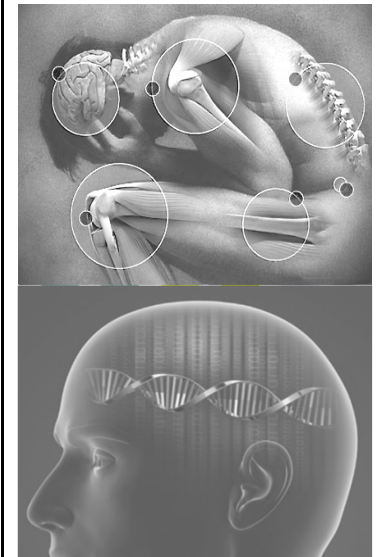


(Cancer) pain in intellectual disabilities

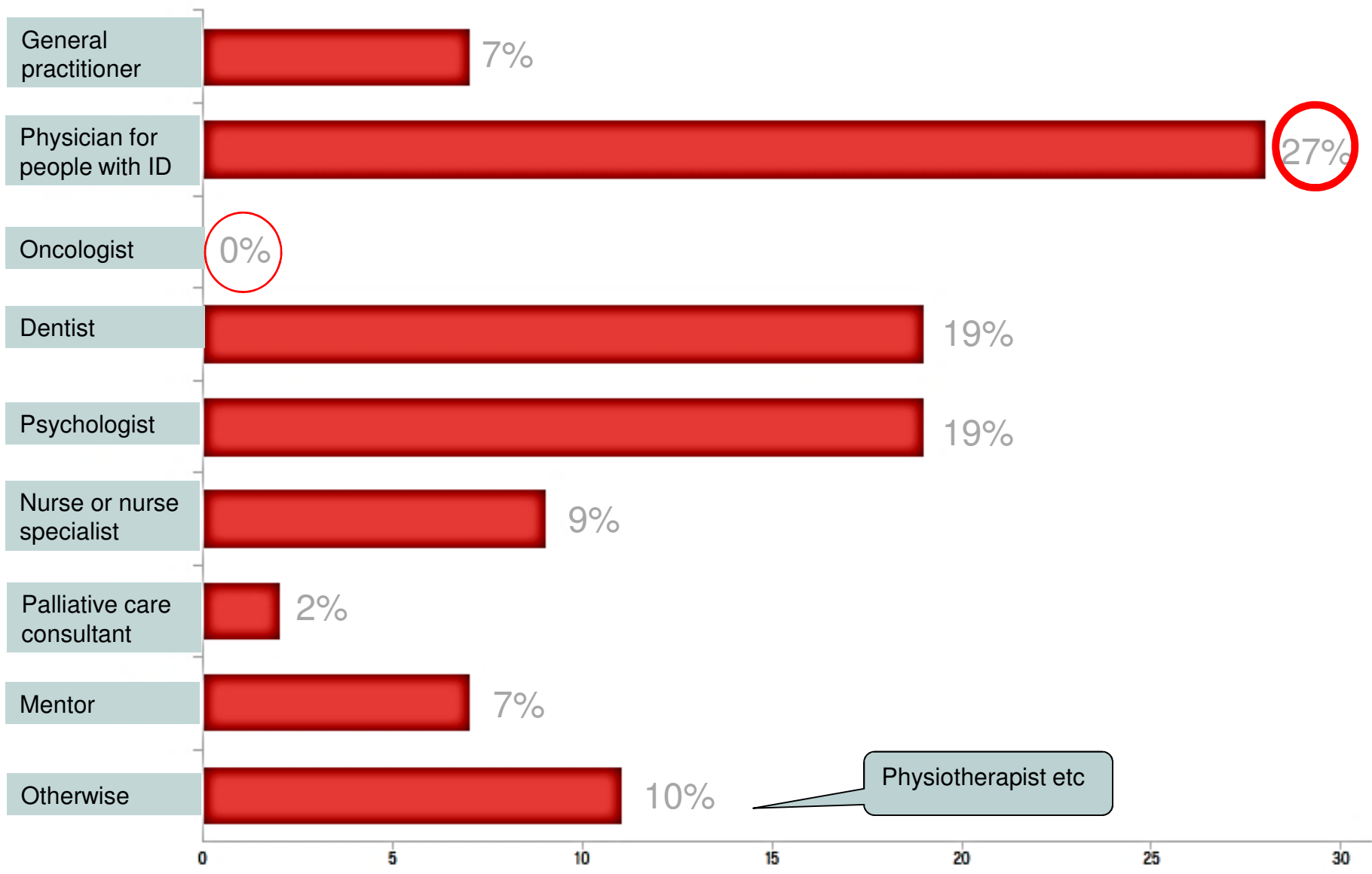
Lecture Montpellier
10 October 2018

Dr. Nanda de Knegt
Psychologist and researcher
Department of Clinical Neuropsychology
VU University, Amsterdam, the Netherlands



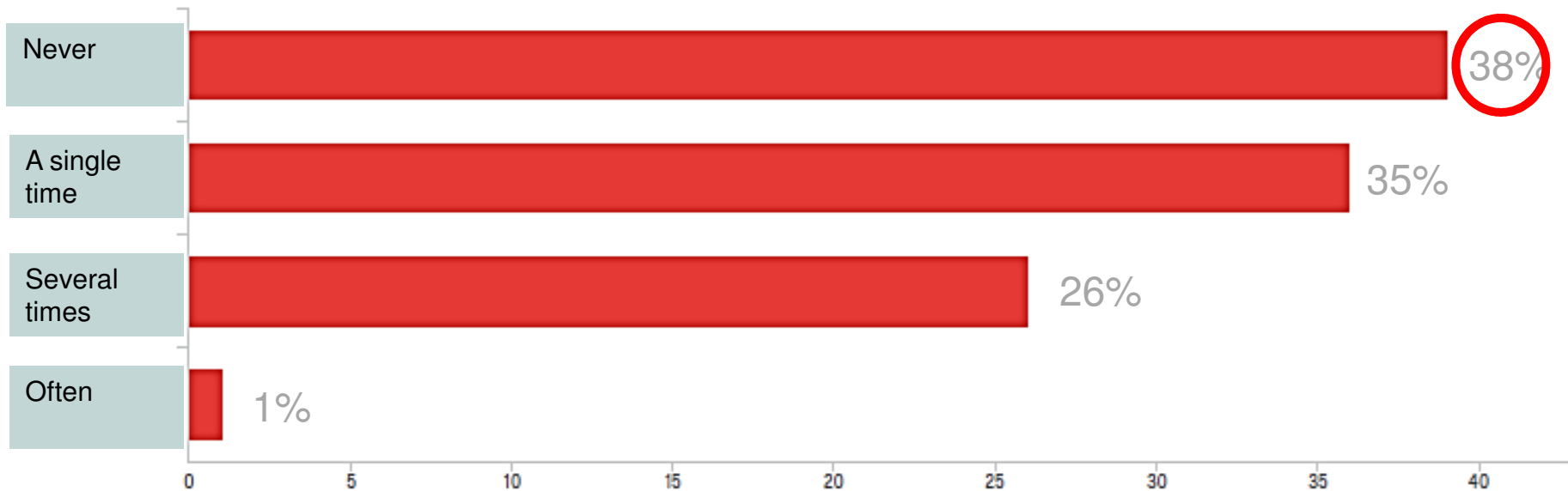


What is your job?



N = 102

How often were you involved with cancer in people with intellectual disabilities?



Median ($n = 58$): 5 patients

$N = 102$

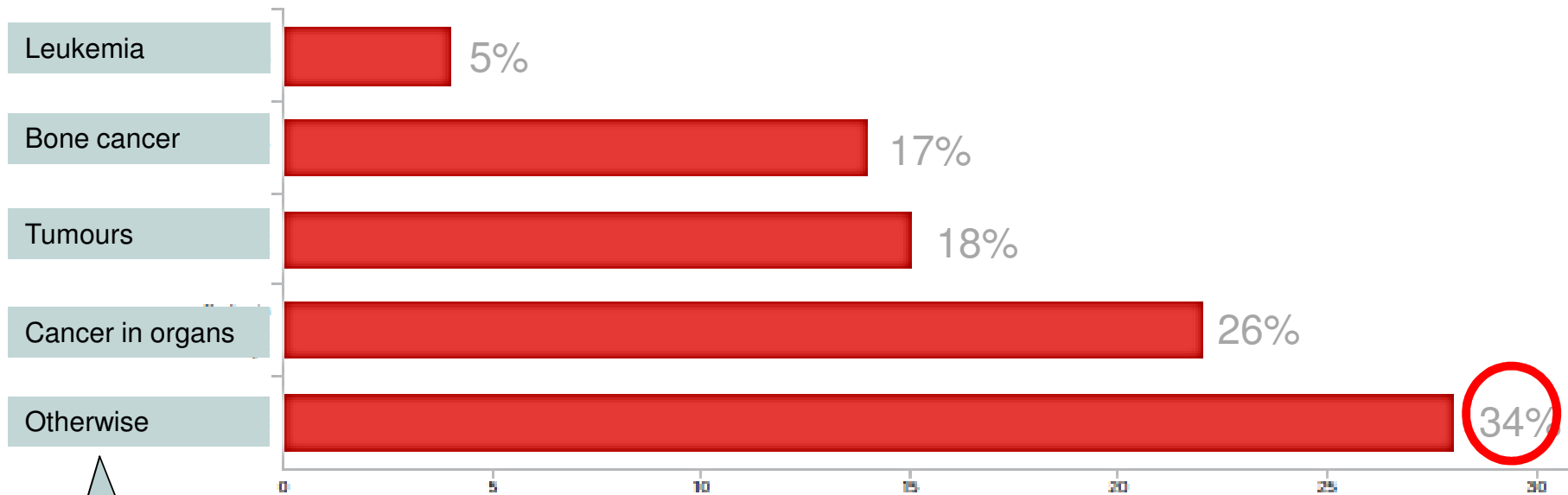
In what percentage of cases was pain the symptom for diagnostics that eventually detected the cancer?

$n = 63$

Mean: 37%

* In following questions = multiple answers possible ($n > 63$)

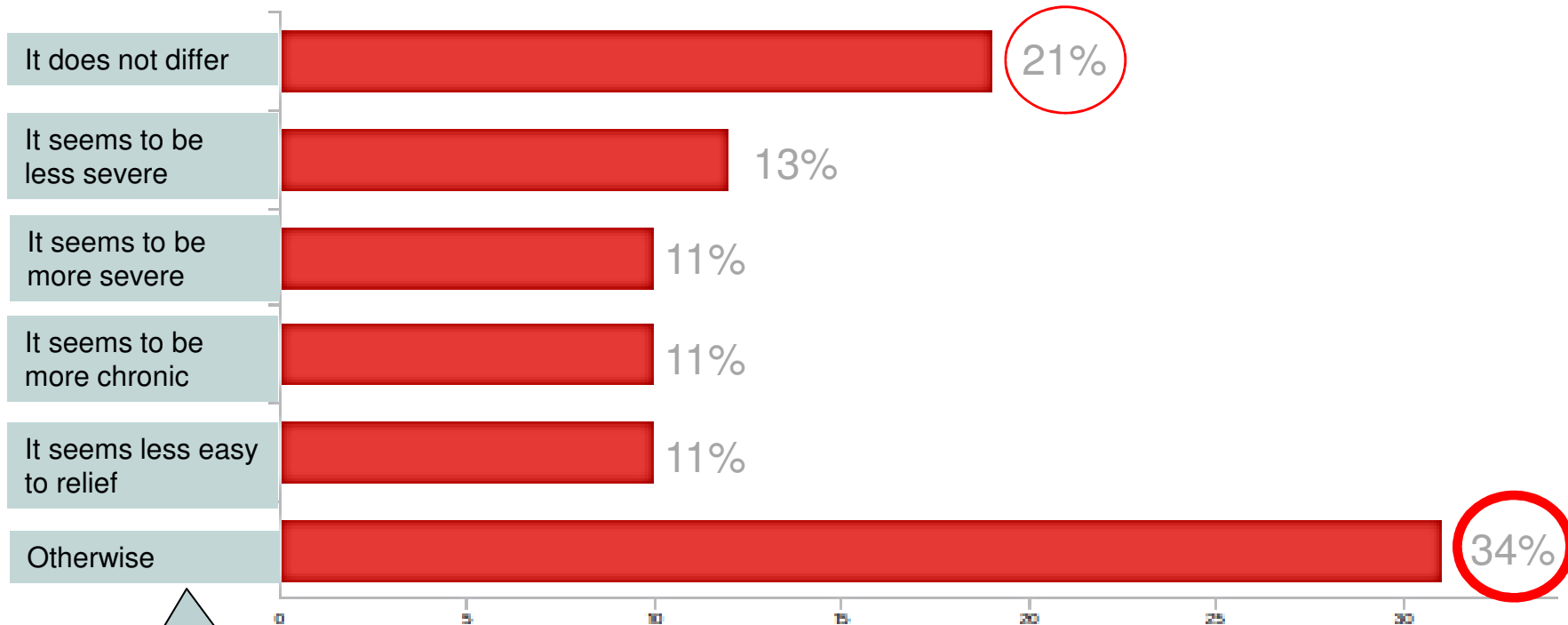
What type of cancer, according to your experience, causes the most pain specifically in people with intellectual disabilities?*



Too little experience, metastasis etc

n = 83

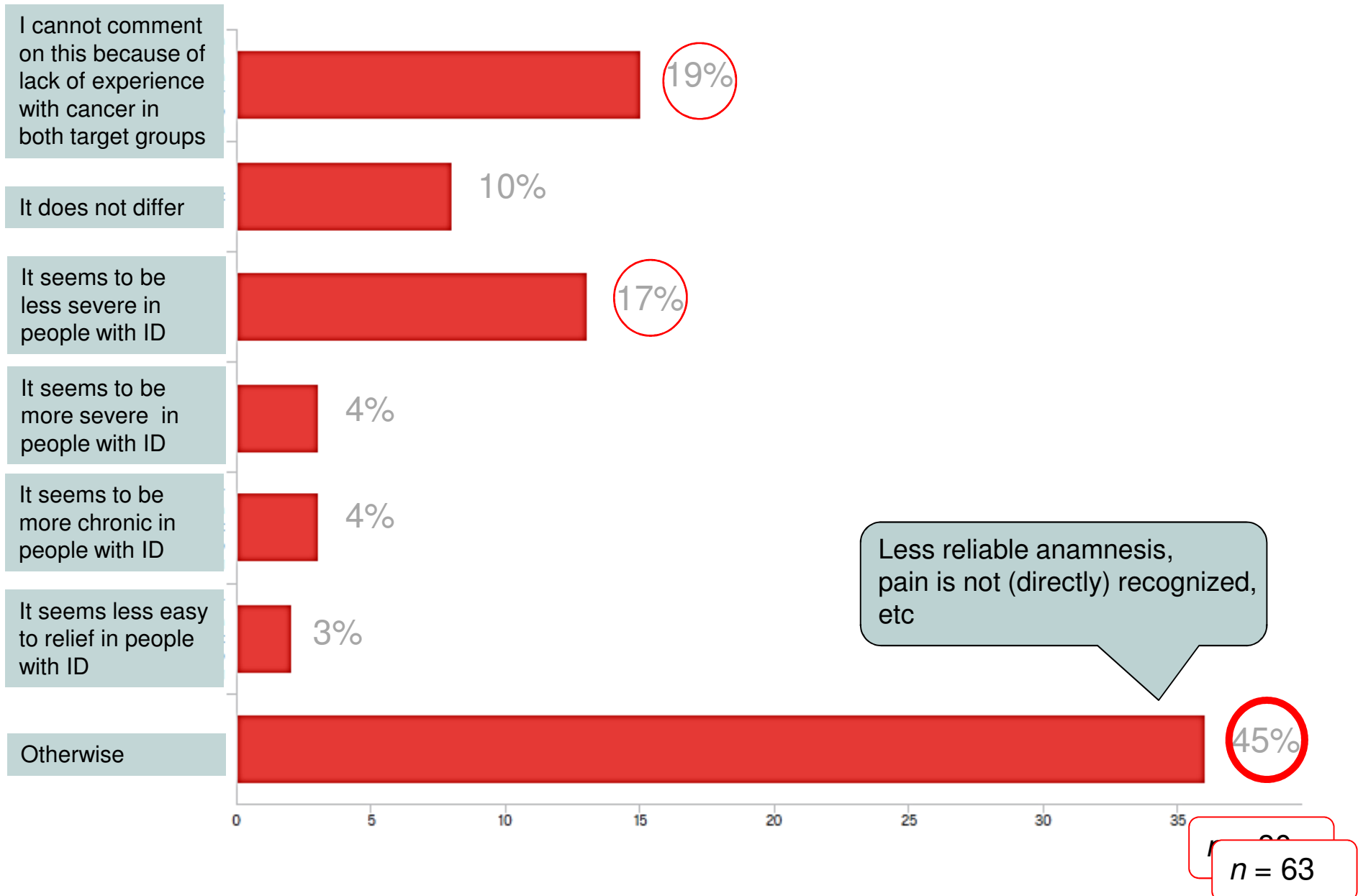
In your experience, how does cancer pain differ from pain due to other causes in people with intellectual disabilities?*



Depends on type of cancer,
more difficult to recognize (gradual course),
Etc

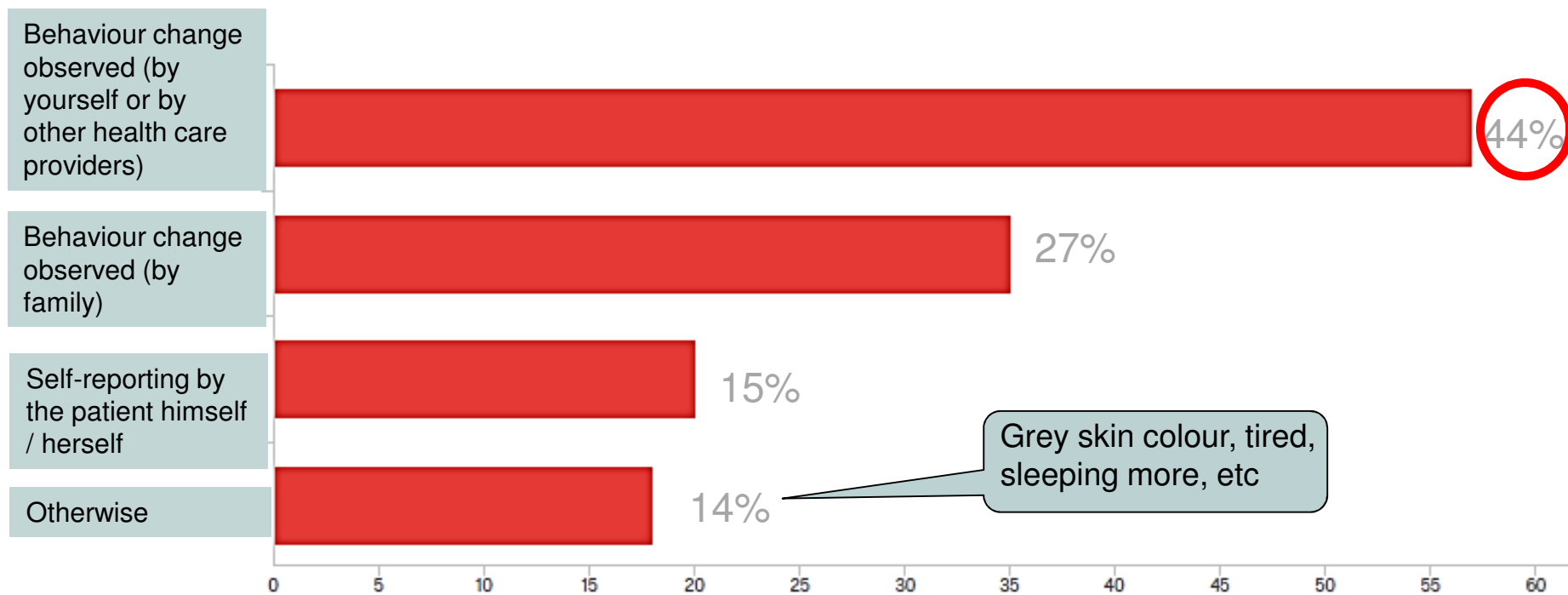
$n = 92$

In your experience, how does cancer pain differ between people with and without intellectual disability?*





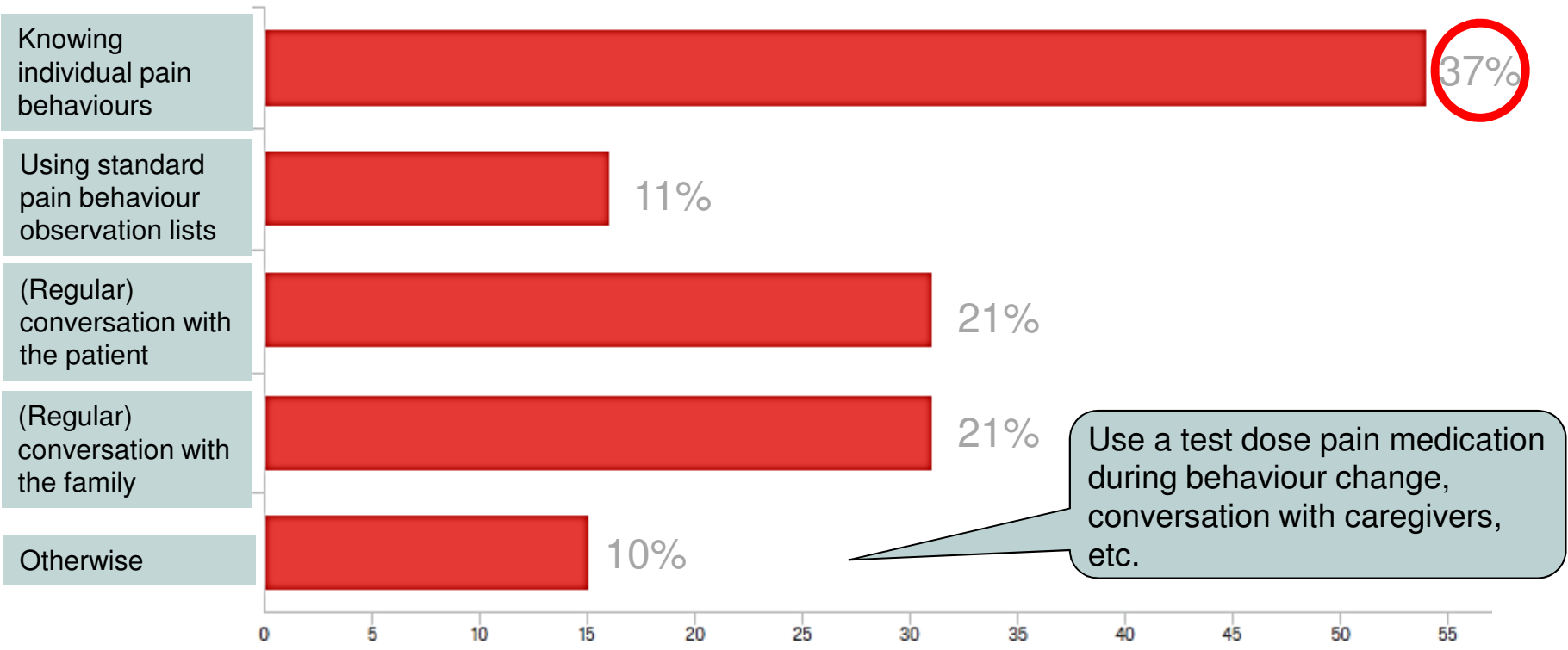
How is cancer pain usually signalled in the people with intellectual disabilities you have been involved in?*



n = 130

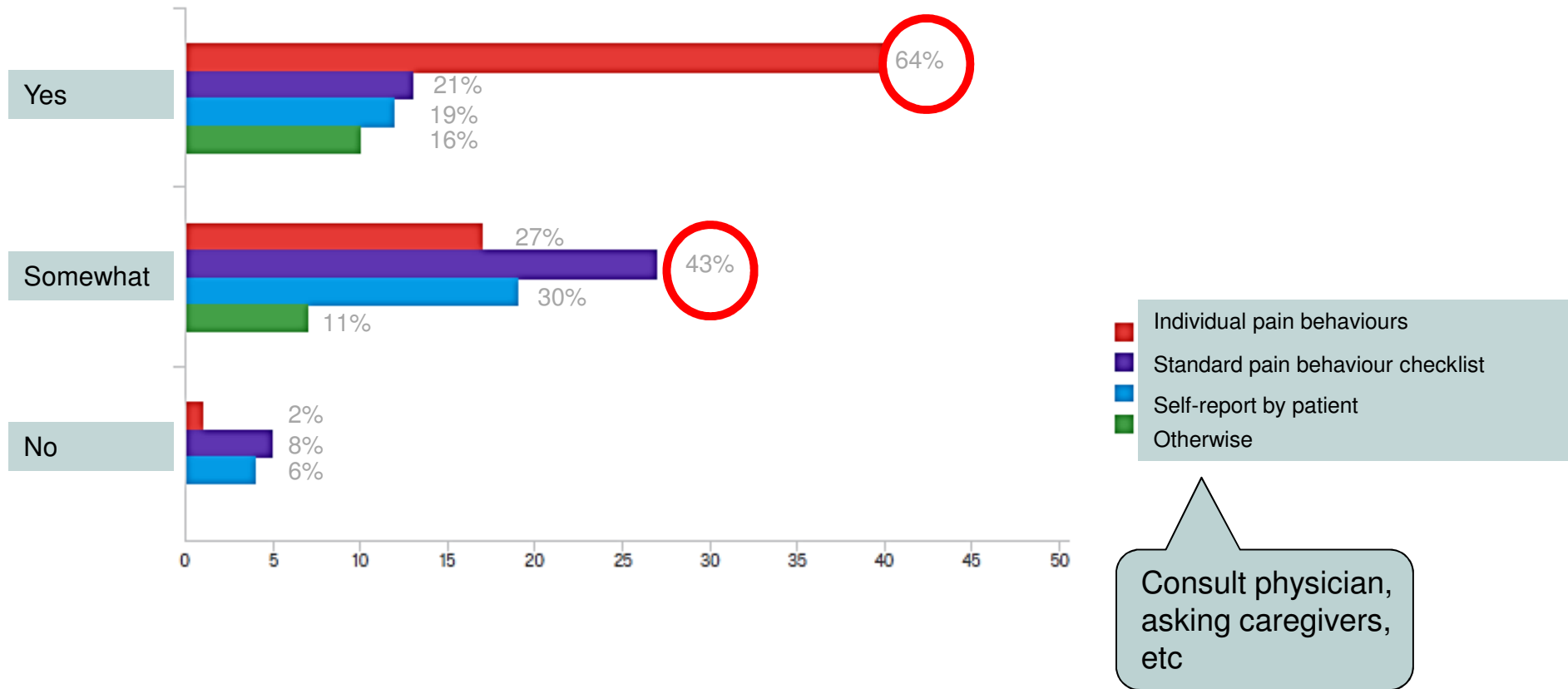


What has turned out to be the most helpful in this pain signalling?*



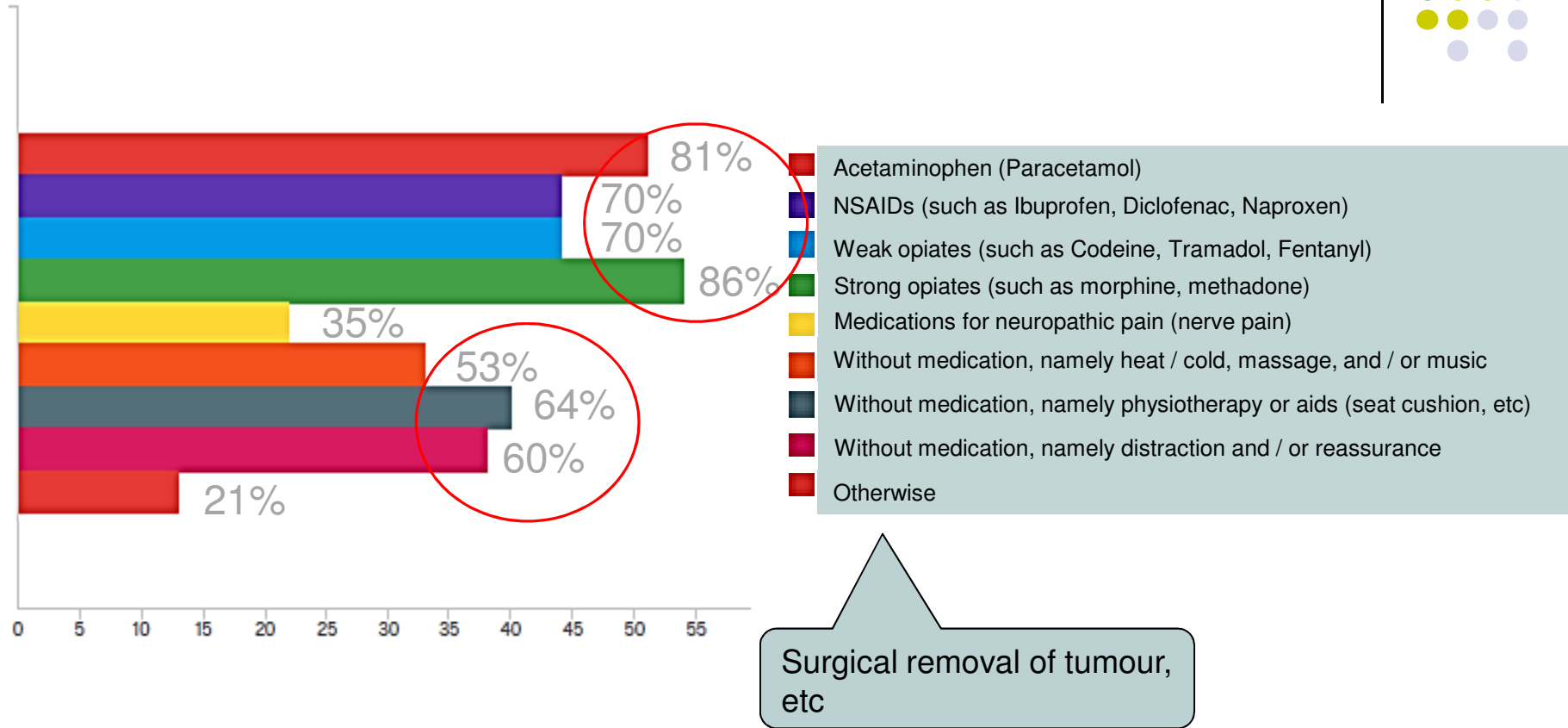
n = 147

Was the method that you used effective to measure cancer pain in people with intellectual disabilities?



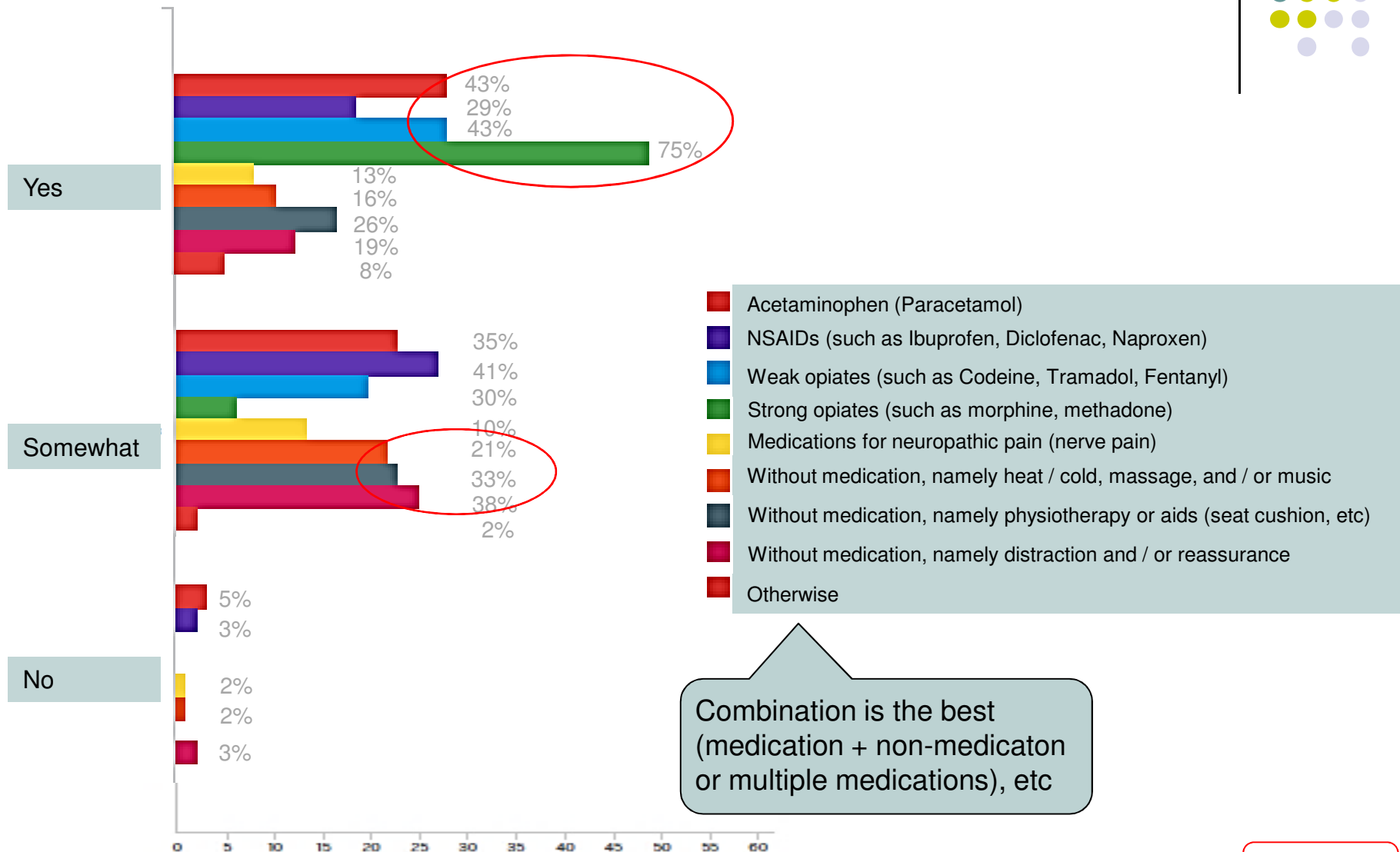
$n = 63$

What did you use to treat cancer pain in people with intellectual disabilities?



n = 63

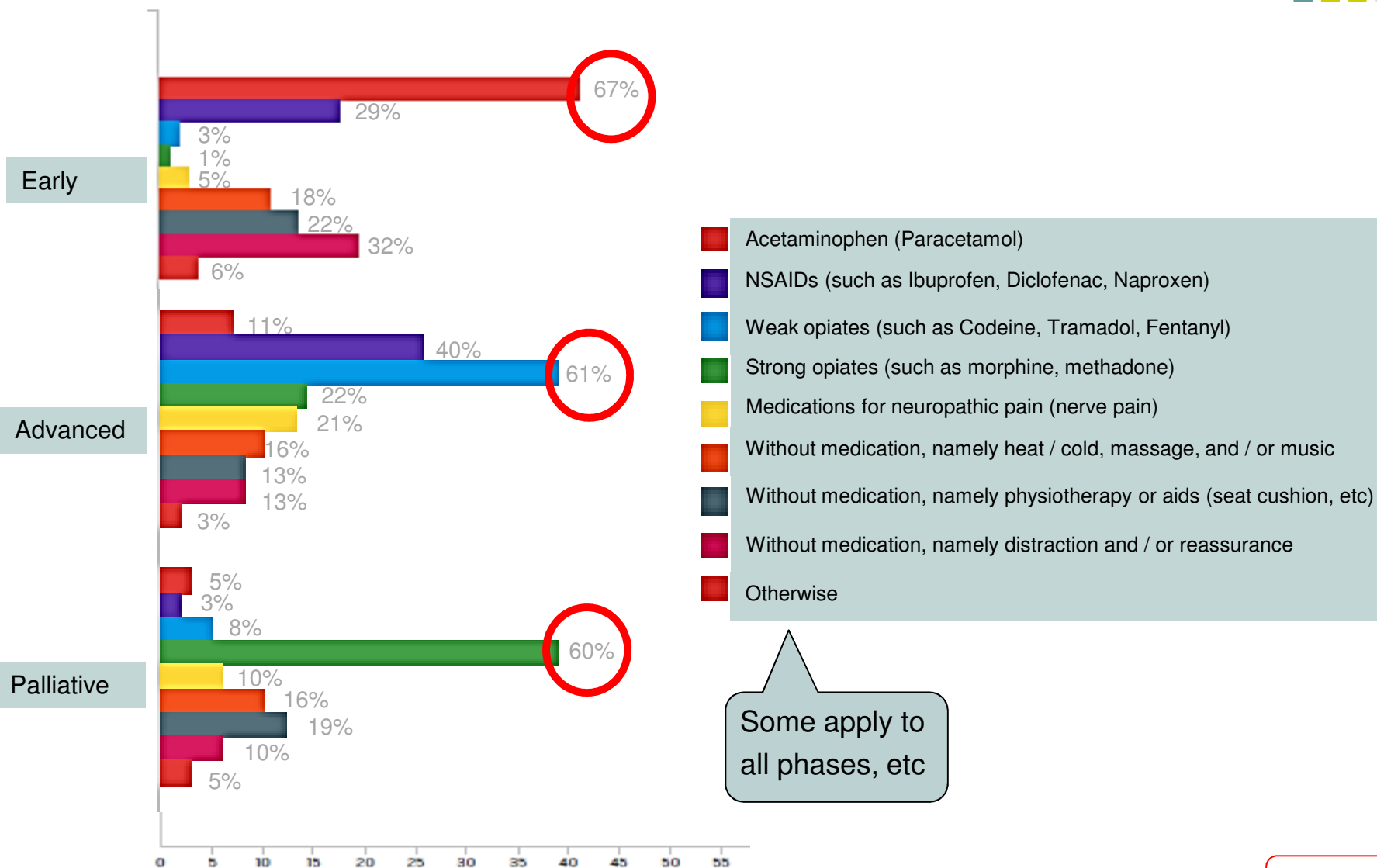
Was the treatment effective for cancer pain in people with intellectual disabilities?



Combination is the best (medication + non-medication or multiple medications), etc

n = 63

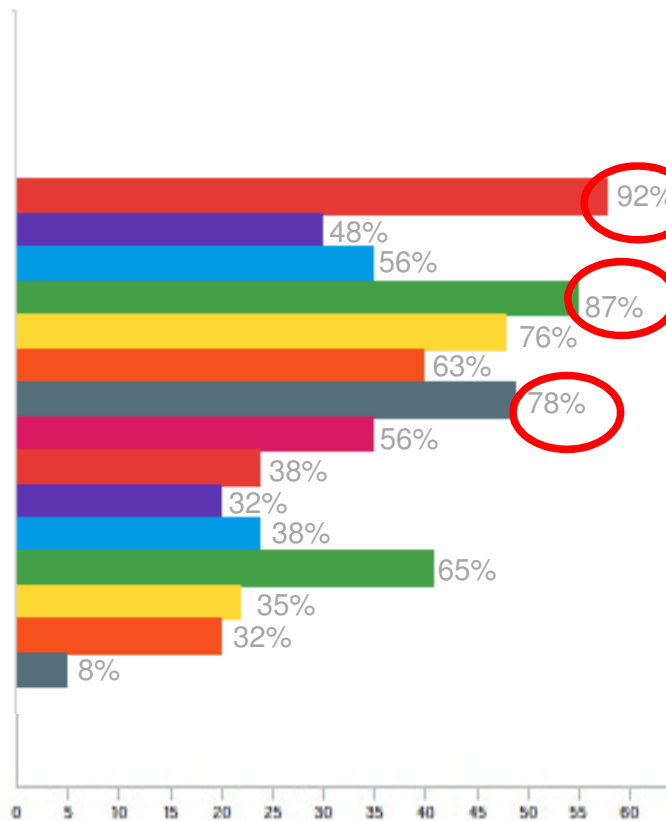
In what phase did you use the treatments for cancer pain in people with intellectual disabilities?



Some apply to all phases, etc

n = 63

In which area do you experience challenges regarding cancer pain in people with intellectual disabilities?



- Communication / cooperation with the patient
- Communication / cooperation with the patient's family
- Communication / cooperation with other health care professionals
- Pain signalling
- Pain measurement
- Pain treatment
- Medical complexity of the target group of people with intellectual disabilities
- Knowledge about the difference between genetic syndromes in tumour profiles and prevalence of cancer types
- Other knowledge about cancer in people with intellectual disabilities
- Knowledge about existing national guidelines
- Lack of a clear national guideline with practical tools
- Lack of scientific research
- Lack of (inter) national conferences / symposiums
- Lack of (inter) national taskforces
- Otherwise

In hospitals little attention for anxiety reduction and adapted Information for patients, etc

n = 63

Challenge (from survey De Knegt)	Solution (most frequent or notable)
Communication / cooperation with the patient	Anxiety and incomprehension: talk by specialised caregiver
Communication / cooperation with the patient's family	Involve family early and frequently: pain signalling plan, etc
Communication / cooperation with other health care professionals	Frequent team evaluation about shared patient file, check cushions/shoes etc before increasing pain medication
Pain signalling	Walks with broken leg due to autism: check abnormal posture
Pain measurement	Individual pain profile, check comprehension of rating scales
Pain treatment	Distraction, effect evaluation, check drug-to-drug interactions
Medical complexity of the target group of people with intellectual disabilities	Education, multidisciplinary cooperation, use multiple protocols (interactions?), consult specialists in hospital
Knowledge about the difference between genetic syndromes in tumour profiles and prevalence of cancer types	No challenge (search for information, pain is a separate symptom), scientific research, education, clinical lessons
Other knowledge about cancer in people with intellectual disabilities	Use palliative care specialists and a biopsychological model, increase awareness in health care specialists
Knowledge about existing national guidelines	Update and distribute guidelines, clinical lessons, use experts
Lack of a clear national guideline with practical tools	Doesn't hinder treatment, specify for intellectual disabilities
Lack of scientific research	Case study, practice-based, long-term medication, syndromes
Lack of (inter) national conferences / symposiums	Ask what the needs are, organize symposium
Lack of (inter) national taskforces	Increase interest, Dutch palliative taskforce is almost set up
Otherwise	Adapted information, mentors accompany patient to physician