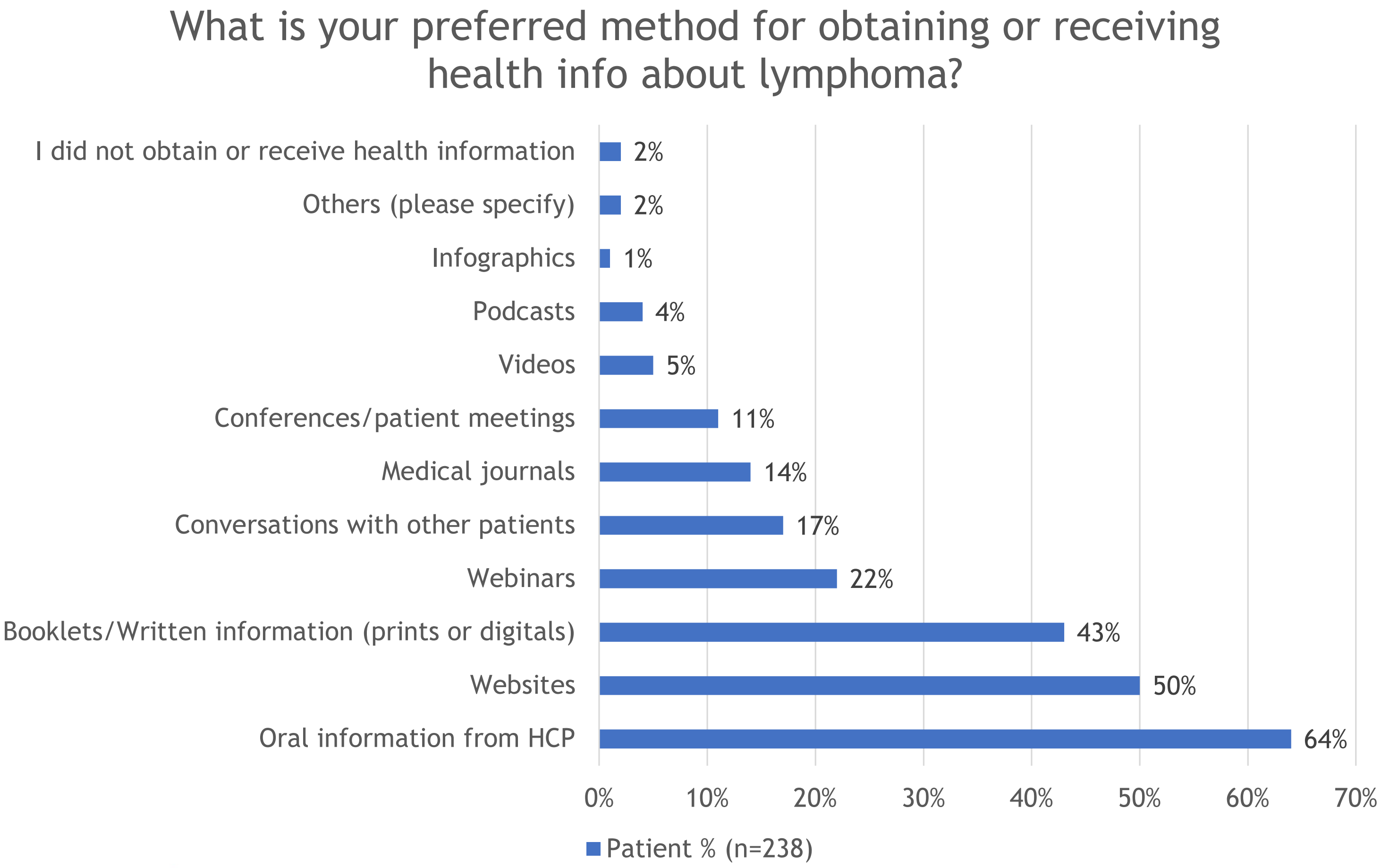


Information

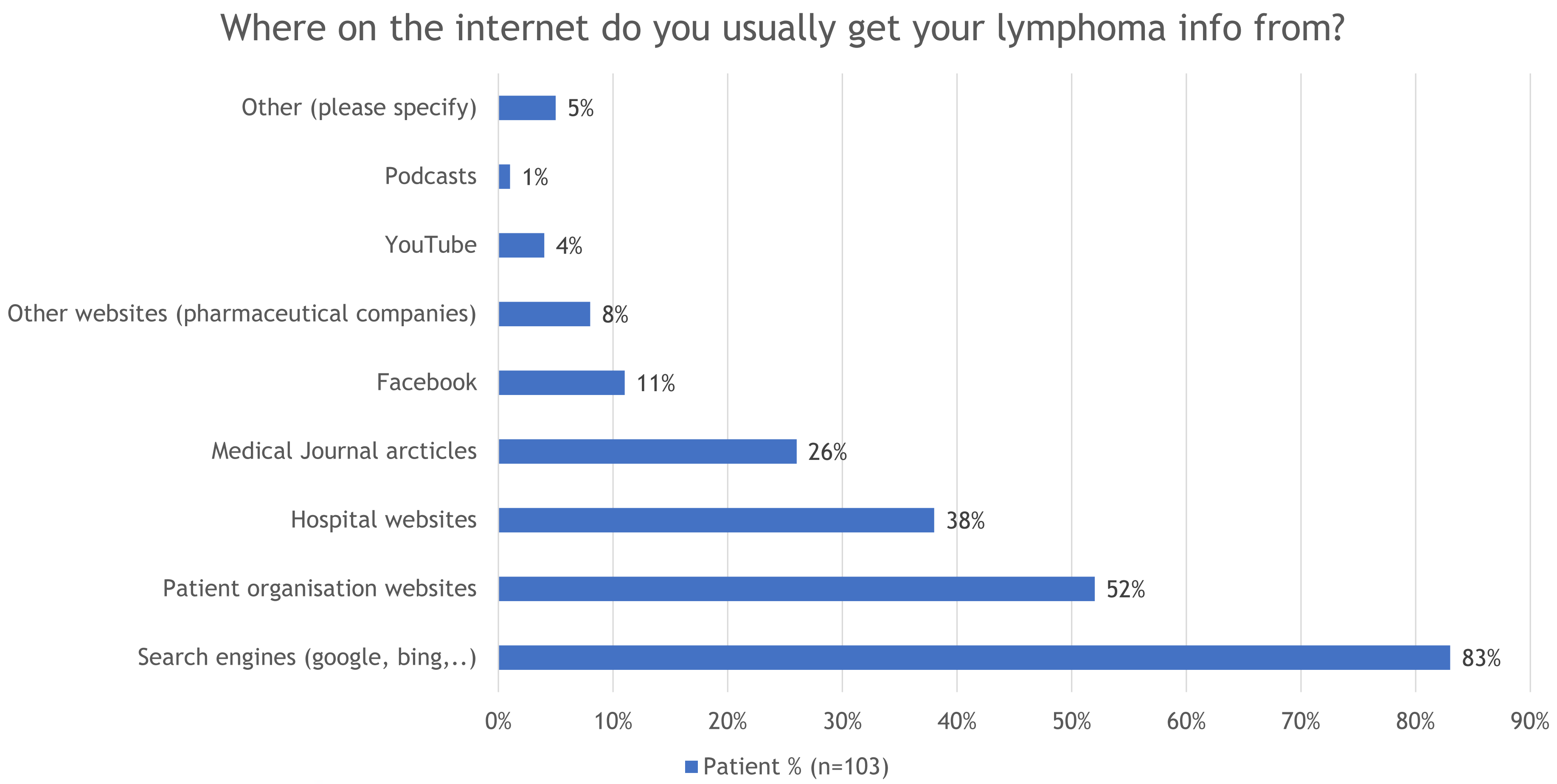
78% of patients felt well or very well informed about the processes and stages of their healthcare (n=238)

(Not at all informed: 1%
Not very well informed: 4%)

Method of information



Internet information



Source of information

92% of patients reported doctors as their preferred source of information for lymphoma (n=238)

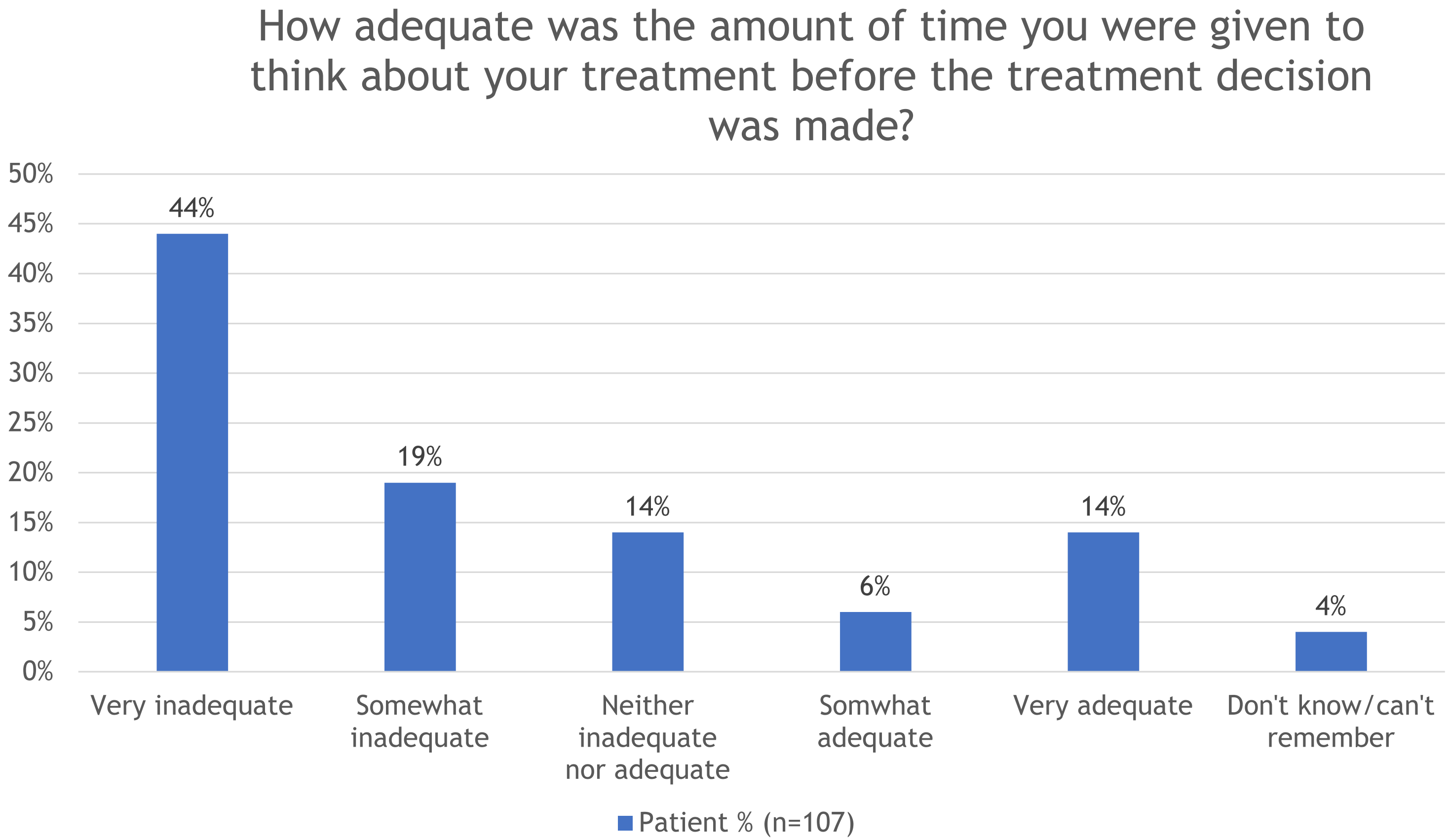
(Internet: 43%
Patient organisation: 34%
Nurse: 21%
Online blogs/social media: 7%)

Shared decision making

65% would like doctors and patients jointly involved in making healthcare decisions

(n=232)

Shared decision-making: time



Importance of information

Telling the truth (84%) and understanding patient goals and concerns about treatment (68%) were ranked most important

(n=?)

Who have you find useful in providing supportive care outside of the speciality physician?

Oncology nurse: 58%
General practitioner: 53%
Dietician: 31%
Therapist/psychologist: 25%
Patient organisations: 24%
(n=124)

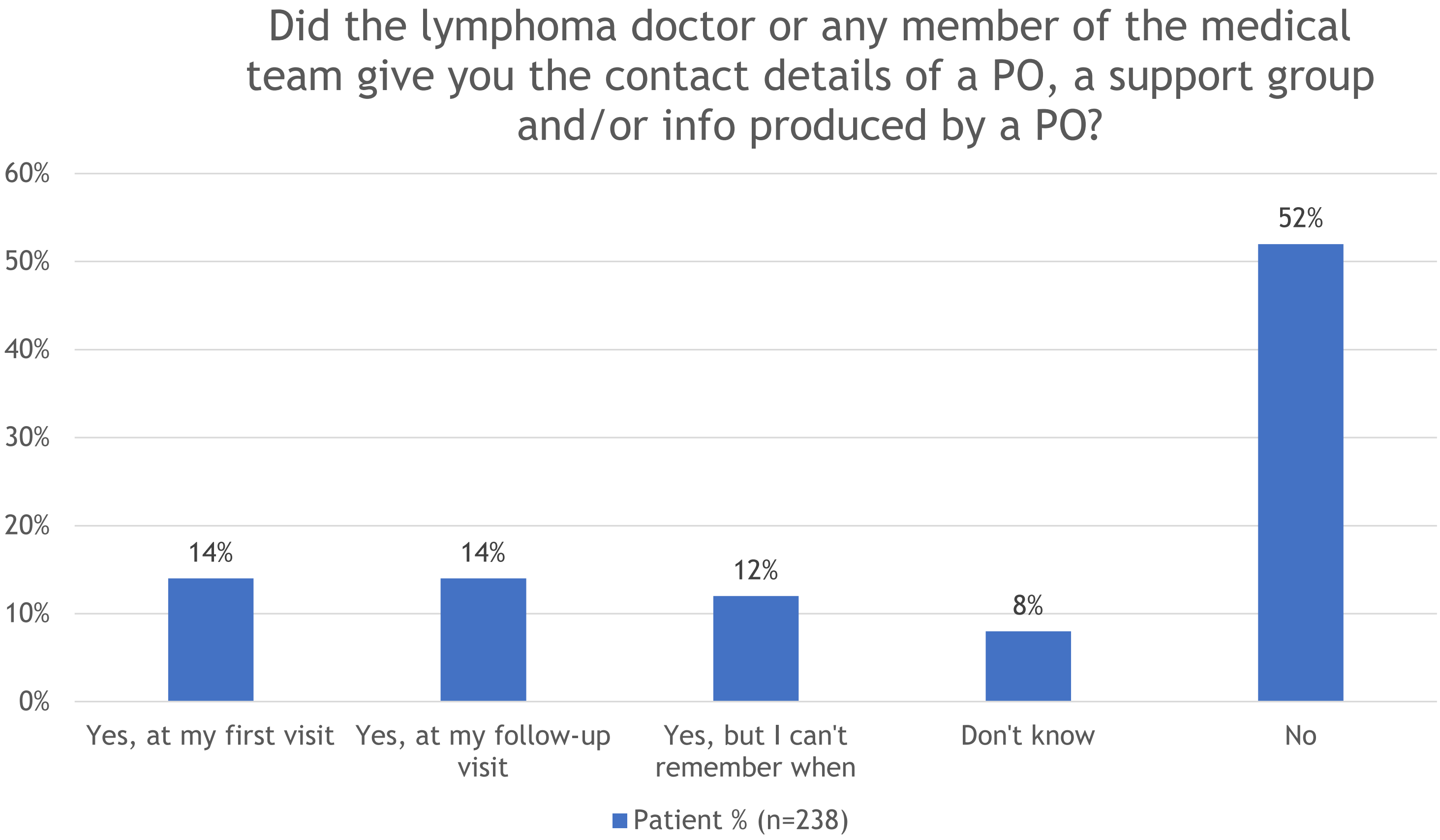
Is er zowel voor Franstalige als Nederlandstalige patiënten met lymfeklierkanker een patiëntenorganisatie? Existe-t-il une association de patients pour les patients néerlandophones et francophones atteints de lymphome ?

a. Nee, enkel voor Nederlandstaligen
Non, seulement pour les néerlandophones

b. Nee, enkel voor Franstaligen
Non, seulement pour les francophones

c. Ja, voor beiden
Oui, pour les deux ✓

Patient organisation (PO)



Information about patient organisations?

ALWB

CMP
VLAANDEREN vzw
Contactgroep Myeloom en Waldenström Patiënten

non-hodgkin
Hodgkin en non-Hodgkin vzw

Lotuz
leven na
een allogene
stamceltransplantatie

Lymfklierkanker Vereniging Vlaanderen vzw

wildgroei
VZW

87% were satisfied or very satisfied with the info given by PO (only asked to those who indicated they had contacted a PO (n=78))

⇔ **Also 87% were satisfied or very satisfied with the info given by HCPs** (n=222)

Information, guidance and support: recommendations

- **Reliable websites (hospitals, Foundation against cancer, Kom op tegen Kanker, PO)**
- **Flyers PO**
- **Ask it regularly: patients can change their mind during their patient journey**
- **BHS website: patient associations**
- **Shared decision making: give patients more time**
  - **Give information to read at home/separate room**
  - **Contact person for more info**
  - **Deadline**

DIAGNOSIS AND TREATMENT

Hoeveel subtypes van lymfomen zijn er?
Combien de sous-types de lymphomes existe-t-il ?

a. >40

b. >60

c. >80 ✓

Source: Lymphoma Coalition

Lymphoma subtype

54% of patients were told their lymphoma subtype at diagnosis

(8% didn’t know – 38% said no)

This question was only asked to those who were diagnosed < 2 years ago (n=76)

Lymphoma subtype: recommendations

- Give information about the lymphoma subtype

DLBCL/LDGCB

De visuele gidsen van de patiënt

Diffuus grootcellig B-cellymfoom (DLBCL)

Folliculair lymfoom
Lymphome folliculaire

De Visuele Gidsen van de Patiënt

Folliculair lymfoom

CLL/LLC

DE BELGISCHE GIDS VAN DE PATIËNT

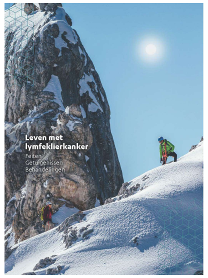
Begrijpen en behandelen

Chronische lymfatische leukemie

waldenström

Leven met Waldenström
Feiten
Getuigenissen
Behandelingen

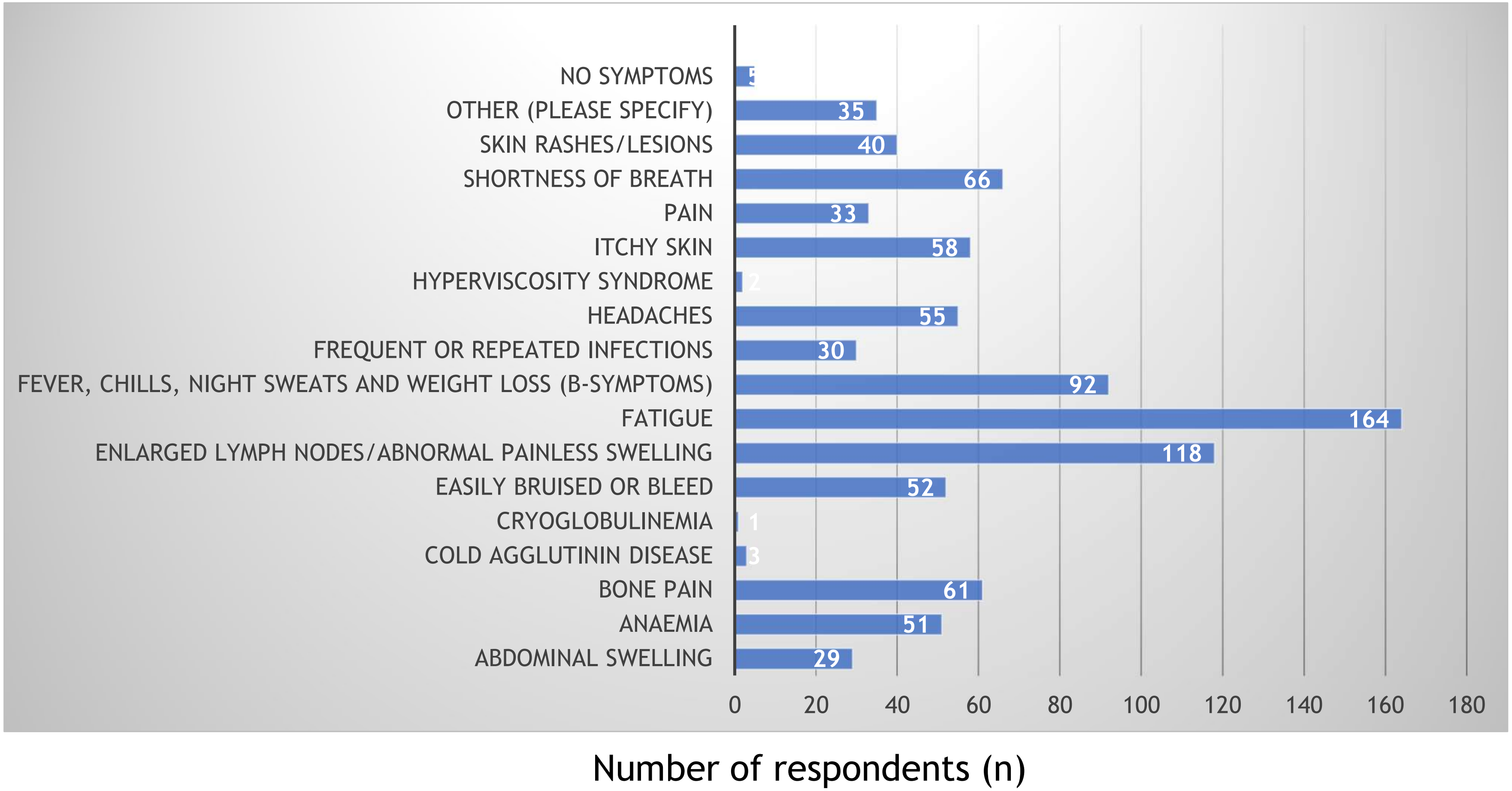
Leven met lymfeklierkanker
Vivre avec un lymphome



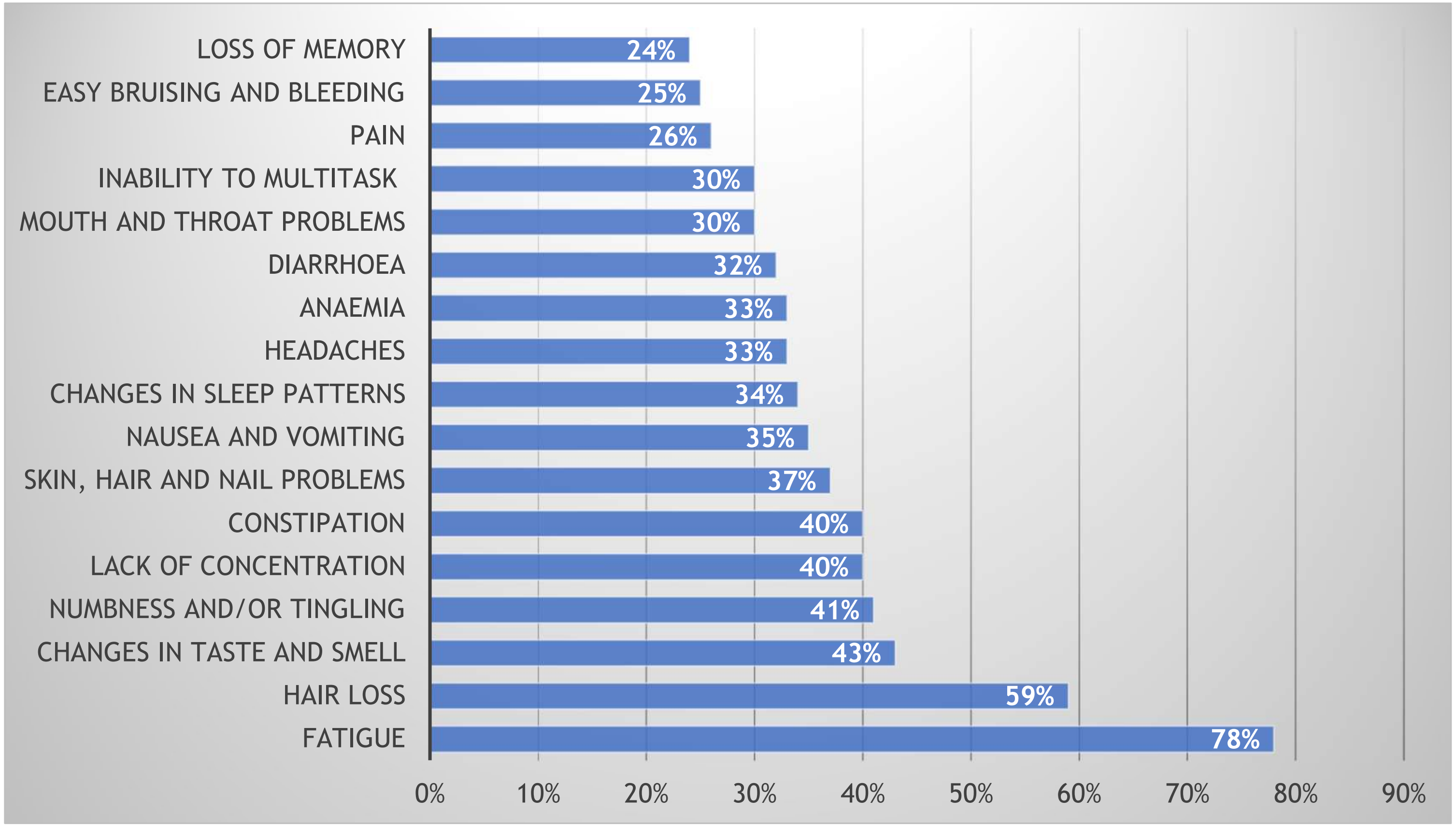
Leven met lymfeklierkanker
Feiten
Getuigenissen
Behandelingen

- Forget the term ‘non-Hodgkin’s lymphoma’
- Only mention the subtype of lymphoma (during every talk/consultation)
- Write the subtype of lymphoma in the medical report

Lymphoma symptoms



Treatment: side effects



Patient %
(n=172)

49% said their medical team helped with some of their side effects
34% said they were helped with all of them

(n=166)

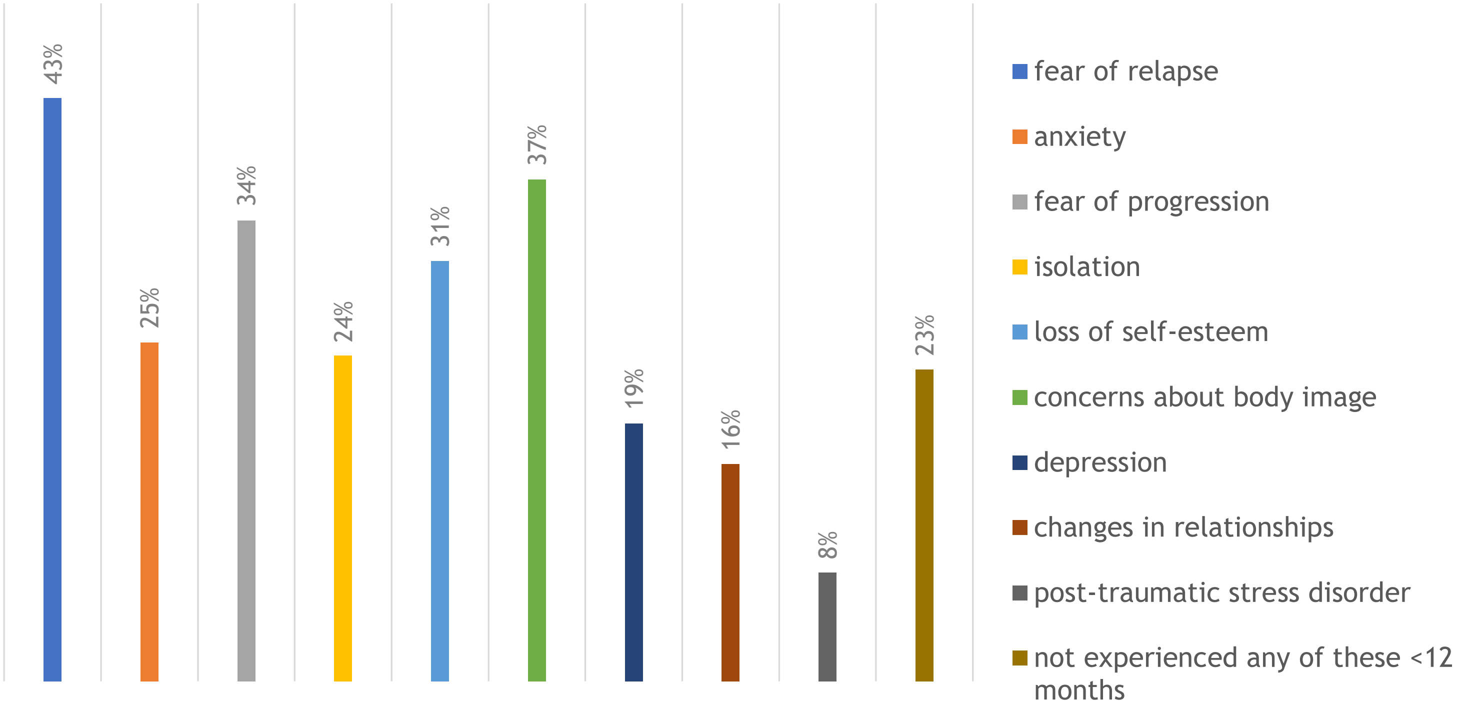
Fatigue

78% experienced fatigue as a side effect of treatment (n=172)
82% have discussed it with their doctor over the past 2 years (n=175)
52% said their doctor followed up about their fatigue (n=?)
74% received some type of info about fatigue from their doctor (n=142)

Fatigue: recommendations

- **Follow-up: ask how it goes**
- **Aftercare program**
- **Exercise programs (untire app)**
- **Balancing time schedules (planning, prioritising)**
- **Mind-body interventions (yoga, meditation)**

Psychosocial effects



Patient %
(n=222)

44% reported their doctor did not follow up on the psychosocial issues (n=117)

Psychosocial effects: recommendations

- Follow up: ask the patient about it
- Be empathic/recognize the feeling
- Referral to other sources of support
- Encourage to exercise
- Medication when needed

Clinical trials

52% received information about clinical trials from their doctor (n=172), yet only 29% were in or had been in a clinical trial for their lymphoma (n=171)

Clinical trials: recommendations

- **Clinical trial brochure (BHS)**

BHS
Belgian Hematology Society

‘De **beste** zorg voor **elke** patiënt met een **bloedaandoening** in België’

Patiëntenbrochure
Klinische studies

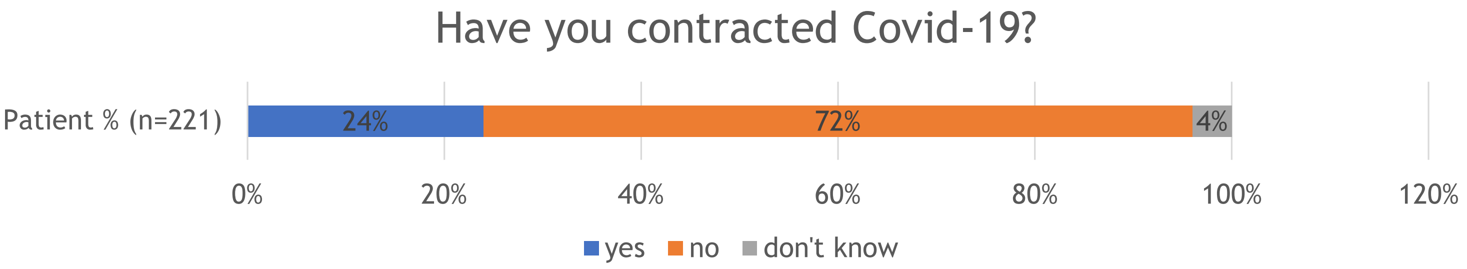
www.bhs.be

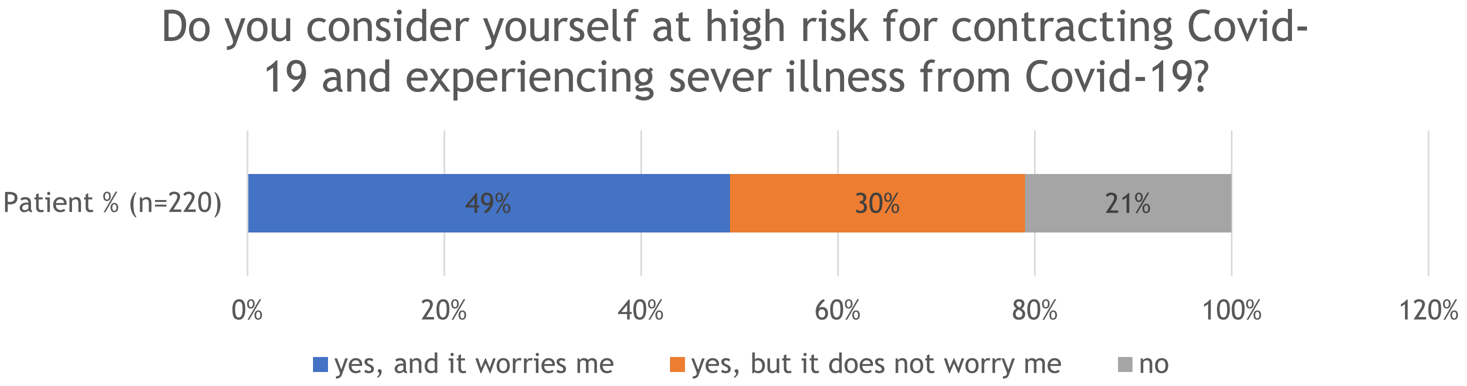
- **Websites**

www.clinicaltrial.be
www.heyleys.be
FAGG/AFMPS

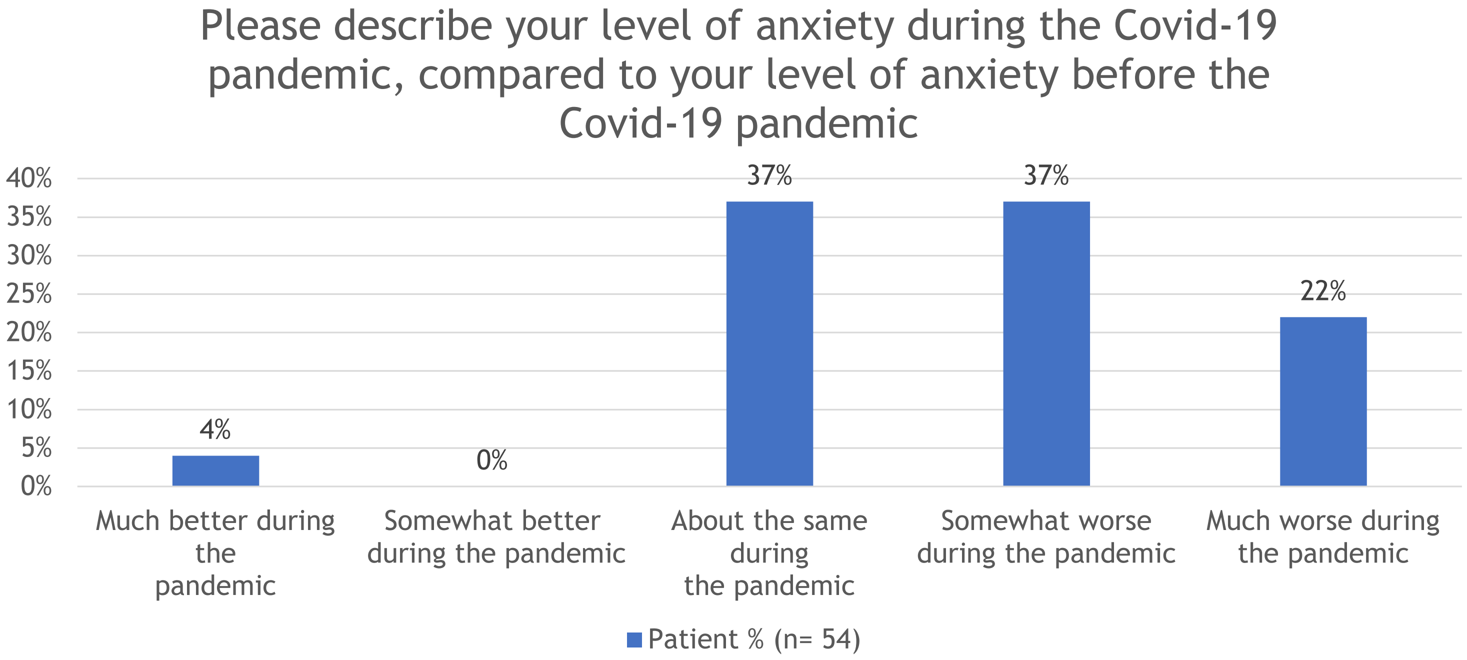
COVID-19 –
IMPACT AND EXPERIENCES

COVID-19

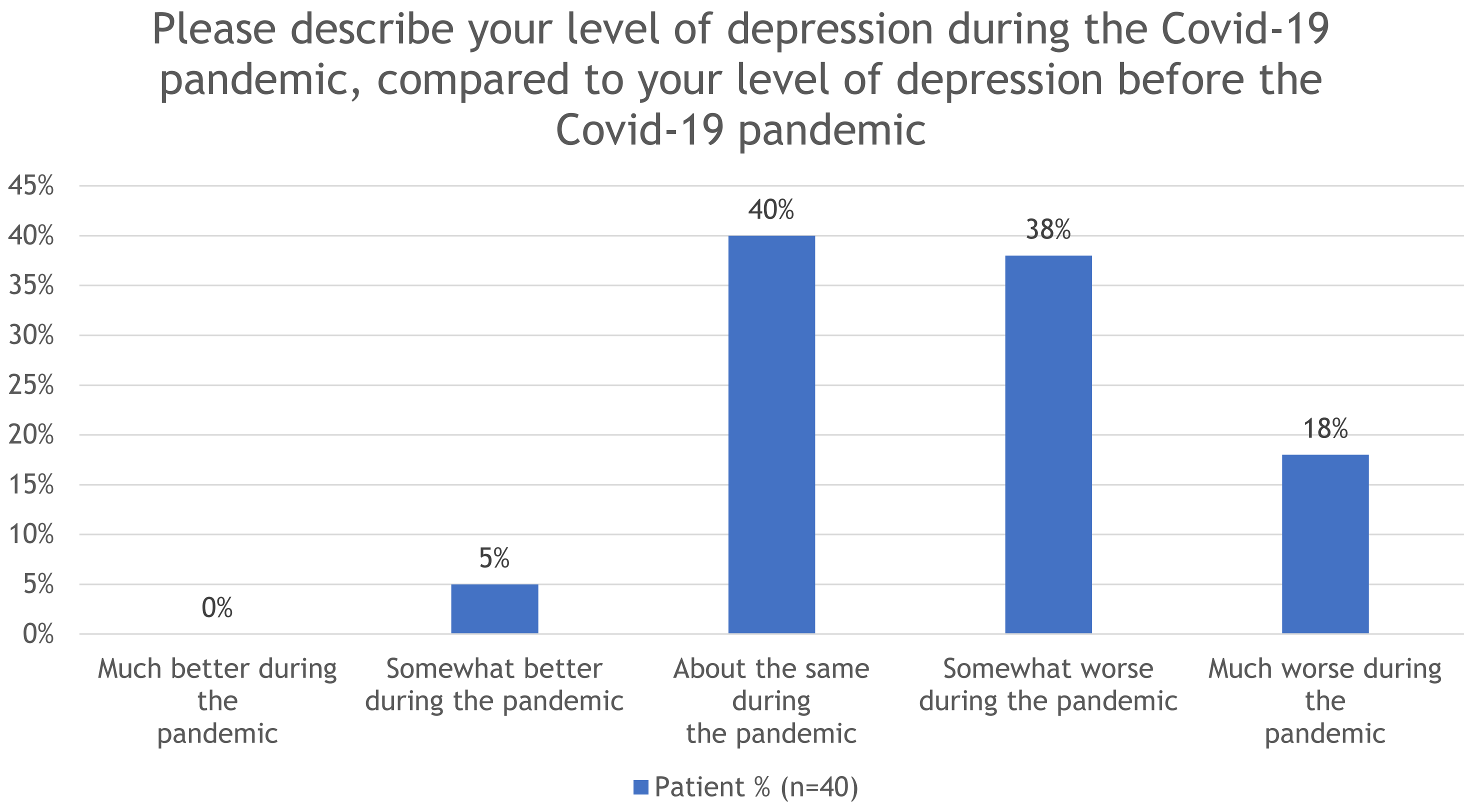

Have you contracted Covid-19?
Patient % (n=221)
24%
72%
4%
0%
20%
40%
60%
80%
100%
120%
yes
no
don't know


Do you consider yourself at high risk for contracting Covid-19 and experiencing sever illness from Covid-19?
Patient % (n=220)
49%
30%
21%
0%
20%
40%
60%
80%
100%
120%
yes, and it worries me
yes, but it does not worry me
no

Anxiety

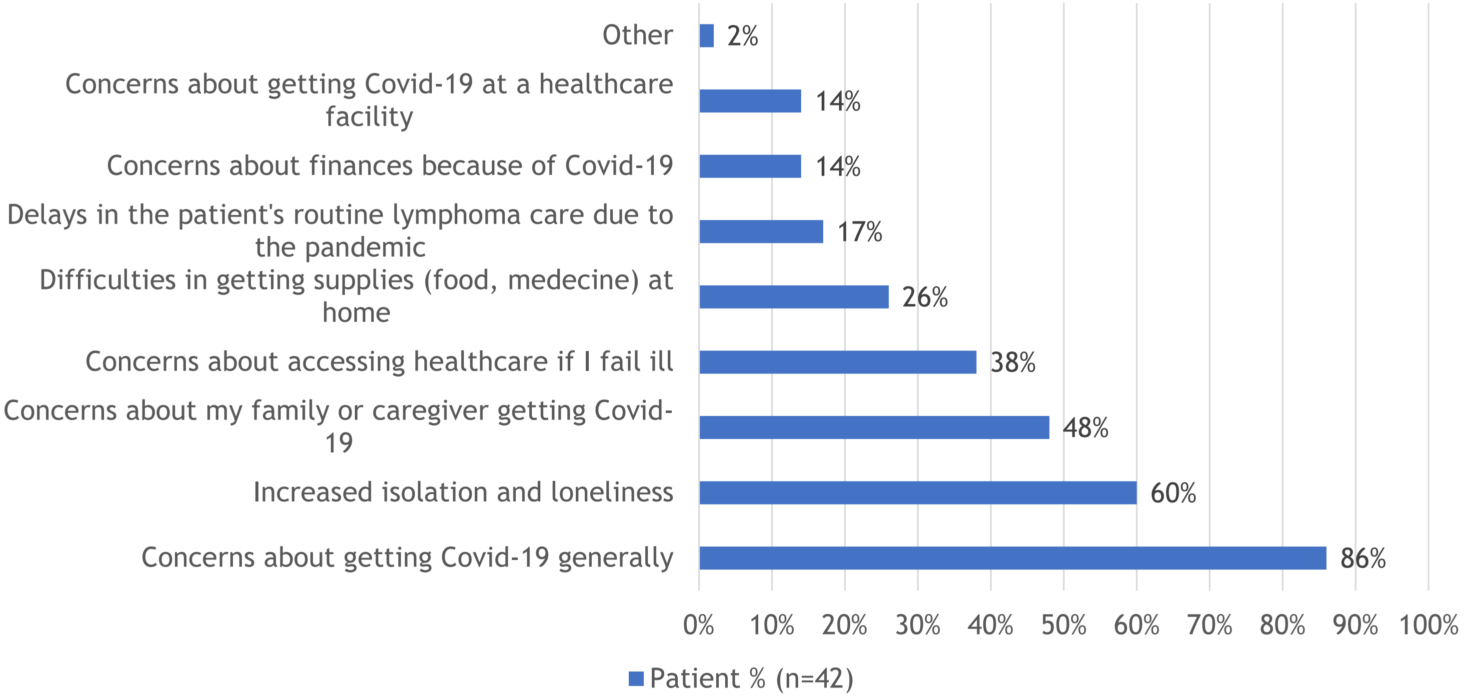

Please describe your level of anxiety during the Covid-19 pandemic, compared to your level of anxiety before the Covid-19 pandemic
40%
35%
30%
25%
20%
15%
10%
5%
0%
4%
0%
37%
37%
22%
Much better during the pandemic
Somewhat better during the pandemic
About the same during the pandemic
Somewhat worse during the pandemic
Much worse during the pandemic
Patient % (n= 54)

Depression


Please describe your level of depression during the Covid-19 pandemic, compared to your level of depression before the Covid-19 pandemic
45%
40%
35%
30%
25%
20%
15%
10%
5%
0%
0%
5%
40%
38%
18%
Much better during the pandemic
Somewhat better during the pandemic
About the same during the pandemic
Somewhat worse during the pandemic
Much worse during the pandemic
Patient % (n=40)

Contributing factors

Which of the following were contributing factors to the worsened anxiety and/or depression?



Telephone/video conference (TC/VC)

49% strongly disagreed and 26% disagreed that they preferred TC/VC to face-to-face visits
Only 3% strongly agreed and 3% agreed that they preferred TC/VC to face-to-face visit

31% strongly disagreed and 21% disagreed that they would like to continue to use TC/VC even after the pandemic is over
6% agreed and 2% strongly agreed that they would like to continue to use TC/VC even after the pandemic is over
(n=?)

Remarks

- Only general results – not age specific
- No specific questions about intimacy and sexuality

TO DO

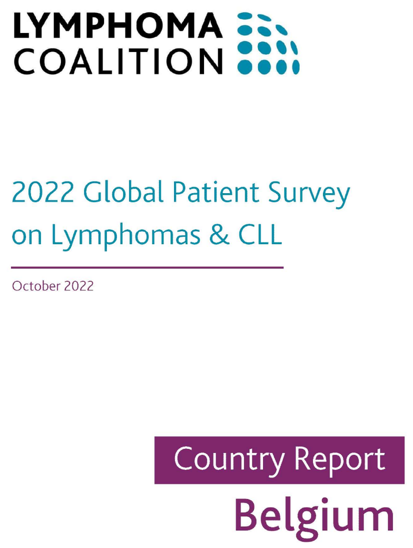
- **Sending the report to:**
  - ✓ the lymphoma committee
  - ✓ nurse committee
  - ✓ lymphoma patient organisations

- **Survey: every 2 year - next in 2024**
  - ✓ Collaboration with BHS and HCPs

Full Belgian lymphoma report

- elkestienissen.lvv@gmail.com
- marijke.quaghebeur@uzgent.be

- Website BHS (www.bhs.be)
  - bhs committees
  - patient associations



LYMPHOMA COALITION

2022 Global Patient Survey on Lymphomas & CLL

October 2022

Country Report

Belgium

THANK YOU!

Questions?