

# GLOBAL CROSS-SECTIONAL SURVEY ON SARCOMA DIAGNOSIS PATHWAY: A CURRENT STATE ANALYSIS



Sarcoma Patient Advocacy Global Network

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## INTRODUCTION

The time of diagnosis can be a crucial point in the course of the disease for sarcoma patients. An early and correct diagnosis can help to ensure that sarcoma patients can be treated quickly and receive the optimal therapy for their situation, potentially improving their prognosis. We know from several previous publications that there are often delays in the diagnosis of sarcoma and that diagnoses are corrected over time. However, until now there has been no data collection that captures the experience from the perspective of those affected.

We aim to provide a clearer global picture of the reality regarding the time from the onset of sarcoma-related symptoms to the first presentation to a doctor, as well as the care interval leading to a correct diagnosis, incl. the occurrence of misdiagnoses.

## METHODS

### Online Survey

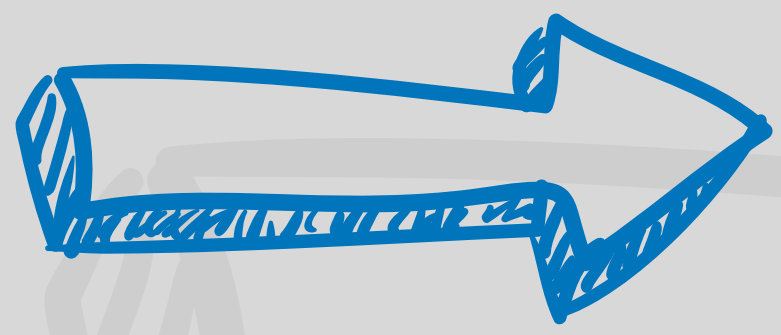
Exploratory research design  
18 languages  
For patients & caregivers  
Address potential bias (review/languages)  
Open from July-December 2024

Sociodemographic Data  
Tumor Characteristics  
Diagnosis Experience

### About this Analysis

- Preliminary evaluation
- All entries (completed surveys) from July 1 to September 16, 2024 (cut-off date)
- Exclusively feedback from the patients (patient survey)
- Outcomes identified and evaluated:
  - Diagnostic Interval: Patient & Care Interval (see below)
  - Misdiagnosis
- Analysis by subgroups: Age, gender, localization of primary tumor, country grouped by income level & sarcoma subtypes

## DIAGNOSTIC INTERVAL



**PATIENT INTERVAL: TIME TO SEEK CARE**  
Onset of sarcoma-related symptoms TO first presentation to a doctor for these symptoms



**CARE INTERVAL: TIME TO CURRENT DIAGNOSIS**  
From first presentation to a doctor TO current diagnosis

**FULL DIAGNOSTIC INTERVAL\***

\*Adapted from Soomers et al., ESMO Open, Volume 5, Issue 1, e000592

## CONCLUSION

These preliminary data show that the **median waiting time** from onset of symptoms to correct diagnosis was **over 3 months for all respondents**. When looking at the range, it is noticeable that both in the overall overview and in almost all subgroups, the time period is very broad, from 0 days up to several years until the correct diagnosis.

In all subgroup analyses, it could be seen that the **care interval is generally longer than the patient interval**. One exception are children and adolescents, for which a shorter time to diagnosis was reported.

With regard to the **percentage of misdiagnoses**, few differences can be identified in the individual groups, only regarding the age distribution.

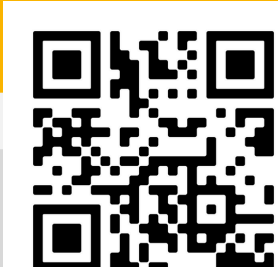
Across all outcome evaluations, the group of **30-44 year olds** stands out: the diagnostic interval is long with a **median total of 5 months**. At 31%, the **number of misdiagnoses** in this age group is also **higher than the average** for all respondents.

Further analysis of the complete dataset, once the questionnaire closes in December 2024, will be required to draw more detailed and comprehensive conclusions.

m: median  
r: range  
d: days  
mo: months  
yrs: years  
y: yes  
n: no  
dk: don't know  
na: no answer

Patient Interval Care Interval

Scan here for survey



1 Sarcoma Patient Advocacy Global Network (SPAGN); 2 Institute for Medical Information Processing, Biometry, and Epidemiology (IBE), Faculty of Medicine, LMU Munich, Germany; 3 School of Nursing, University of British Columbia, Canada; 4 Chordoma Foundation, Germany/USA; 5 Campaigning for Cancer, South Africa; 6 SPANDAN/V Care Foundation, India; 7 Sarcoma UK; 8 Mannheim University Medical Center, Mannheim Cancer Center (MCC), University of Heidelberg, Germany.

THANK YOU

... to all of our participating members & patient advocacy groups, HCP supporters and CTOS!  
... to our partners from the pharmaceutical industry for financial support!

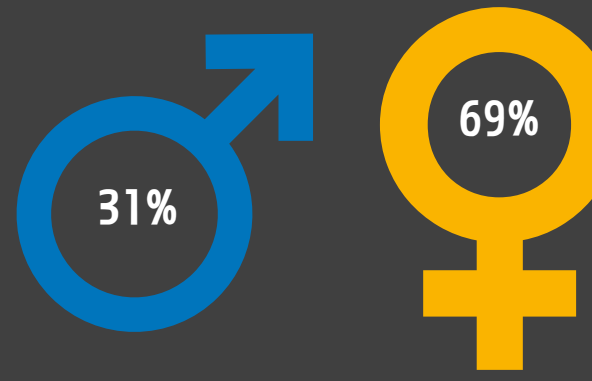


## RESULTS

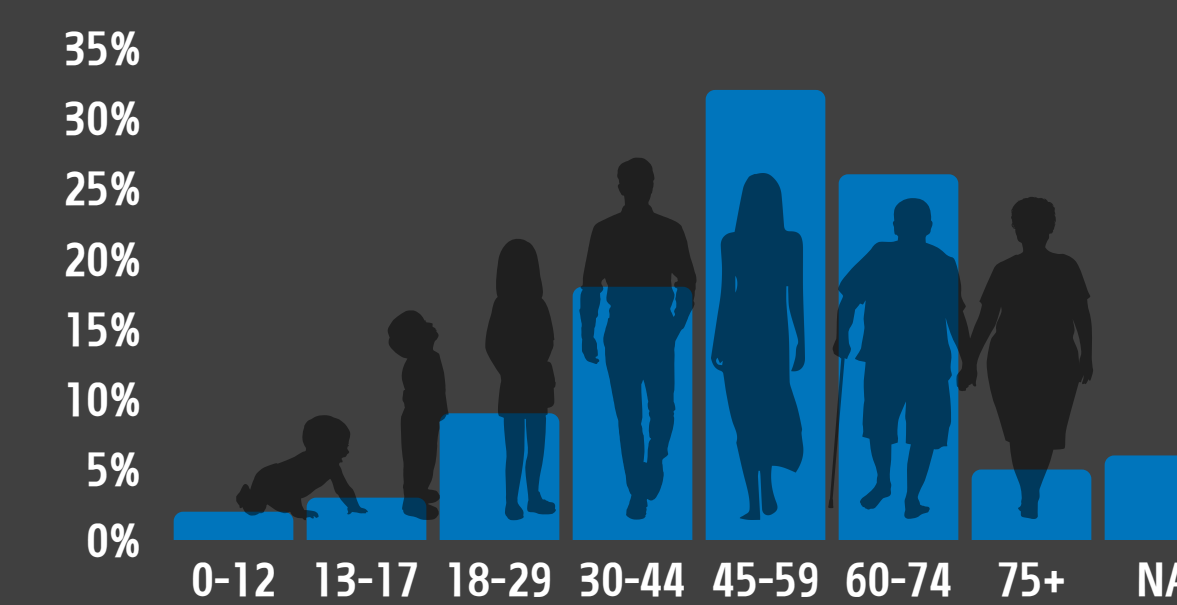
### RESPONDENTS' CHARACTERISTICS

- Total responses from patients: **886**
- Total of **40 countries**
- Median age: **49**

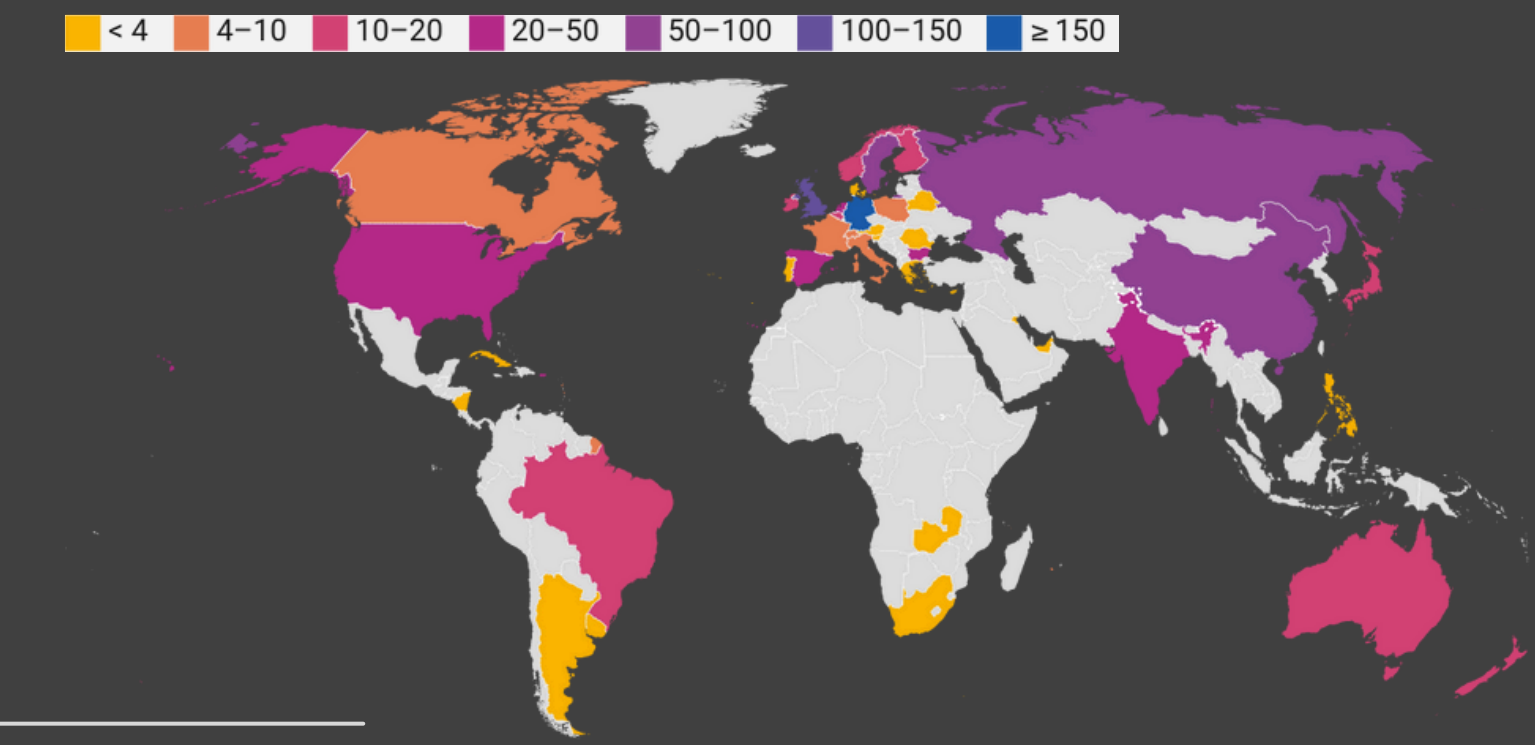
#### Responses by Gender



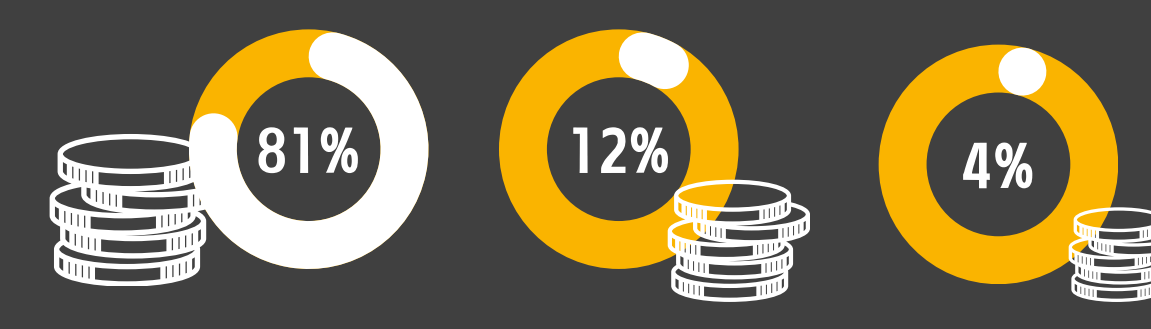
#### Responses by Age



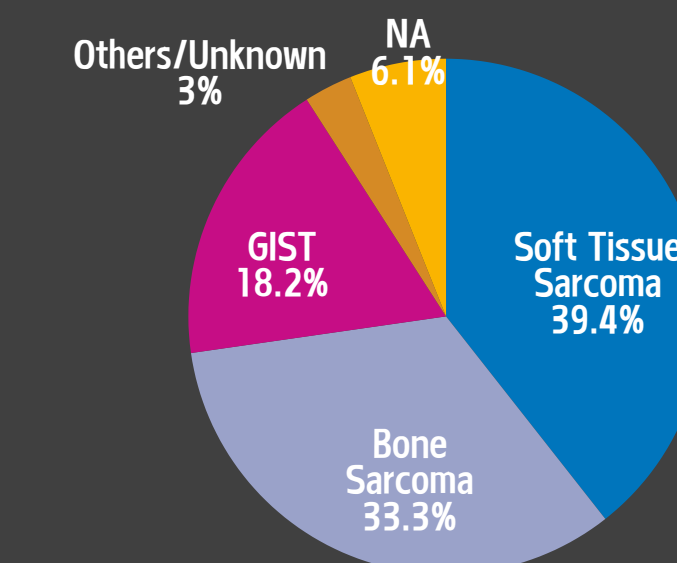
#### Number of Responses by Country



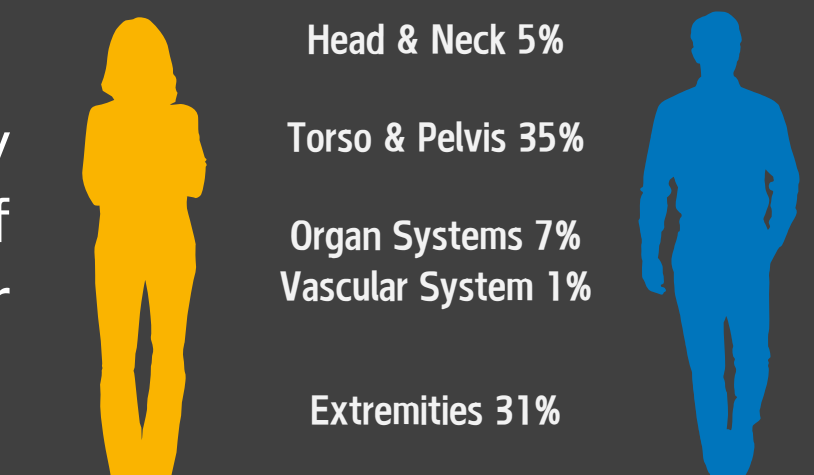
#### Responses by Country Income Level\*



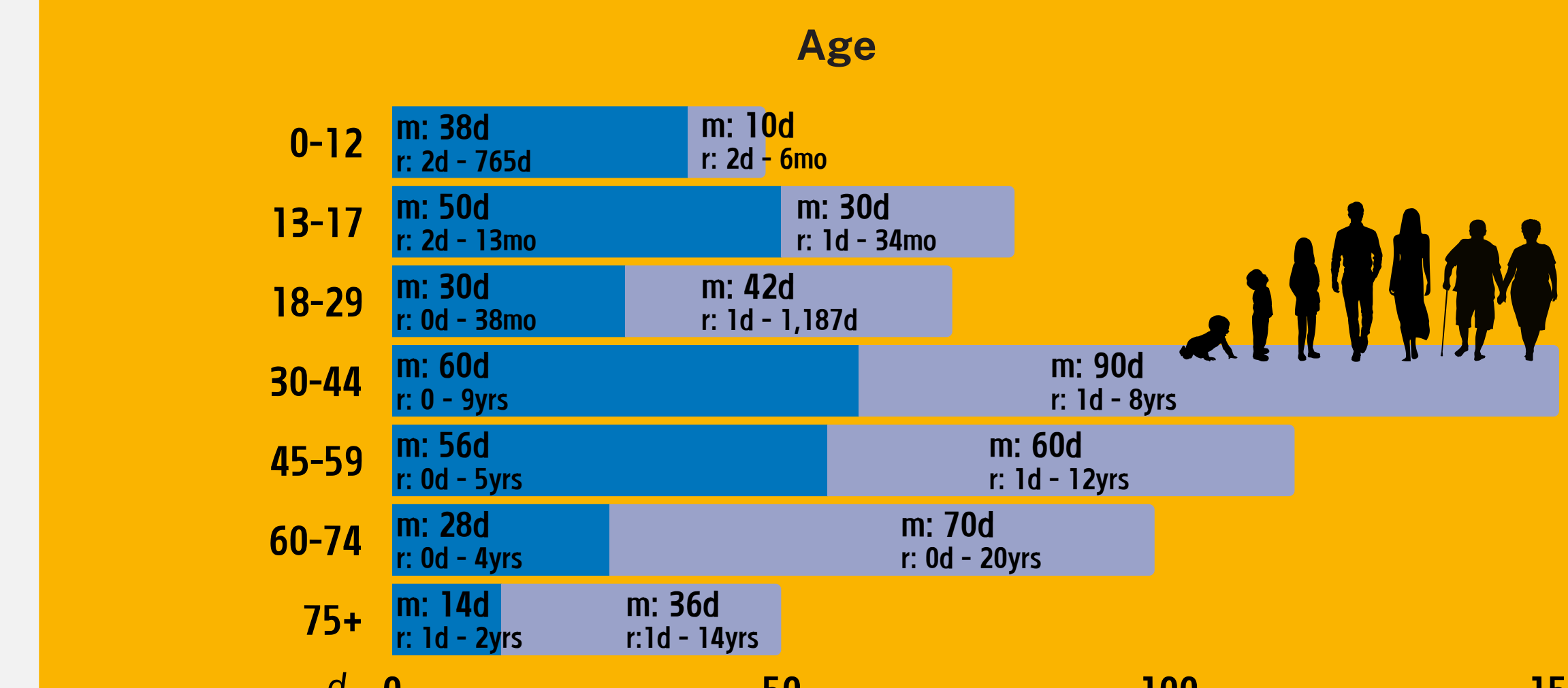
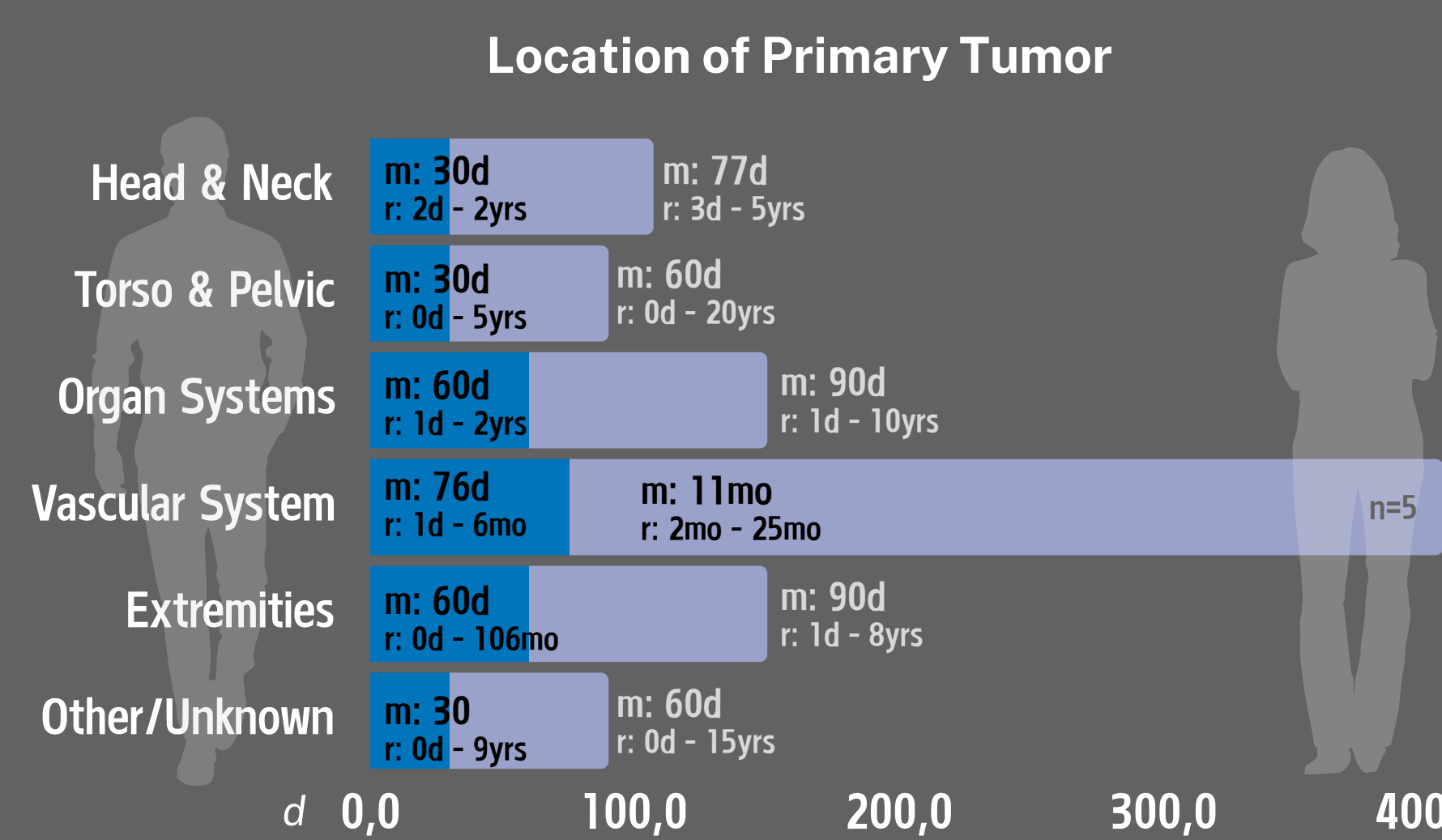
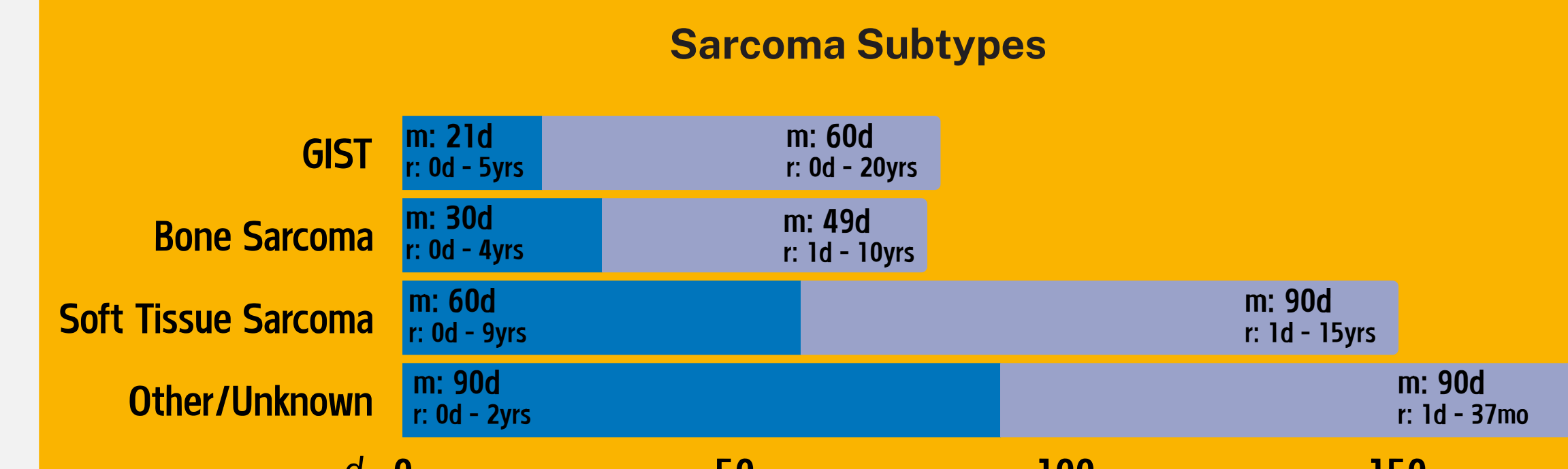
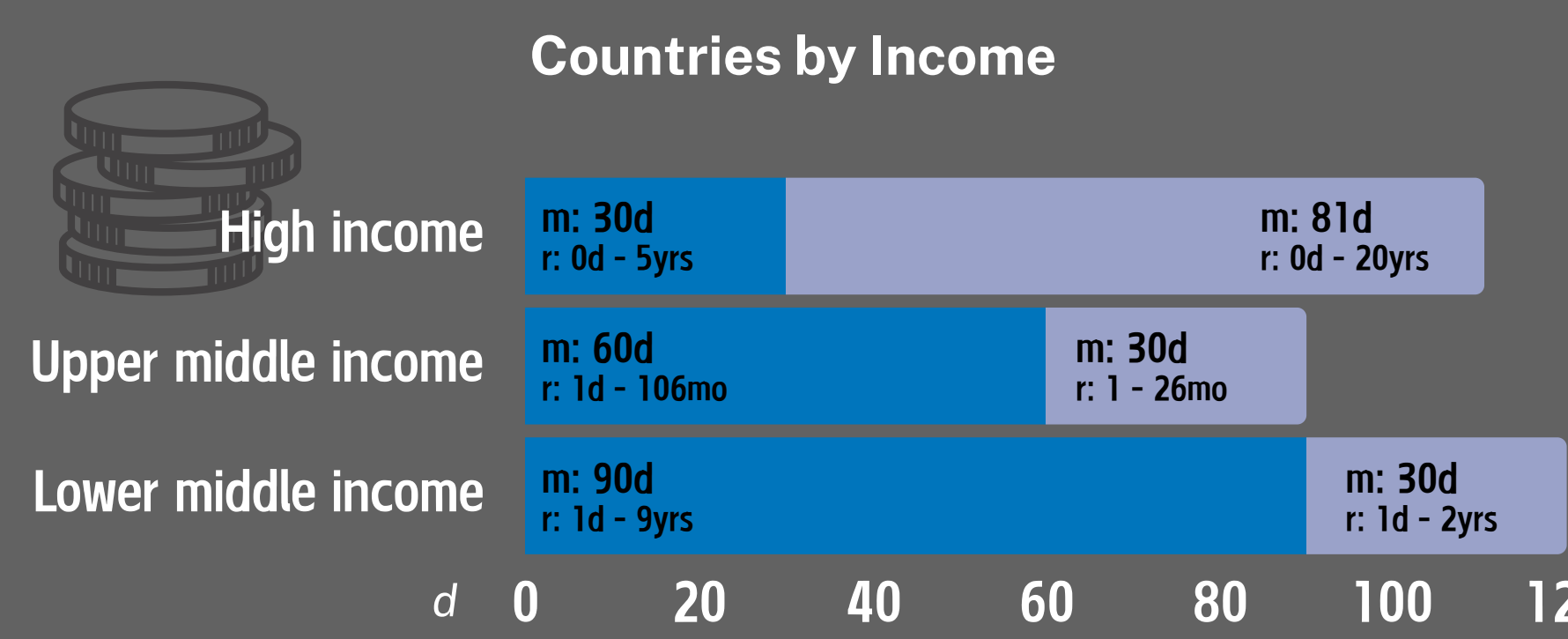
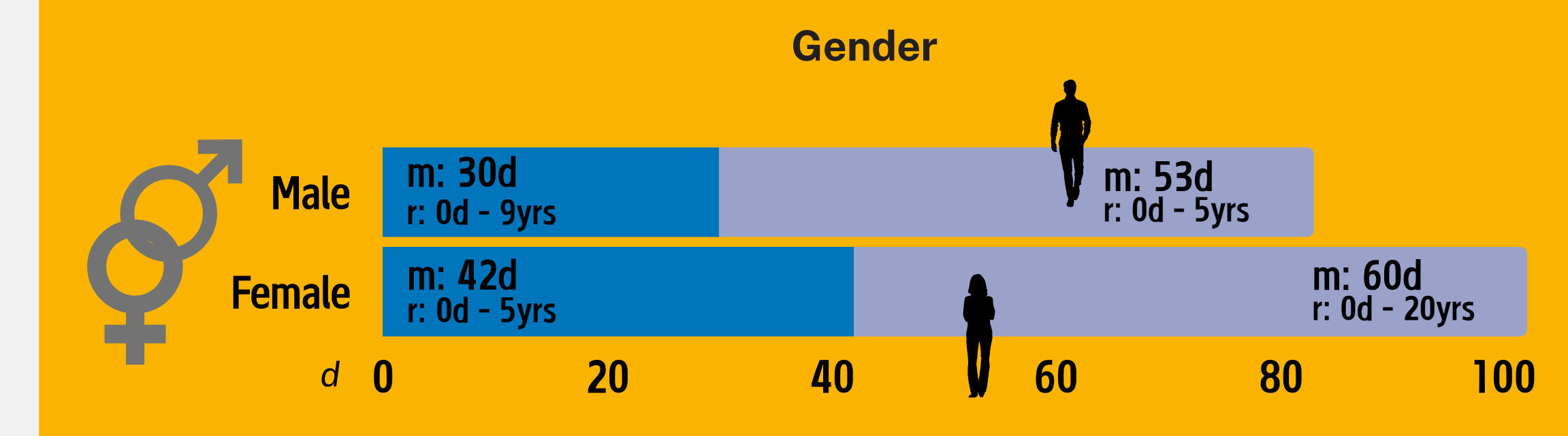
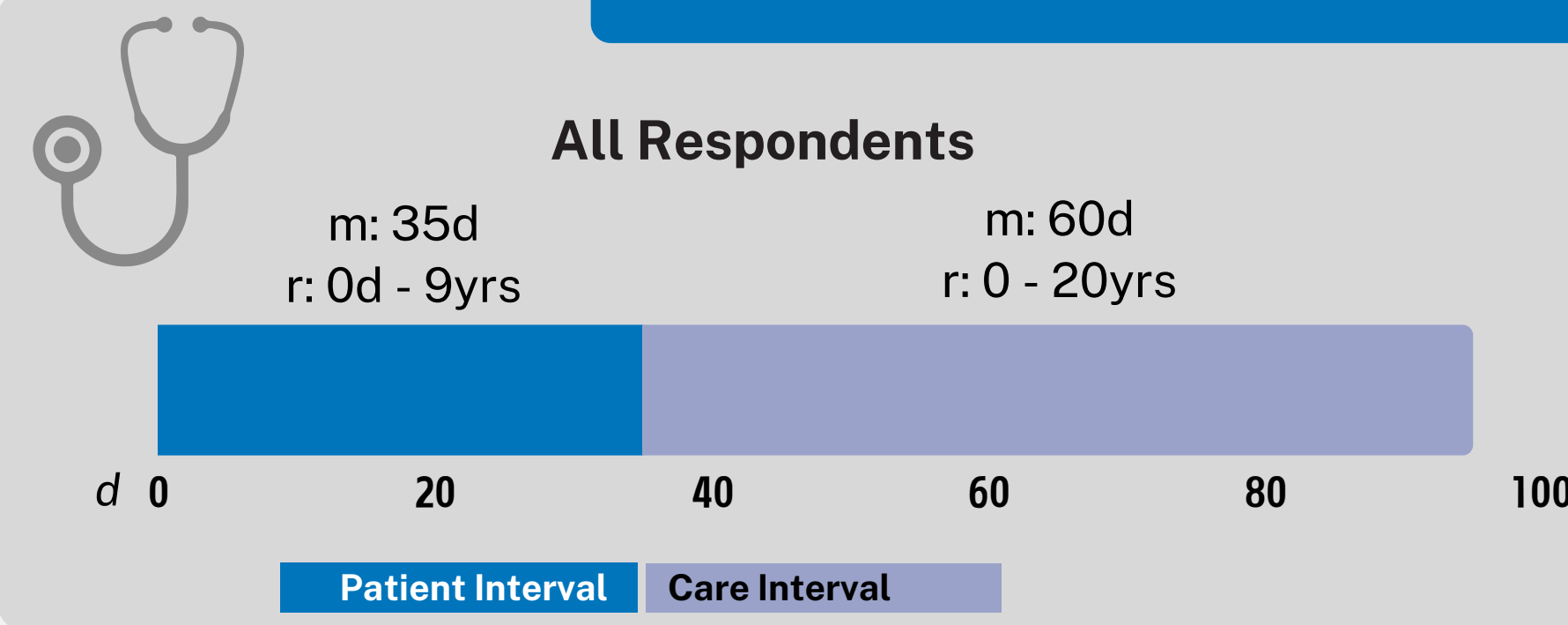
#### Responses by Subtype



#### Responses by Location of Primary Tumor

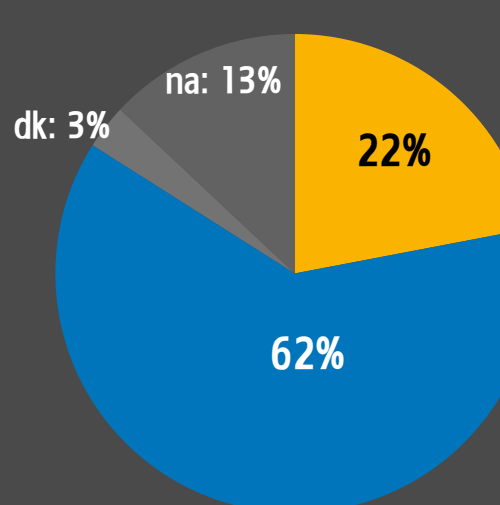


### DIAGNOSTIC INTERVALS

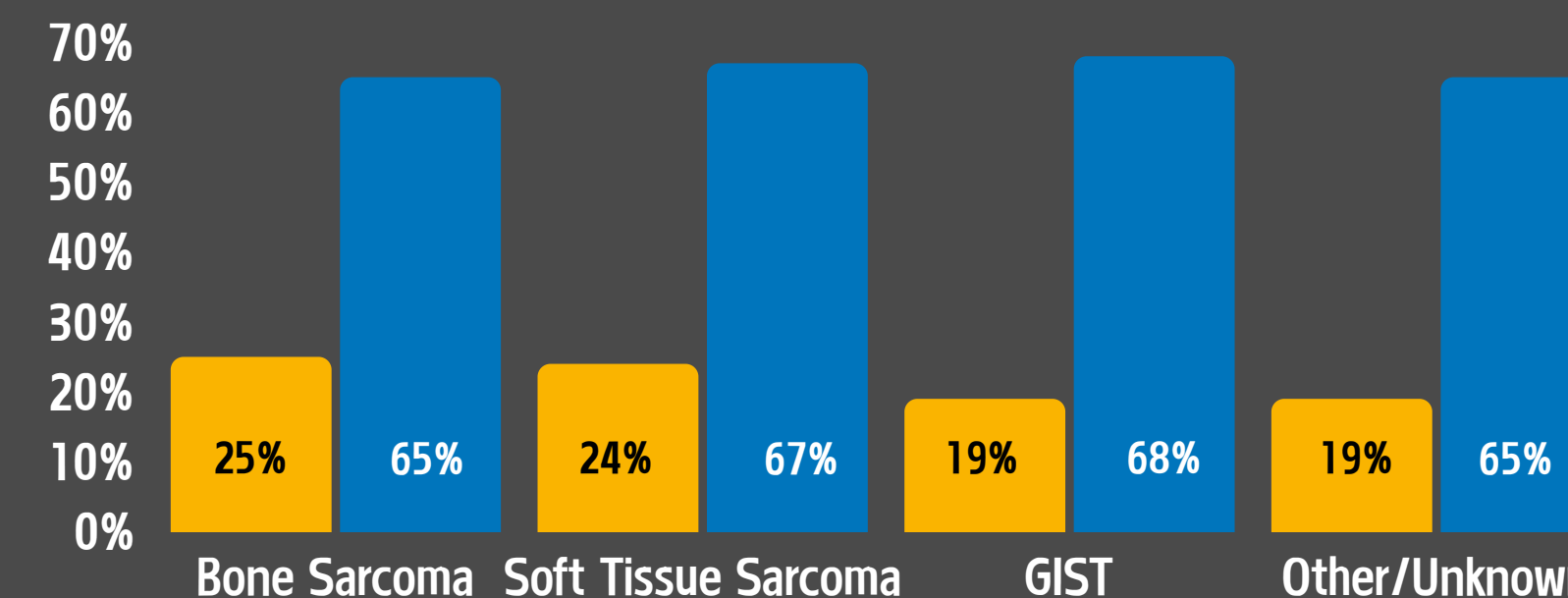


### MISDIAGNOSIS

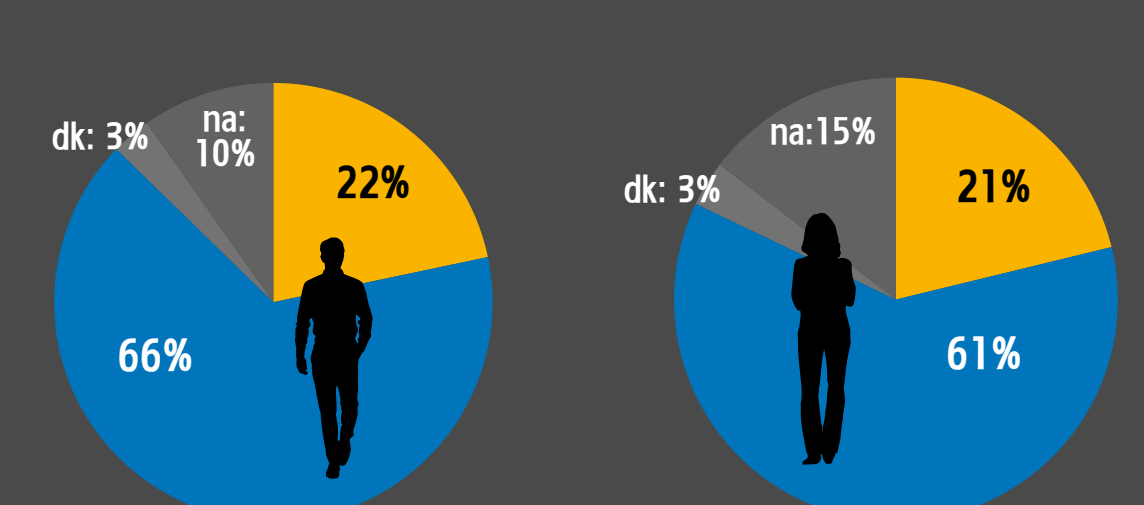
#### All respondents



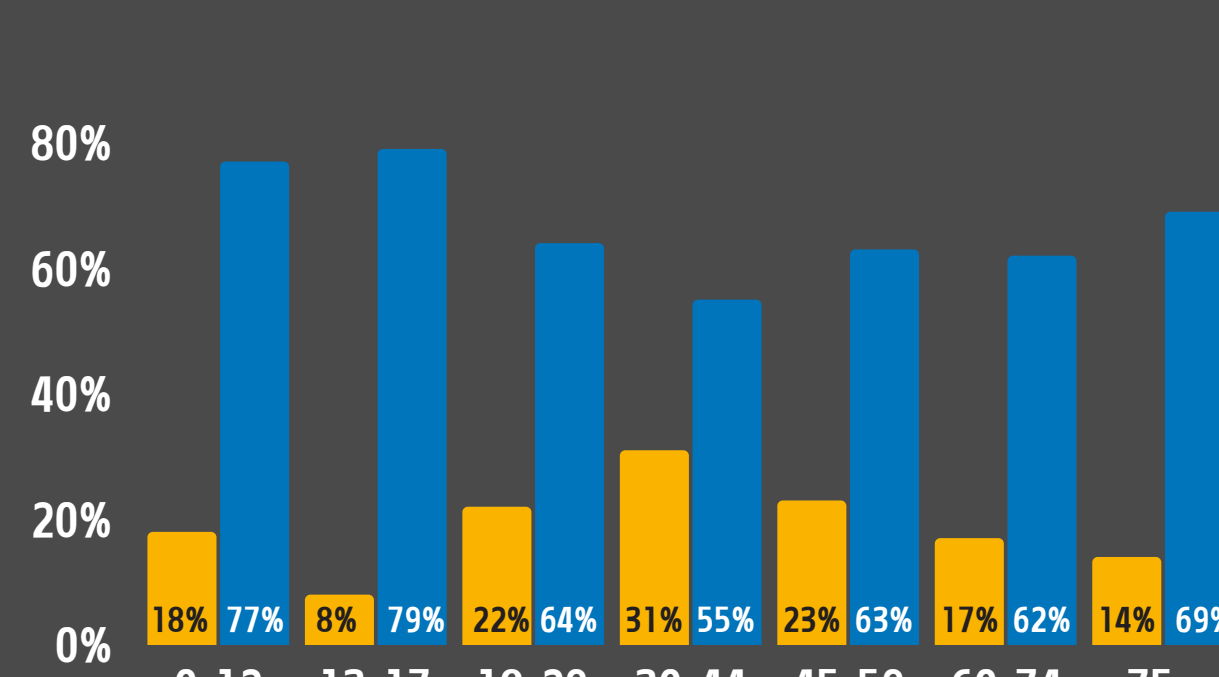
#### Sarcoma Subtypes



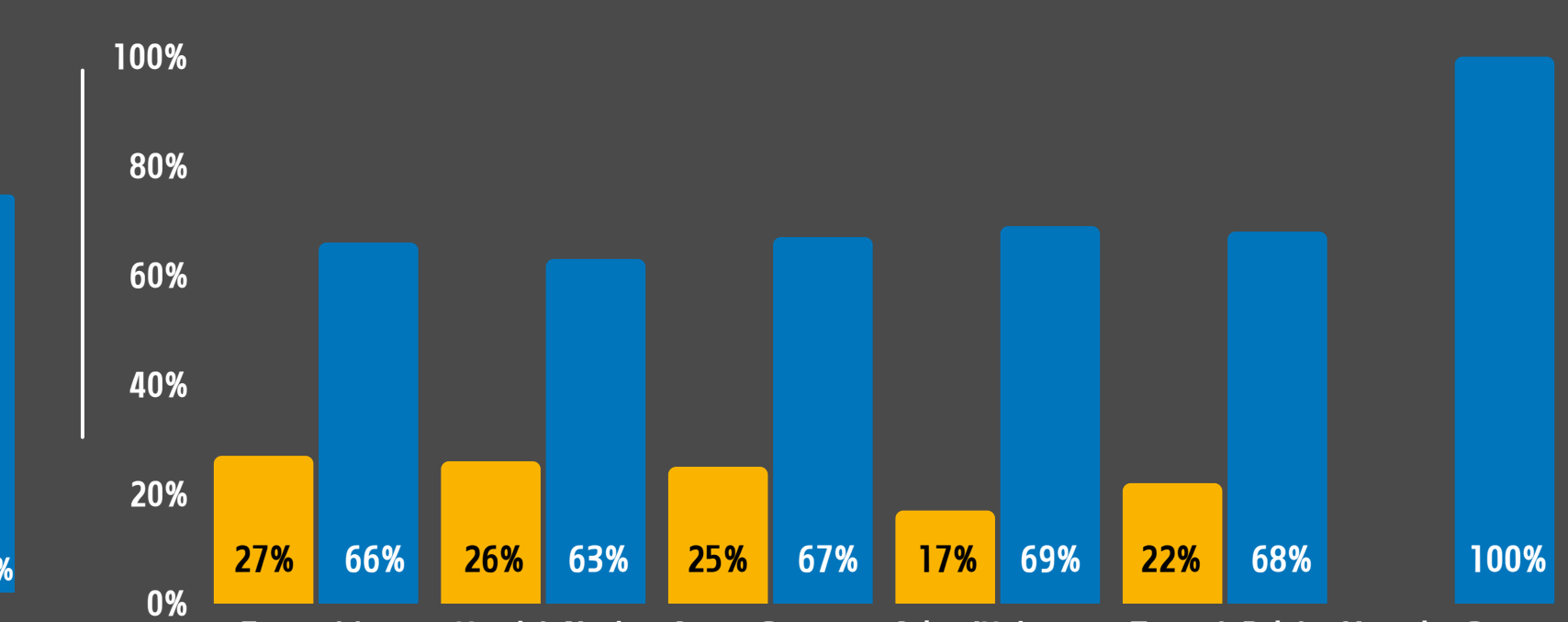
#### Gender



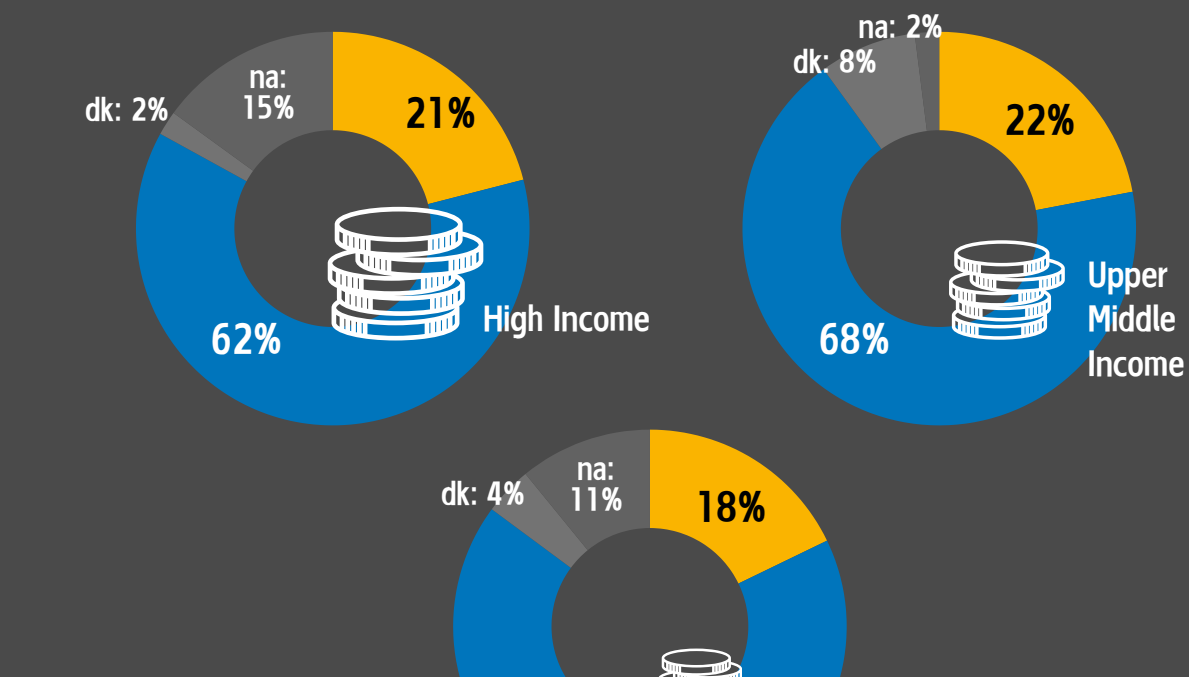
#### Age groups



#### Location of Primary Tumor



#### Countries by Income



Sarcoma Patient Advocacy Global Network e.V./Association