

Experiences of People with Cancer of the Unknown Primary: What do we know and what do we need to do?

The Australian Perspective

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AUSTRALIA



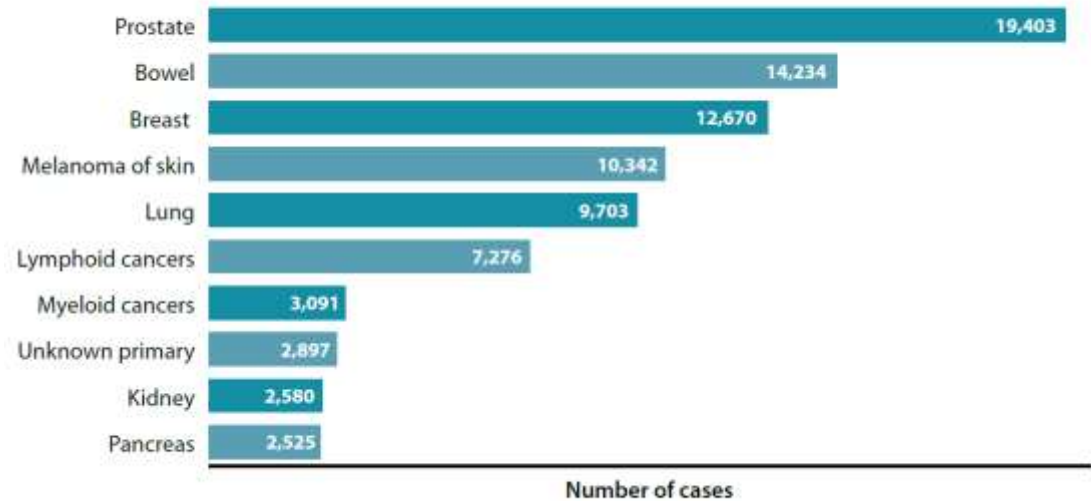
Acknowledgements: Project support- Cancer Australia and Cancer Council NSW
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The logo for Peter MacCallum Cancer Centre, featuring the name "Peter Mac" in a blue script font and a stylized "iir" logo in red and blue.

CUP in Australia

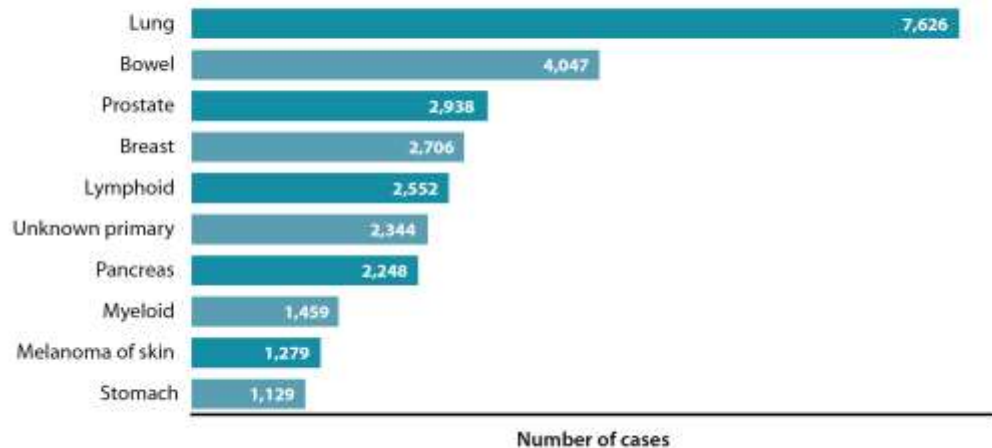
- In 2007, 8th most common cancer and 9th most common cause of death
- In 2003, 7th most common cancer and 3rd most common cause of death

THE 10 MOST COMMONLY DIAGNOSED CANCERS, AUSTRALIA, 2007



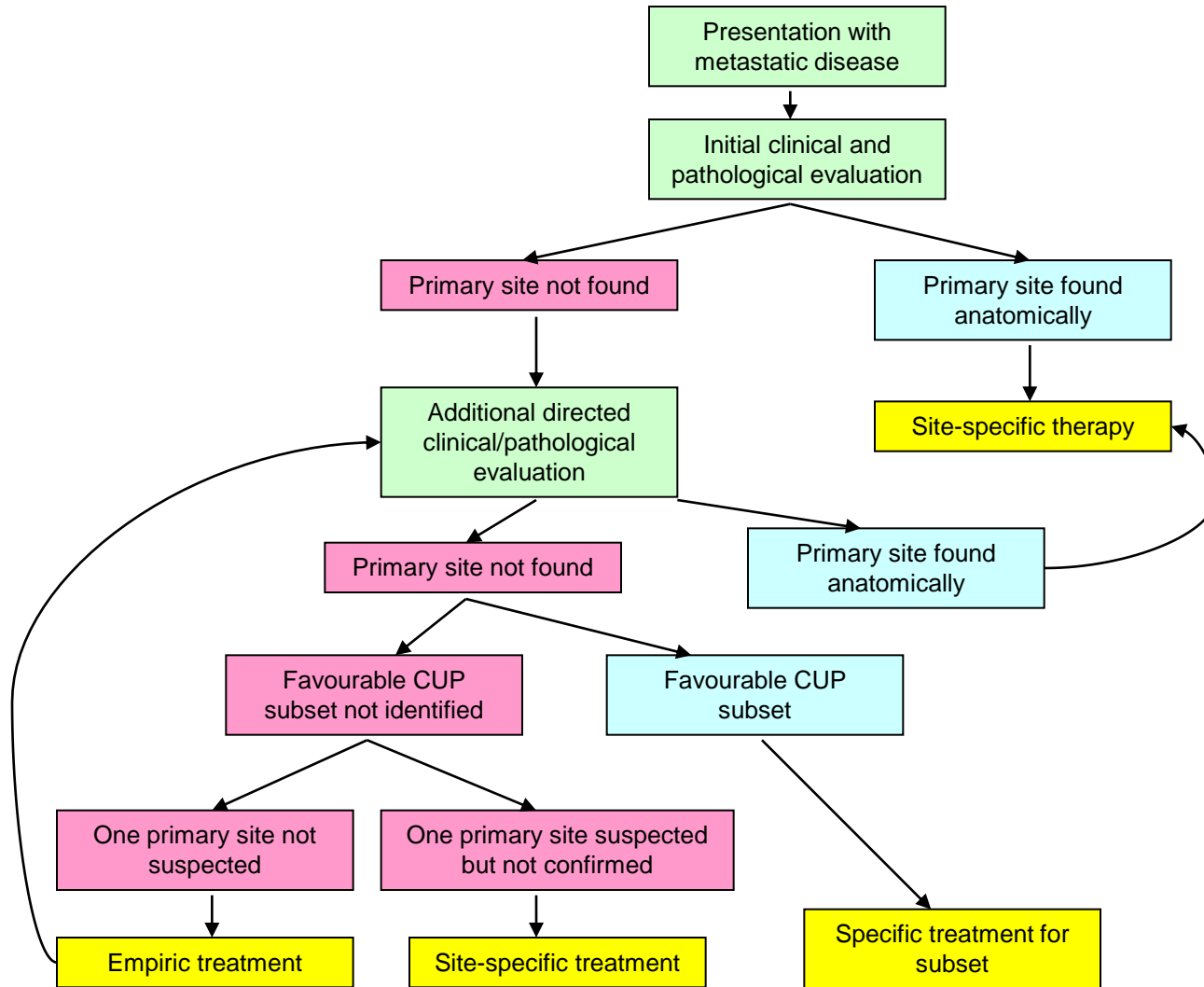
Source: AIHW Australian Cancer Database.

THE 10 MOST COMMON CAUSES OF DEATH FROM CANCER, AUSTRALIA, 2007



Source: AIHW National Mortality Database.

Complex and arduous illness trajectory



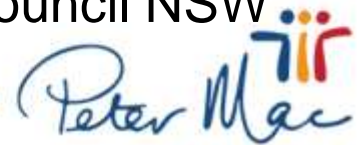



Health professional perspective

“The under-supported cancers, they often feel neglected when they see the sea of pink. This is raising them up so people know about them. Providing support when there is none. **For the unknown primary, it’s raising that it exists, and validating that it’s a real form of cancer.”**

Gill Batt, Director, Cancer Information and Support Services,

Cancer Council NSW

 Peter Mac 

Consumer perspective

“It’s like having a child go missing, in the end the NOT KNOWING is worse than if they had of died. There is no closure and CUP is exactly the same. It’s psychological torture. My father felt this and many patients I’ve cared for whilst we are biopsying this or that have said that’s how they are feeling.”

Cindy Bryant, bereaved carer and nurse

What do we know about the experience of CUP ?

- Extensive literature search revealed **virtually no quality of life research** and **limited clinical research** on CUP

CUP Psychosocial Unmet Needs Study (CUP-PSUN Study)

Principle Investigator: Helen Gooden



Mixed method study

- Qualitative telephone interview: Thematic analysis utilising NVivo9®
- Quantitative surveys post interview
 - Patients: psychological distress, quality of life, unmet needs (HADS; BSI; EORTC-QLQ; SCNS)
 - Caregivers: psychological distress, quality of life, unmet needs, self-efficacy (BSI; SCNS; CASES)

Participant recruitment

Eligibility

- Diagnosis of CUP
- Caregiver for person with CUP (current or bereaved)

Recruitment

- Opt-in via Cancer Council Helplines and clinician referral
- 15 expressions of interest from Dec to April
- To date: N= 5 patients N=5 carers
- Response rates 10/12 = 84%

The experiences of people with CUP

Difficulty understanding diagnosis

“How can you have a cancer without a primary? I mean it was just so extraordinary, so bizarre!” Patient, Female

Difficulty of living with “uncertainty”

“It’s the isolation, the fear, the not-knowing that gnaws away at you.” Patient, Female

The experiences of people with CUP

Uncertainty regarding treatment

“(Dr) said, while we are filling you up with all these chemo poisons, the cancer is just laughing at us.” Patient, Male

*“I thought, God, is it worse to find the primary or not find it.”
Patient, Female*

Feeling lost and abandoned

“Because there was nothing, I just stopped expecting anything.” Patient, Female

Clinician Survey



Investigators: A/Prof Chris Karapetis and Helen Gooden

Aim: To determine clinical practices in approach to management of CUP amongst Australian medical oncologists

Design: Cross-sectional survey design using an electronically completed questionnaire administered via email

Participants: National membership of Medical Oncologists of Australia (MOGA) N= 86; Response rate= 28% (86/302)

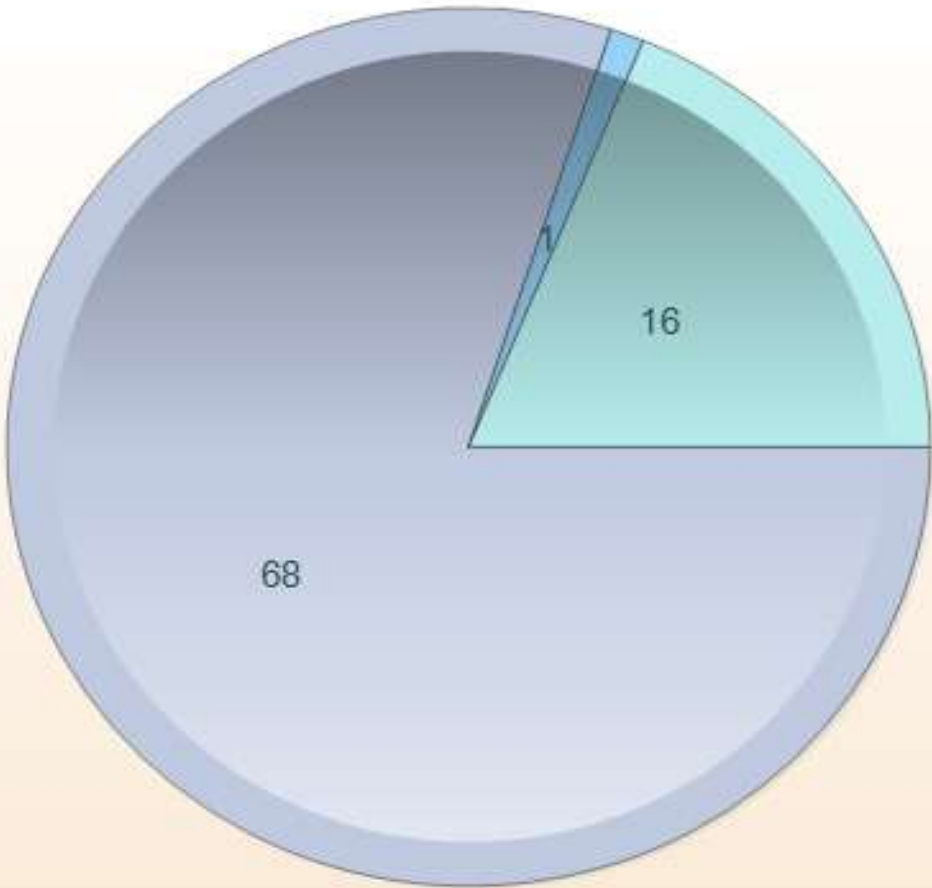
Sample characteristics

Cancer Specialty	Medical Oncologist Other	96% 4%
Age	<40 40-49 50-59 >60	35% 29% 28% 8%
Work location	Public, capital city Private, capital city Public, regional Private, regional	76% 14% 6% 5%

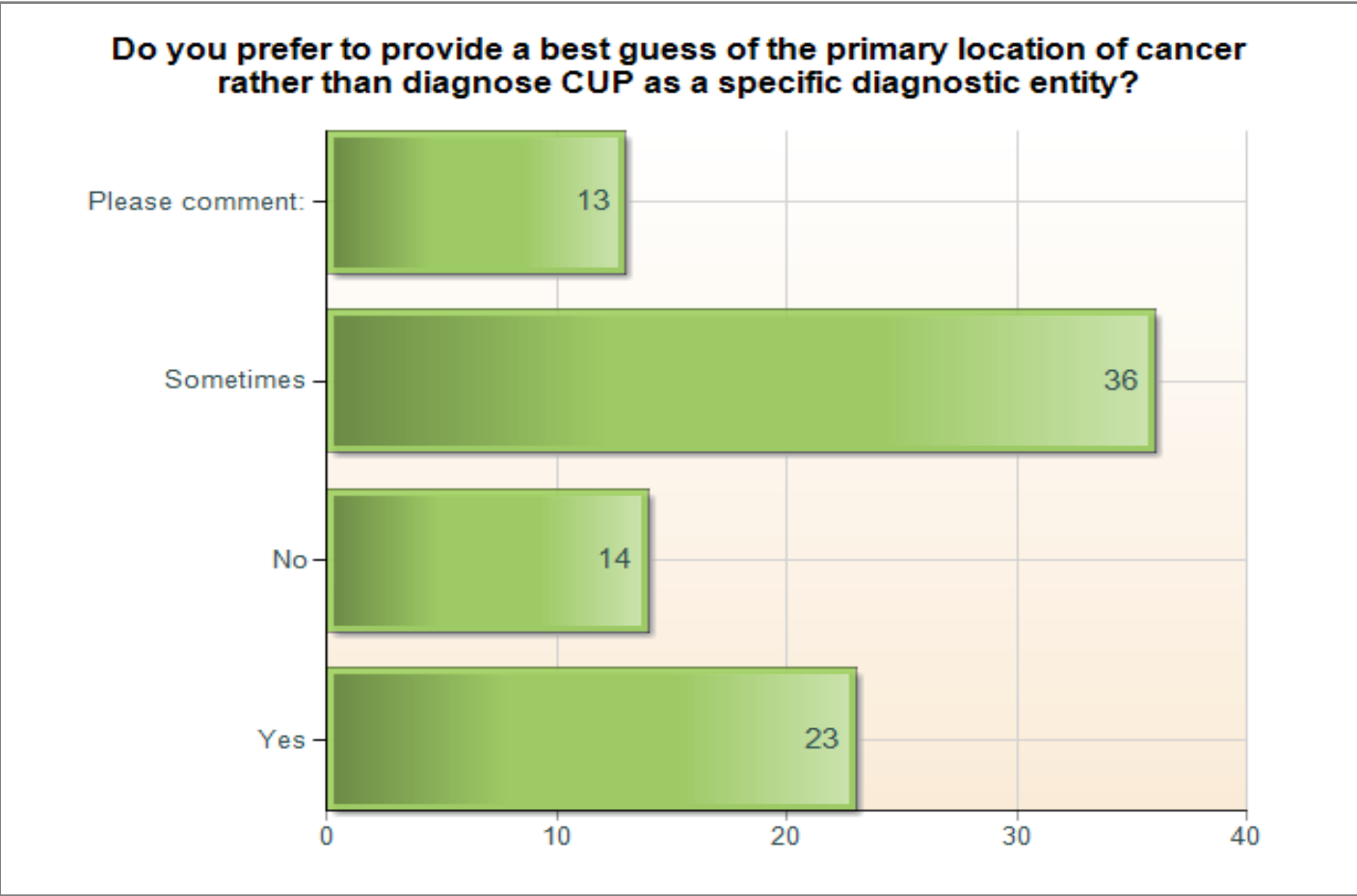
Cancer of Unknown Primary Clinician Survey

Are you prepared to provide a final diagnosis of CUP if you remain uncertain as to the primary location of the cancer?

Yes No Sometimes

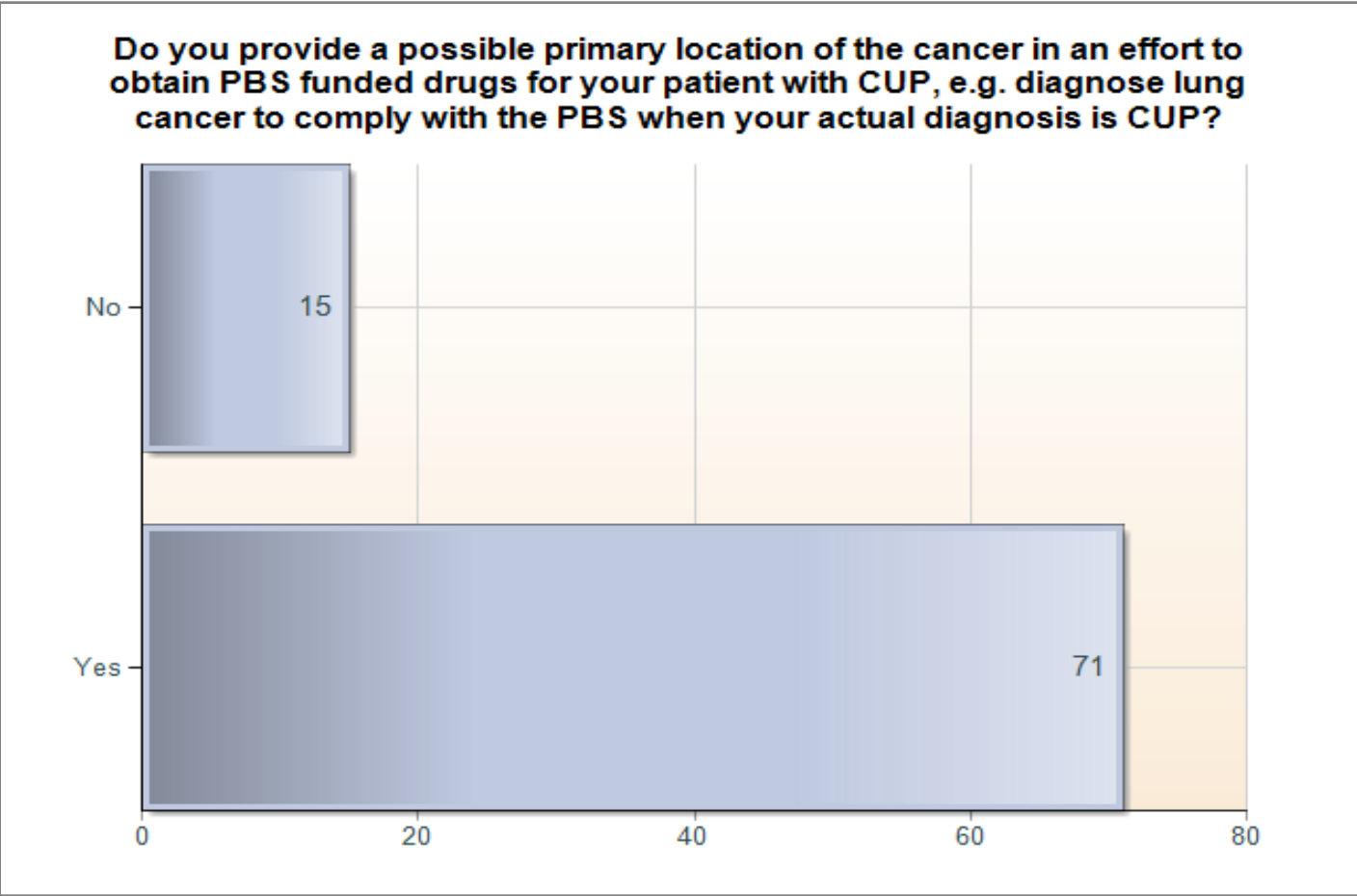


Cancer of Unknown Primary Clinician Survey



➤ 98% of respondents DID NOT believe that all CUP cancers are the same entity.

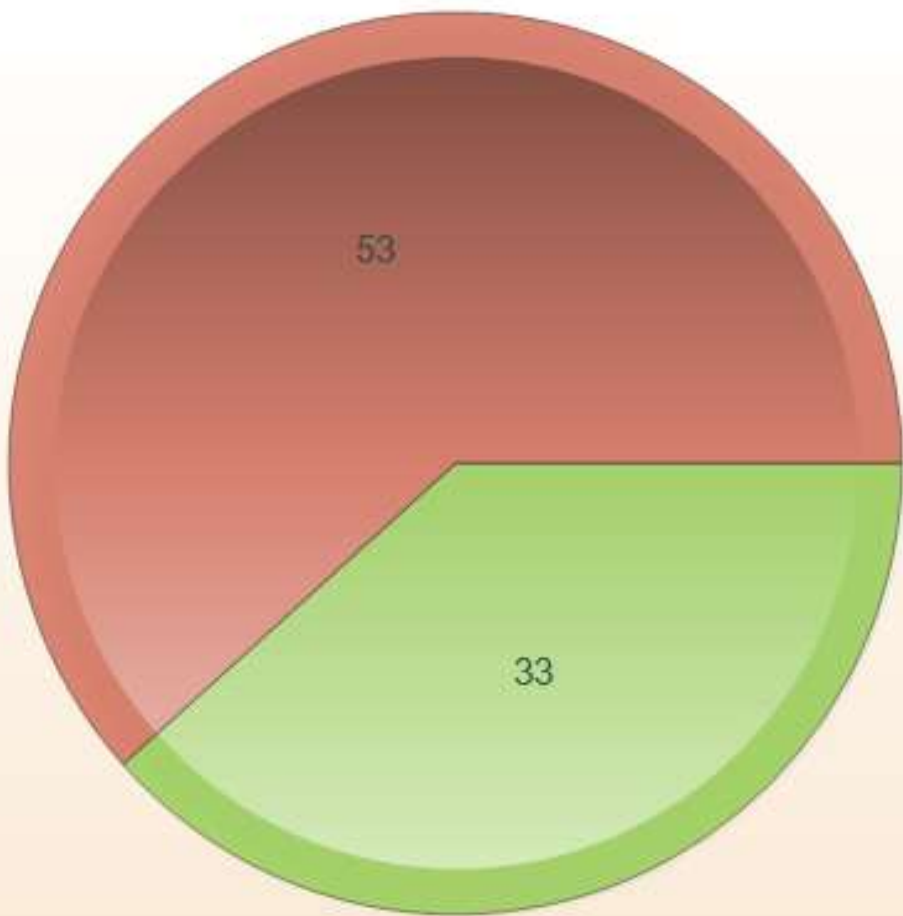
Cancer of Unknown Primary Clinician Survey



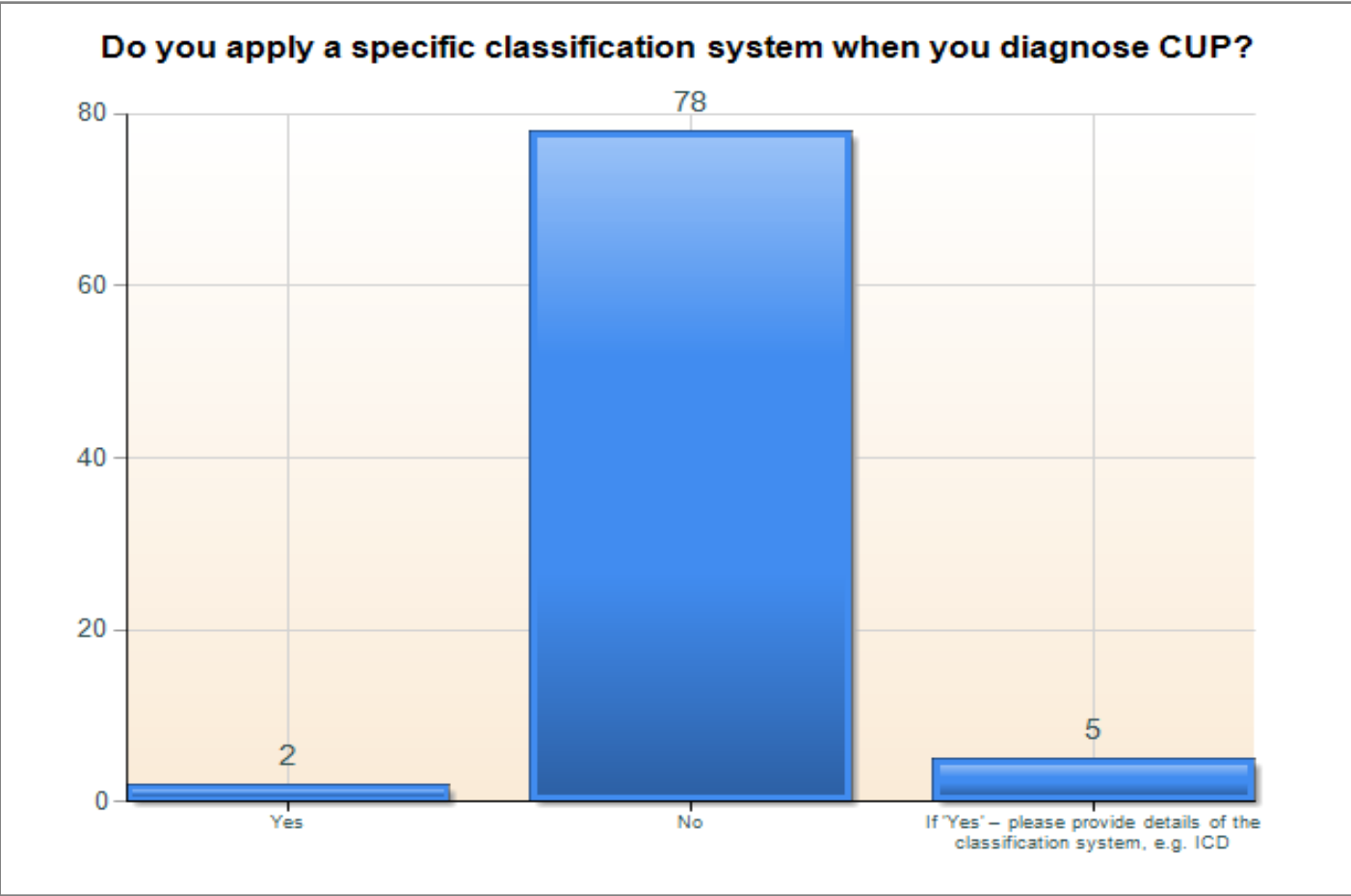
Cancer of Unknown Primary Clinician Survey

At your institution do you have treatment protocols (e.g. accepted chemotherapy regimens) that are recommended specifically for CUP?

Yes No



Cancer of Unknown Primary Clinician Survey



How do you describe or discuss a diagnosis with patients and families?

Use term CUP and explain

“Primary (parent) appears to have regressed but metastases (children) have grown”

Don't use term CUP; discuss likely primary

“No don't use CUP; Usually talk about my best guess primary”

Discuss poor prognosis:

“Whilst we can offer chemotherapy, it is not curable and prognosis is often in the realm of months rather than years”

Treatment implications

“I use the term of CUP and explain that it is a well recognised situation. Treatment is guided by the histology and overall clinical picture/pattern of disease”

Recognised Common Cancer type

“I inform them that it is a legitimate, recognised entity in our specialty.”

Future Research Directions

- Establish comprehensive longitudinal description of supportive care needs of people affected by CUP
- Develop and test acceptable, clinically feasible and sustainable intervention targeting these needs

SUPER: Patient Reported Outcomes

Aims

To establish the quality of life and psychosocial needs of patients with CUP compared to a matched sample of patients with metastatic cancer of a known primary

Design

A prospective, longitudinal study with matched control group over one year with 120 cases per group. Data collection will occur 3 monthly.

Measures

Hospital Anxiety and Depression Scale

EORTC Quality of Life Questionnaire Core Questionnaire

Needs Assessment for Advanced Cancer Patient

Memorial Symptom Assessment Scale Short Form

Hopelessness Assessment in Illness

Research Challenges

CUP patients are a **sizable group of patients with unique and complex needs**

There is virtually no evidence to guide communication or supportive care practices

- Difficulties in **defining** and **identifying** these patients within the system
- Many doctors provide a **'likely' diagnosis**, so patients don't identify with CUP label.
- Maybe recorded as a definitive diagnosis to **access drugs**
- Poor prognosis means research is **challenging**