

# An Evidence Map of Instruments for Caregiver Reported Outcomes

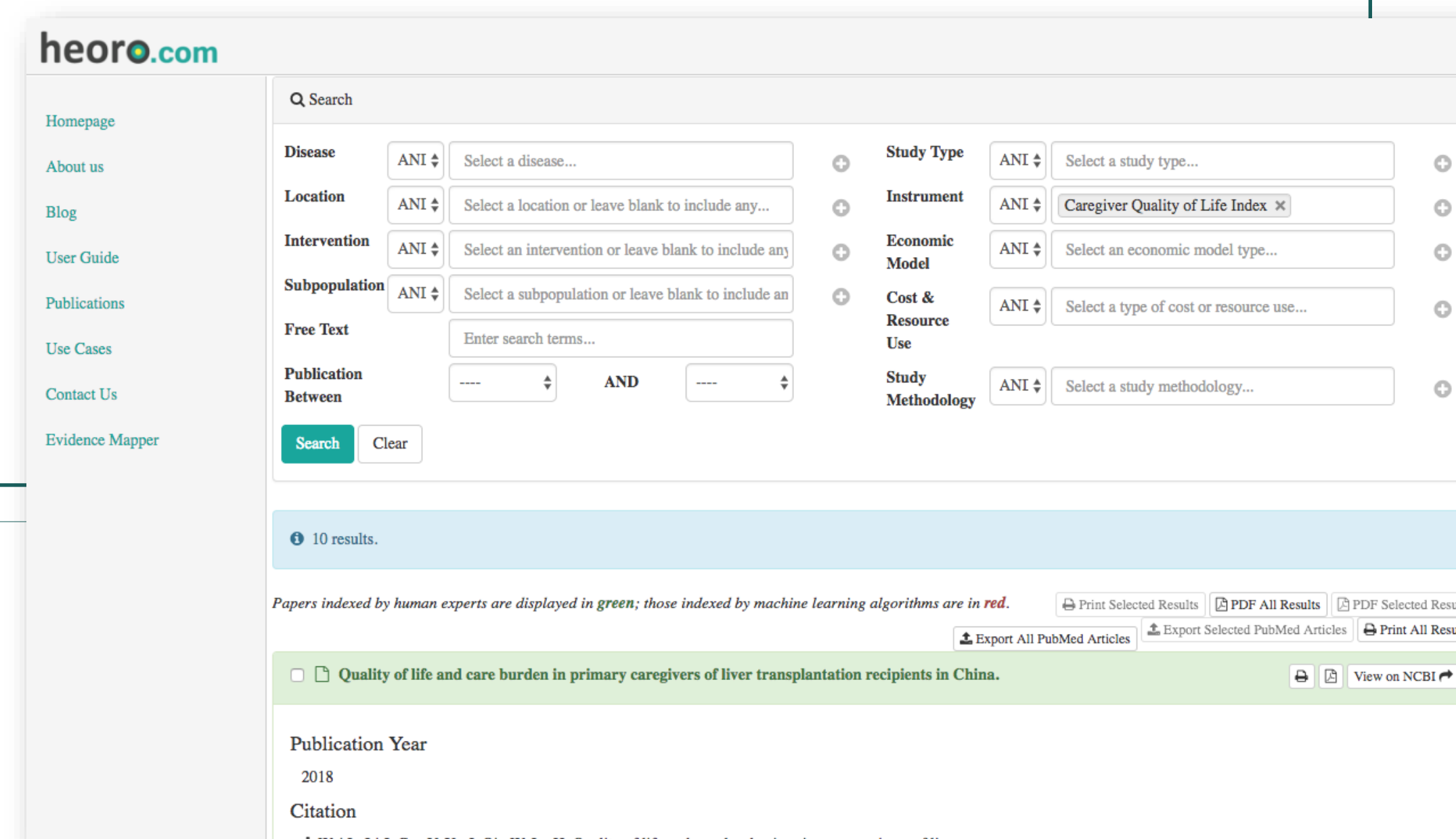
Cassie Springate;<sup>1</sup>  
<sup>1</sup> Crystallise Ltd cassie.springate@crystallise.com

## Objectives:

To identify studies that used PRO tools to assess caregiver burden and caregiver-specific quality of life, and to assess their patterns of use.

## Methods:

- The **heoro.com** database indexes publications available on PubMed according to several ontologies.
- Using the **PRO filter**, we identified studies in the database that were published between 1960-2018 that used an instrument to assess **caregiver-reported outcomes**.
- We also limited the search to generic caregiver instruments.



## Results:

- The ontology included 51 generic caregiver-reported outcome instruments
- The search identified 169 independent publications

Publication dates: from 1989 to 2017 (more than half after 2010)

Tools most often cited in the abstracts were (10+):

- Zarit Burden Interview (Zarit; 46)
- Carer Strain Index (CSI; 33)
- Caregiver Burden Index (CBI; 14)
- Caregiver Burden Scale (CBS; 13)
- Family Impact Scale (FIS; 10)

Figure 1: Abstracts by publication year.

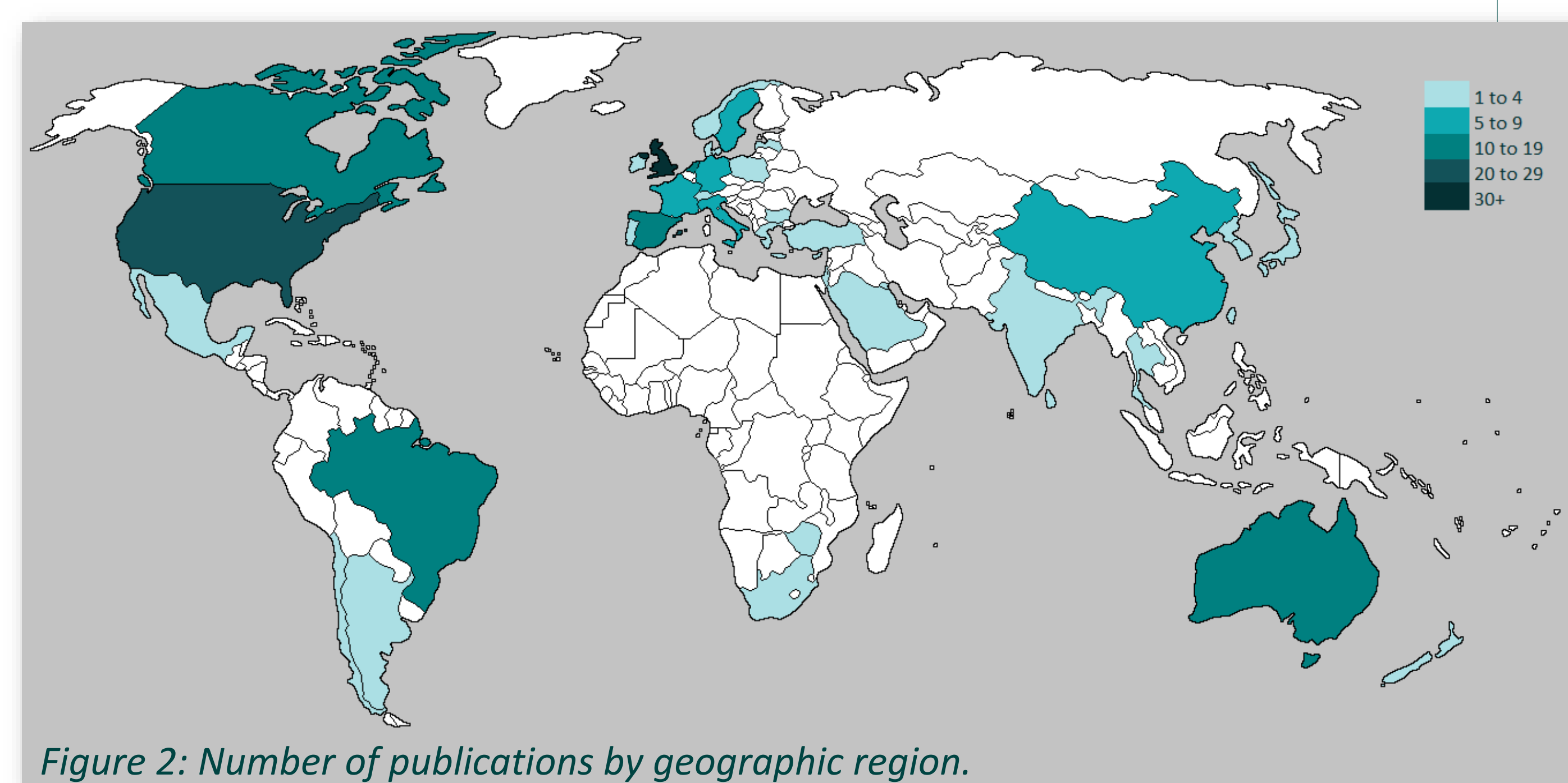
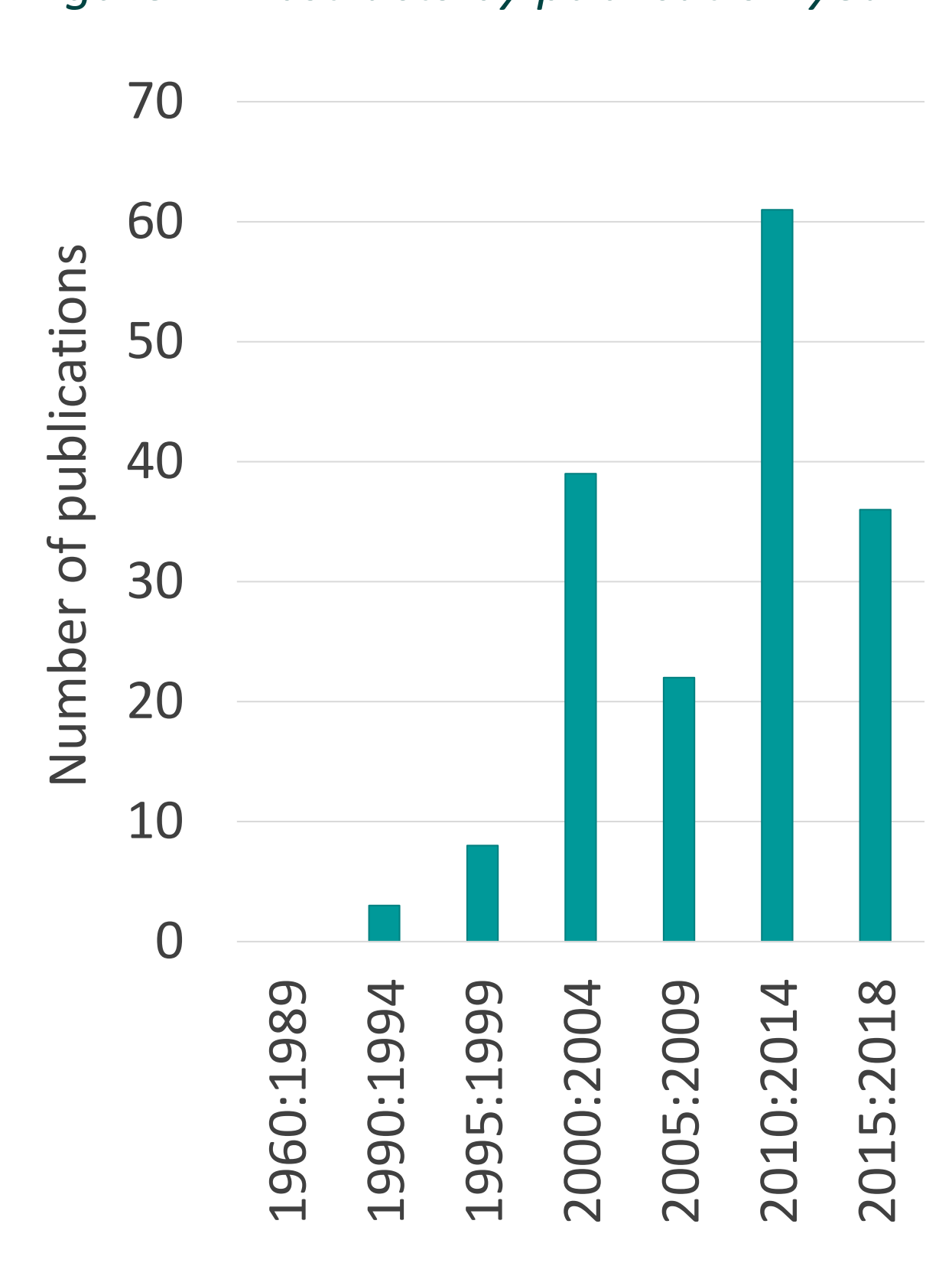


Figure 2: Number of publications by geographic region.

Table 1: Most cited PRO tools by disease or disease area

	CBI	CBS	CSI	FIS	Zarit
ALS	1	0	3	0	2
Cancer	1	0	1	1	1
Cardiac	0	0	0	0	3
Dementia	5	0	1	0	18
Developmental	0	0	0	1	0
Diabetes	0	0	0	0	1
End of life	0	0	1	0	0
Frailty	2	1	2	0	2
Genetic	0	1	0	1	1
Multiple Sclerosis	0	0	1	0	2
Musculoskeletal	0	2	1	0	0
Neurology	2	0	1	1	2
Oral Health	0	0	0	6	0
Parkinson's	1	0	3	0	7
Psychiatric	0	1	1	0	2
Renal	0	2	0	0	4
Respiratory	0	1	2	0	0
Sensory	0	0	0	0	0
Stroke	1	3	14	0	3
Unspecified	1	2	4	0	3
Various	0	0	1	0	0

Table 2: Most cited PRO tools by date band

	CBI	CBS	CSI	FIS	Zarit
1960:1989	0	0	0	0	0
1990:1994	0	1	0	1	0
1995:1999	2	1	4	0	1
2000:2004	3	3	10	1	8
2005:2009	1	2	4	5	5
2010:2014	5	5	11	3	18
2015:2018	3	1	4	0	14

40 validation studies were found.

Tools most often cited in the validation studies were:

- Carer Strain Index (CSI; 5)
- Family Impact Scale (FIS; 5)
- Carer Experience Scale (CEXS; 4)
- CarerQol (4)
- Parental-Caregiver Perception Questionnaire (P-CPQ; 4)
- Zarit Burden Interview (Zarit; 4)

Table 3: Most validated PRO tools by disease or disease area

	CarerQol	CEXS	CSI	FIS	P-CPQ	Zarit
ALS	0	0	0	0	0	1
Cancer	0	0	0	0	0	0
Cardiac	0	0	0	0	0	0
Dementia	0	0	1	0	0	1
Developmental	0	0	0	0	0	0
End of life	1	1	1	0	0	0
Frailty	1	1	0	0	0	1
Neurology	0	0	0	0	0	1
Oral Health	0	0	0	5	4	0
Parkinson's	0	0	0	0	0	1
Psychiatric	0	0	0	0	0	1
Stroke	0	0	2	0	0	1
Unspecified	2	2	1	0	0	0

Table 4: Most validated PRO tools by population of interest

	CarerQol	CEXS	CSI	FIS	P-CPQ	Zarit
Adults	0	1	2	0	0	1
Children and Adolescents	0	0	0	5	4	0
Older Persons	2	2	2	0	0	2
Unspecified	2	1	1	0	0	1

## Conclusions:

- Only 8 PRO instruments were cited in the abstracts of 5 or more papers
- The majority of abstracts mentioned neurological and long-term degenerative diseases such as dementia, stroke and Parkinson's disease
- Nearly half of the studies found assessed the reliability, responsiveness or validity of an instrument

