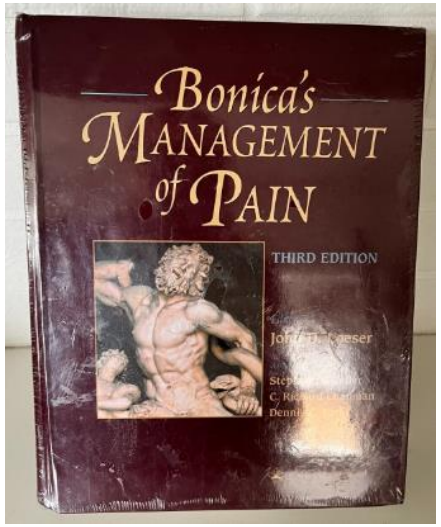
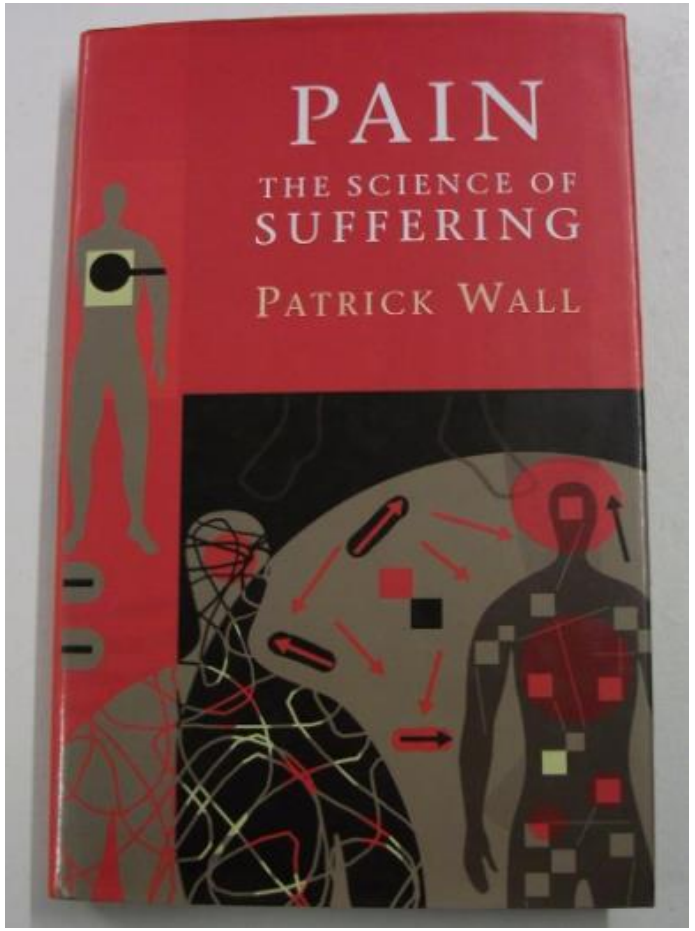
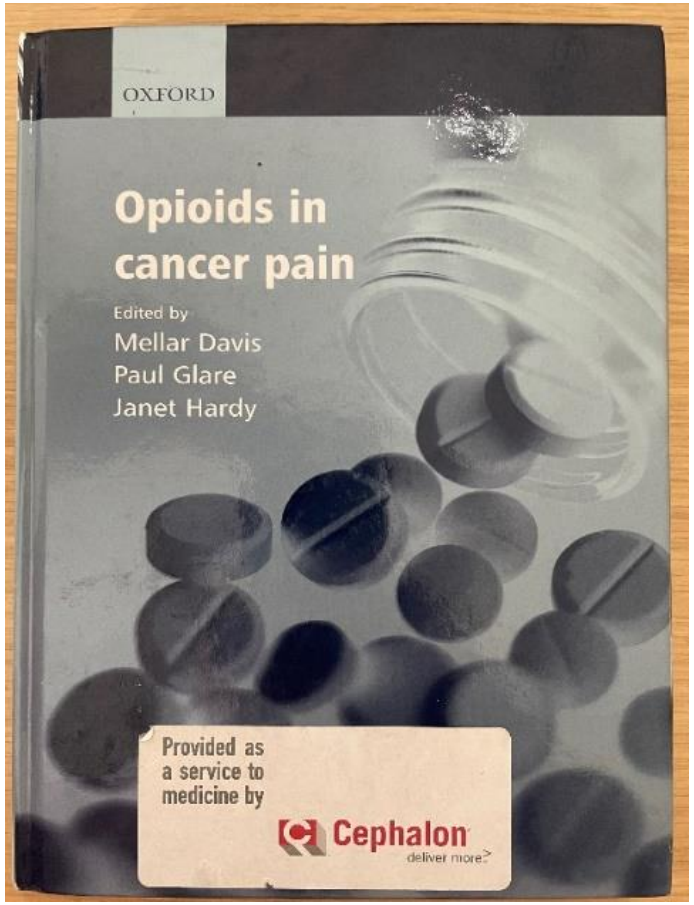
Unseen, unequal and unfair: assessment and management of pain in the margins

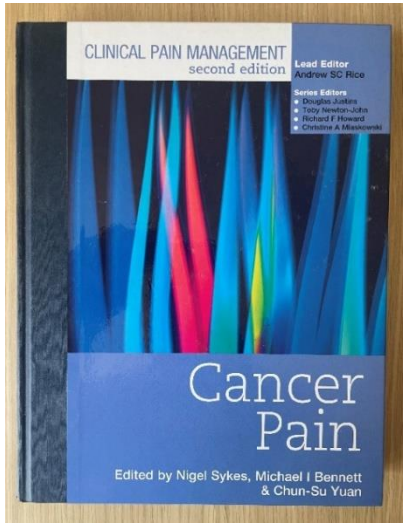
Professor Jonathan Koffman
Wolfson Palliative Care Research Centre
Hull York Medical School

@jonathankoffman


Bonica's
MANAGEMENT
of PAIN
THIRD EDITION


PAIN
THE SCIENCE OF
SUFFERING
PATRICK WALL


OXFORD
Opioids in
cancer pain
Edited by
Mellar Davis
Paul Glare
Janet Hardy
Provided as
a service to
medicine by
Cephalon
deliver more


CLINICAL PAIN MANAGEMENT
second edition
Lead Editor
Andrew SC Rice
Cancer
Pain
Edited by Nigel Sykes, Michael I Bennett
& Chun-Su Yuan

JOURNAL OF THE ROYAL SOCIETY OF MEDICINE Volume 94 September 2001

The evolution of palliative care

Cicely Saunders OM DBE FRCP

J R Soc Med 2001;**94**:430–432

'Care must reach the most hidden places of distress '

BMC Palliative Care

RESEARCH ARTICLE Open Access

Does ethnicity affect pain management for people with advanced disease? A mixed methods cross-national systematic review of 'very high' Human Development Index English-speaking countries

Gemma Clarke[1*], Emma Chapman[1], Jodie Crooks[1], Jonathan Koffman[2], Shenaz Ahmed[3] and Michael I. Bennett[1]

Sub-therapeutic treatment of cancer pain?

Lamba et al. 2020 USA	Patients with brain metastases (n=17,957) White (75.2%) African American (11.3%) Hispanic (6.5%) Asian (6.7%)	Compared to white patients, Asian patients received significantly fewer opioid analgesics
Pinheiro et al. 2019 USA	Breast cancer patients (n=23,091) US born non-Hispanic (88%) US born Hispanic (4%) Non-US born Hispanic (6%) Foreign born Hispanic (2%)	Compared to US-born non-Hispanic women, foreign-born women, and US born Hispanic women used significantly fewer opioids, even when adjusting for demographic, tumour and treatment
Burgio et al. 2016 USA	EOL patients in veterans' hospitals (n=6,066) White (65%) African-American (35%)	Compared to White patients, African-American patients were significantly less likely to have active opioid orders, opioid medications
Cea et al. 2016 USA	Hospice patients (n=3,918) Non-Hispanic white (84.1%) Non-Hispanic black (11.1%) Hispanic (3.3%) Other race/ethnicity (1.5%)	Compared to reference population, odds of assessment and subsequent management of pain significantly lower for non-Hispanic black, Hispanic and other race/ethnicity

Aim and objectives of study

Examine relationship between patient ethnicity and primary care prescribing patterns of opioids among UK cancer patients towards the end of life.

Study objectives:

1. Analyse prescription patterns of opioids among cancer patients by ethnicity at end of life in UK primary care
2. Evaluate the independent association between prescribing of opioids and ethnicity among cancer patients at the end of life in UK primary care

Research Team: Sophie Law-Clucas, Dr Emeka Chukwusa, Dr Sabrina Bajwah, Professor Martin Gulliford, Rashmi Kumar, Professor Stephen Barclay, Tanya Siriwimala & Dr Gemma Clarke

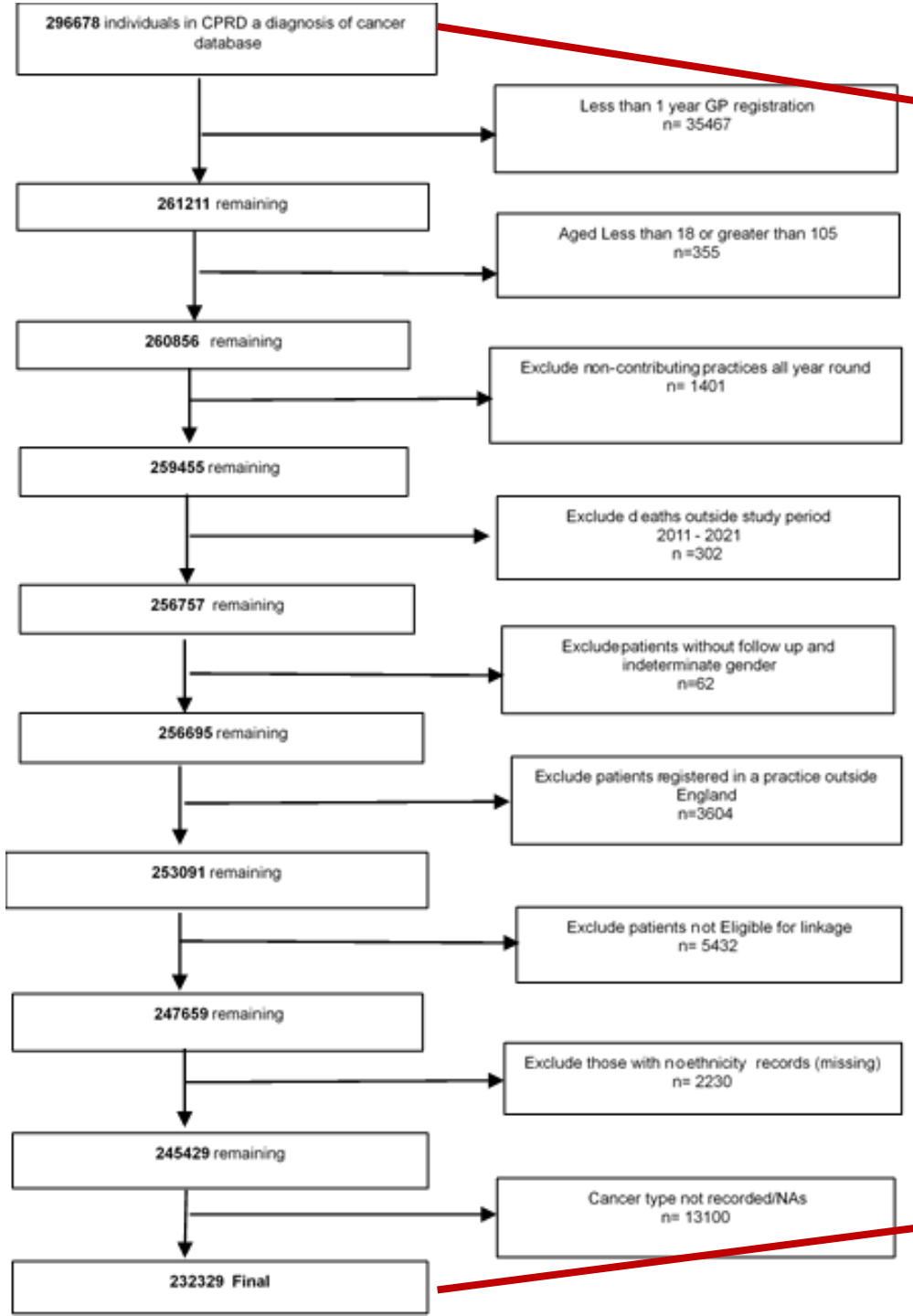
FUNDED BY
NIHR | National Institute for Health and Care Research

Linked data sets examined

- Clinical Practice Research Datalink (CPRD)
  - Anonymised database of routinely recorded information representing >16 million people from 650 GP practices throughout entire UK
- Hospital Episode Statistics (HES)
- Office for National Statistics (ONS)

Study population and variables

- UK cancer patients who died from 2011-2020
- People with diagnosis of cancer closest to death: myeloma, breast, cervix, colorectal, head & neck, liver, lung, pancreas, stomach and prostate
- **Primary outcome:** Number of Step 2 and Step 3 opioid prescriptions received in final three months of life. Prescriptions identified using codes from British National Formulary



n=296678 cases

n=232329 cases

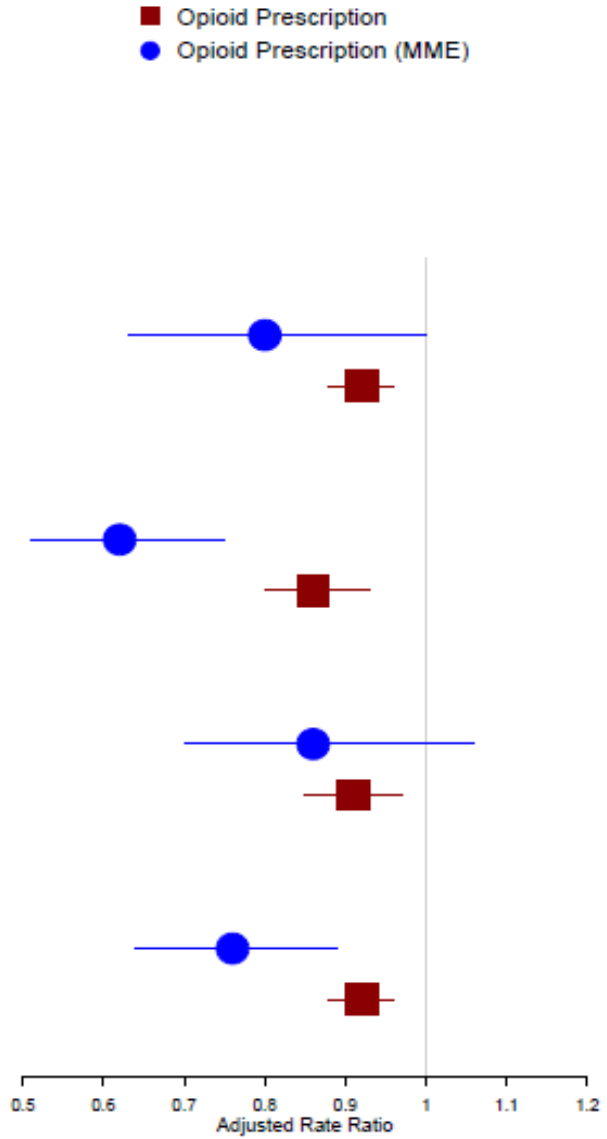
Characteristics of patients prescribed opioids 2011 to 2019

Variables		Overall	Black	Mixed	Other	South Asian	White
n	Total	**232329**	4752	1073	1621	4463	220420
Age (mean SD)		77.16 (12.23)	72.36 (14.42)	71.71 (14.68)	71.19 (15.14)	71.85 (13.80)	77.44 (12.04)
Age group (%)	18-50 years	6942 (3.0)	411 (8.6)	103 (9.6)	183 (11.3)	364 (8.2)	5881 (2.7)
	50-59 years	16433 (7.1)	712 (15.0)	156 (14.5)	215 (13.3)	544 (12.2)	14806 (6.7)
	60-69 years	38592 (16.6)	699 (14.7)	182 (17.0)	325 (20.0)	940 (21.1)	36446 (16.5)
	70-79 years	66508 (28.6)	1210 (25.5)	286 (26.7)	371 (22.9)	1222 (27.4)	63419 (28.8)
	80+ years	103854 (44.7)	1720 (36.2)	346 (32.2)	527 (32.5)	1393 (31.2)	99868 (45.3)
Sex (%)	Female	108819 (46.8)	1837 (38.7)	477 (44.5)	743 (45.8)	1974 (44.2)	103788 (47.1)
	Male	123510 (53.2)	2915 (61.3)	596 (55.5)	878 (54.2)	2489 (55.8)	116632 (52.9)
Cancer Site (%)	Bone	3582 (1.5)	59 (1.2)	19 (1.8)	31 (1.9)	67 (1.5)	3406 (1.5)
	Myeloma	5477 (2.4)	290 (6.1)	57 (5.3)	37 (2.3)	148 (3.3)	4945 (2.2)
	Breast	42710 (18.4)	703 (14.8)	163 (15.2)	251 (15.5)	809 (18.1)	40784 (18.5)
	Cervix	2784 (1.2)	64 (1.3)	12 (1.1)	32 (2.0)	48 (1.1)	2628 (1.2)
	Colorectal	43524 (18.7)	663 (14.0)	178 (16.6)	280 (17.3)	701 (15.7)	41702 (18.9)
	Head & neck	9109 (3.9)	112 (2.4)	34 (3.2)	68 (4.2)	207 (4.6)	8688 (3.9)
	Liver	8974 (3.9)	196 (4.1)	51 (4.8)	116 (7.2)	348 (7.8)	8263 (3.7)
	Lung	56779 (24.4)	839 (17.7)	250 (23.3)	423 (26.1)	1097 (24.6)	54170 (24.6)
	Pancreas	12051 (5.2)	269 (5.7)	64 (6.0)	95 (5.9)	279 (6.3)	11344 (5.1)
	Prostate	40719 (17.5)	1322 (27.8)	203 (18.9)	212 (13.1)	585 (13.1)	38397 (17.4)
	Stomach	6620 (2.8)	235 (4.9)	42 (3.9)	76 (4.7)	174 (3.9)	6093 (2.8)

Forest plots depicting adjusted rate ratio (aRR) of association between patient ethnicity and opioid prescriptions and MME in last three months of life

A Opioid Prescription

B Opioid Prescription (MME)



Ethnicity	aRR	LL	UL	P value	aRR	LL	UL	P value
Black	0.92	0.88	0.96	<0.001	0.8	0.63	1.00	0.05
Mixed	0.86	0.8	0.93	<0.001	0.62	0.51	0.75	<0.001
Other	0.91	0.85	0.97	<0.001	0.86	0.7	1.06	0.16
South Asian	0.92	0.88	0.96	<0.001	0.76	0.64	0.89	<0.001

Sensitivity analysis – strength of medication

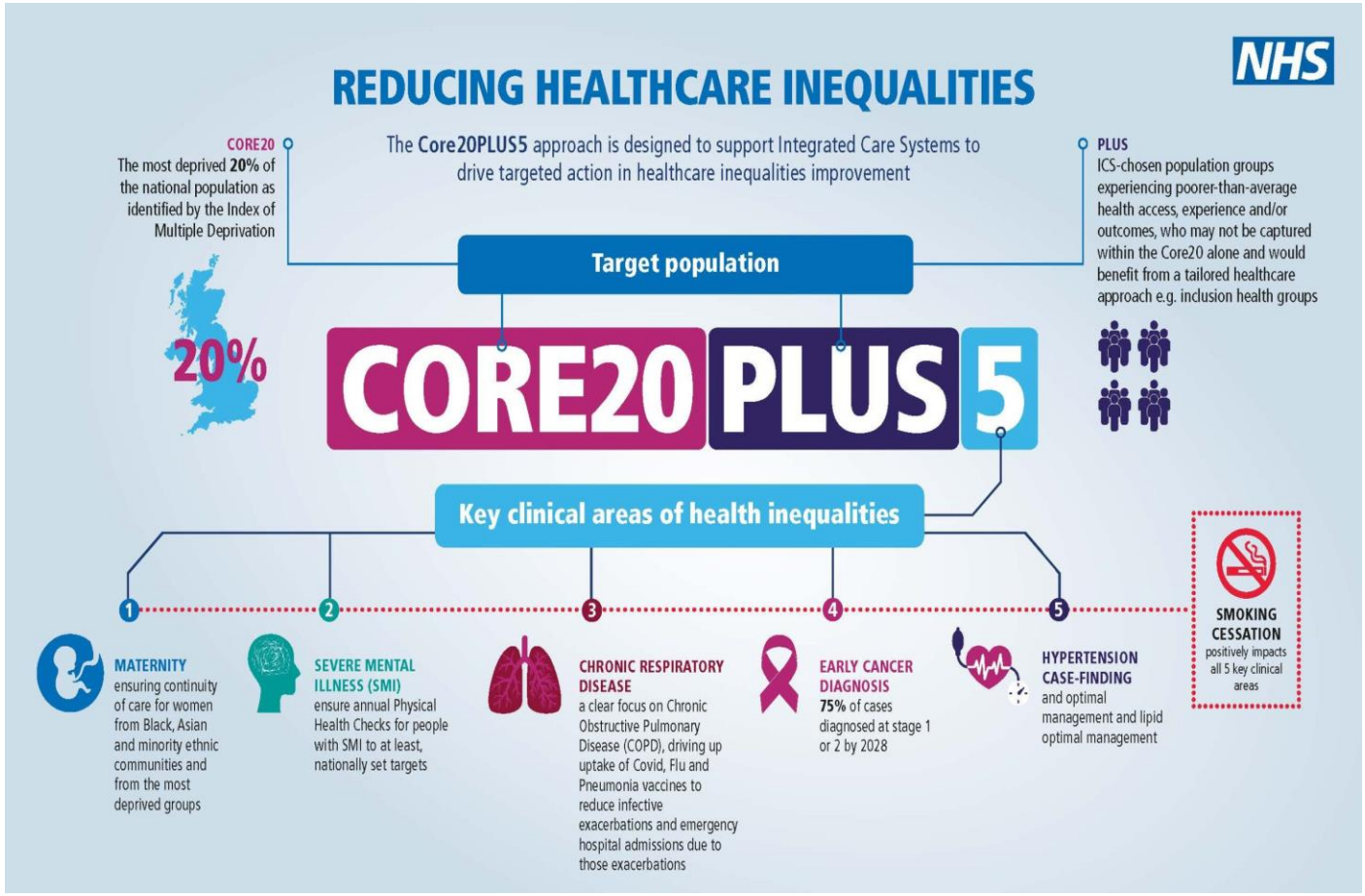
Ethnicity	Step 3 opioids		Step 2 opioids	
	aRR (95% CI.)	P value	aRR (95% CI.)	P value
Black	0.92(0.88 to 0.97)	P < 0.001	1.03(0.95 to 1.11)	P = 0.51
Mixed	0.86(0.79 to 0.94)	P < 0.001	0.97(0.86 to 1.1)	P = 0.68
Other	0.92(0.86 to 0.99)	P = 0.02	0.94(0.85 to 1.04)	P = 0.21
South Asian	0.92(0.88 to 0.97)	P < 0.001	0.94(0.88 to 1.01)	P = 0.10

Study limitations

- CPRD database only captures opioids prescribed by GPs - missed prescriptions through non-GP routes
- Instances of missingness of opioid data.
- Ability to estimate opioid equivalence for some medications challenging
- Could not evaluate analgesic prescriptions concerning pain prevalence and intensity
- No data available effectiveness of pain medications
- Evidence of **potential 'ethnicity pain gap'** in primary care prescribing of opioids

People with serious mental illness receive sub-optimal pain management at the end of life

- Definitions vary
- Judged by diagnosis, duration, disability and function
- Common use limits the definition to people with:
  - Schizophrenia
  - Schizoaffective disorder
  - Major depressive disorder
  - Bipolar disorder
  - Emotionally unstable personality disorder



People with serious mental illness experience health inequalities

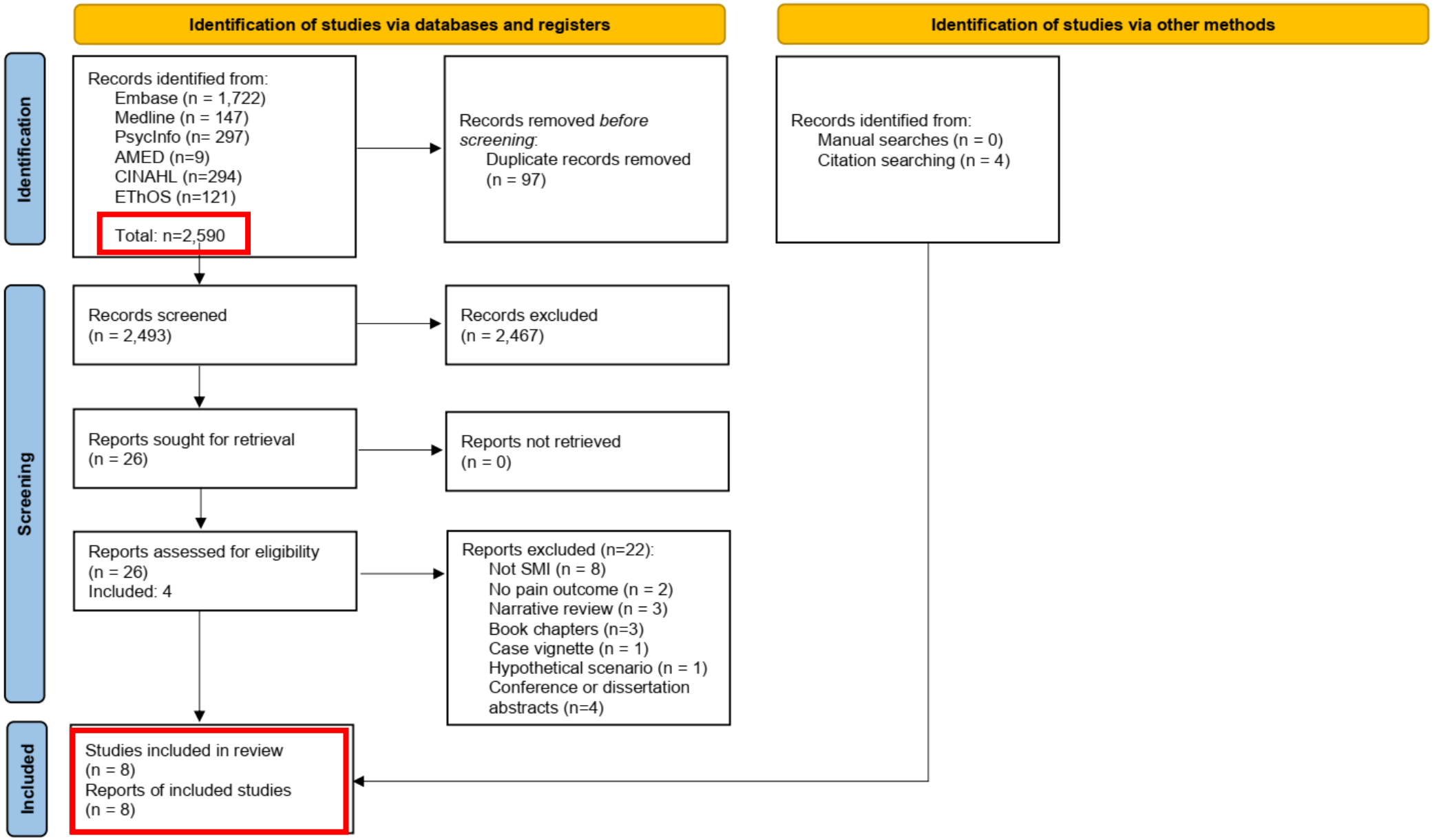
- Sub-optimal healthcare throughout life [1]
- Social disadvantage
- Lower life expectancy (natural and unnatural causes)
- Inequities extend into end-of-life care [2]

- We aimed to examine whether disparities are present in assessing or managing pain for people with SMI living with life-threatening diseases.

[1] Grassi L & Riba M, Psycho-Oncology 2020;29:1445
[2] Edwards D et al., Pall Med 2021;35(10):1747

Research Team: Dr Gilli Erez, Dr Annabel Price & Professor Jonathan Koffman

Figure 1: PRISMA flow diagram



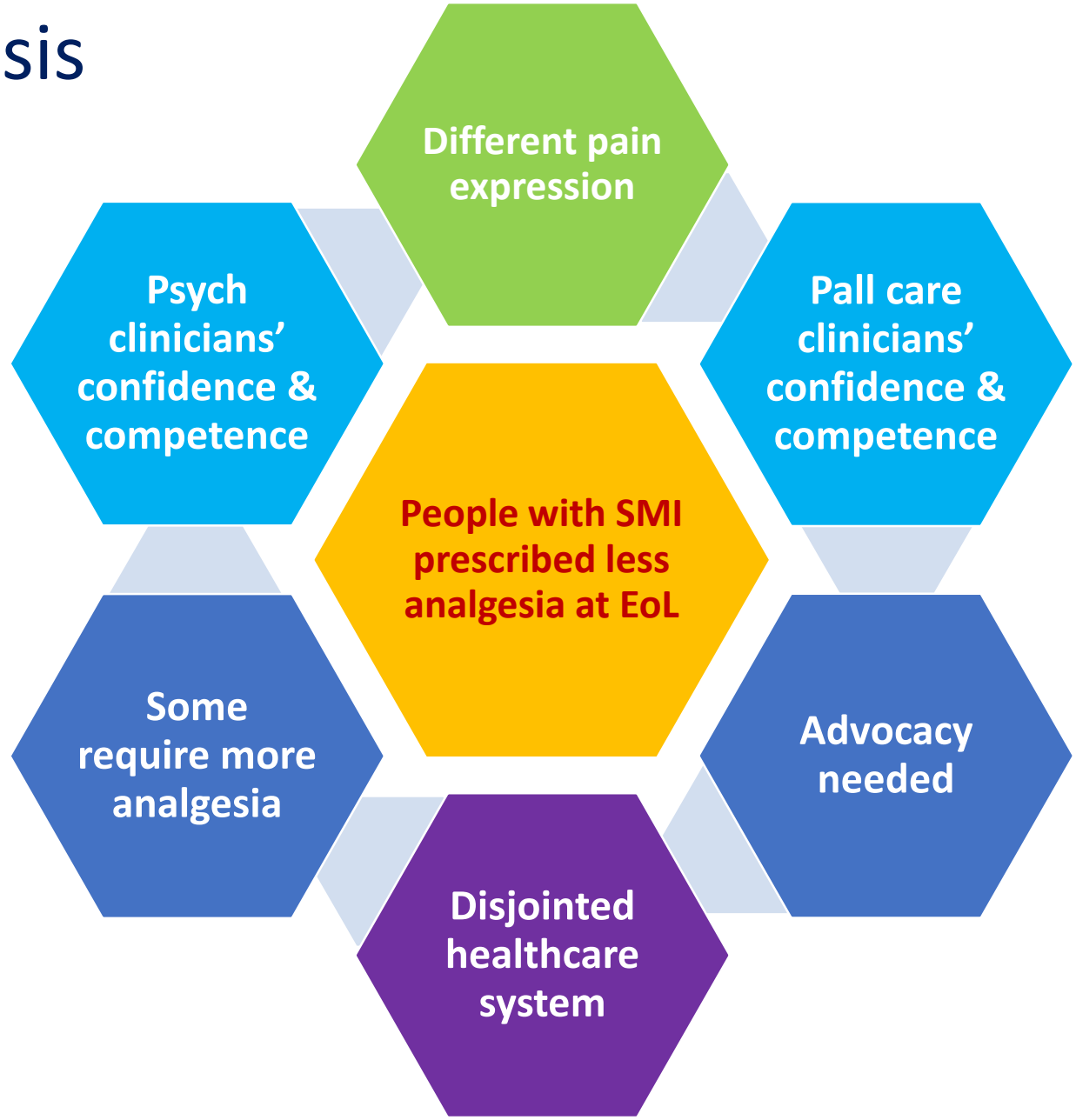
Results: quantitative studies

1st Author	Year	Country	Study design	Critical appraisal score (JBI)	Weight of evidence (Gough)	Key findings
Lin	2020	Taiwan	Population-based retrospective cohort study	Medium	High	People with schizophrenia are **less likely** to receive opioids; **doses always lower**
Chochinov	2012	Canada	Population-based retrospective cohort study	Medium	Medium	
Ganzini	2010	USA	Retrospective cross-sectional	Very low	Low	

Results: qualitative studies

1st Author	Year	Country	Study type	Critical appraisal score (JBI)	Weight of evidence (Gough)	Key findings
Knippenberg	2020	The Netherlands	Qualitative	Low	High	Patient-, clinician- and system-related factors result in **inadequate pain management**
Morgan	2016	USA	Qualitative	High	Medium	
Evenblij	2016	The Netherlands	Mixed-methods	Low	Medium	
Jerwood	2016	UK	Qualitative	Very low	Low	
McGrath & Forrester	2006	Australia	Qualitative	Low	Low	

Mixed methods synthesis



EDITORIAL • Palliative Care Canada 1999 — A Question Period

DAVID J. ROY, Center for Bioethics, Clinical Research Institute of Montreal, Montreal, Quebec, Canada

NOw, at the end of this century, I find my- tive care programs who have any extensive

"There are not too many of us who have first-hand experience of how those who are socially utterly marginalized, live and die. ***Do we really want to know?*** *That knowledge could be very disturbing, loaded as it might well be with imperatives for action."*

Thank you, and any questions?