

## Equity in End of Life Experience: session links

Wednesday 7 February 11:00-13:00



Everyone should have the best possible end of life experience, whatever their culture, race, religion, sex, gender, sexuality, or disability. Yet too many people are going without the care that they need and deserve, in some cases made worse by their geographical location, financial circumstance, or their protected characteristics.

Part of this session will focus on pain management for people from ethnic minority backgrounds as well as showcase research addressing inequities submitted as abstracts.

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#### Welcome to day three of the conference

Professor Richard Harding

#### Are we all equal when it comes to the assessment and management of pain at the end of life?

Professor Jonathan Koffman (Hull York Medical School)

#### Improving experiences of pain and pain management for people from South Asian communities in Leeds and Bradford UK: A qualitative interview study

Dr Gemma Clarke (Marie Curie & University of Leeds) & Ruby Bhatti, OBE, DL (Independent Patient and Public Involvement Representative, Bradford)

#### Intersection between ethnicity and area-based deprivation and the association with place of death: evidence from the UK Census (selected abstract)

Dr Joanna Davies (King's College London)

#### Evaluating the Impact of Healthcare Policies on the Delivery of Palliative and End-of-Life Care in the UK (selected abstract)

Laima Khan (University of Oxford)

#### The experiences of family carers looking after older people at home towards the end-of-life in rural and remote locations (selected abstract)

Dr Caroline Mogan (Liverpool John Moores University)



## Marie Curie links

Organisations who offer support on gender and sexuality, recommended by Marie Curie: <https://www.mariecurie.org.uk/help/support/support-directory/gender-and-sexuality>

For healthcare professionals: helpful resources on providing palliative and end of life care for LGBTQ+: <https://www.mariecurie.org.uk/professionals/palliative-care-knowledge-zone/proving-good-quality-care/lgbt-end-of-life>

Helpful resources for LGBTQ+ people living with a terminal illness and those close to them here: <https://www.mariecurie.org.uk/help/support/lgbtq>

### **Are we all equal when it comes to the assessment and management of pain at the end of life?**

Professor Jonathan Koffman (Hull York Medical School)

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:

<https://bmcpalliatcare.biomedcentral.com/articles/10.1186/s12904-022-00923-6>

NIHR Project page on Professor Koffman's research:

<https://arc-oe.nihr.ac.uk/research-implementation/research-themes/palliative-and-end-life-care/role-ethnicity-opioid>

Trauma Informed Palliative Care Project Platform page for networking, information sharing, discussion, mutual support and collaboration:

<https://trauma-informed-palliative-care.mn.co/>

## Discussion/take home messages

- **Study exploratory and hypothesis generating**
- Evidence of **material disparities** in community prescribing of opioids to manage cancer pain for patients from minority ethnic groups. Compares with studies from USA (Burgio et al. 2016, Lamba et al. 2020, Thompson et al 2023)
- Cannot demonstrate causation, however, relationship exists between community prescribing of opioids, patient ethnicity and use of health services in final three months of life:
  - Higher rate of **burdensome hospital admissions** and **ED attendances** in last three months of life. Reflected in other studies (Bardsley et al 2019, Henson et al 2018) but reasons opaque
- Implications for patient experience, outcomes, patient safety and NHS costs

## Improving experiences of pain and pain management for people from South Asian communities in Leeds and Bradford UK: A qualitative interview study

Dr Gemma Clarke (Marie Curie & University of Leeds) & Ruby Bhatti, OBE, DL  
(Independent Patient and Public Involvement Representative, Bradford)

Experiences of pain and pain management in advanced disease and serious illness for people from South Asian communities in Leeds and Bradford: a qualitative interview study:

<https://bmcpalliatcare.biomedcentral.com/articles/10.1186/s12904-023-01208-2>

How does ethnicity affect presence of advance care planning in care records for individuals with advanced disease? A mixed-methods systematic review:

<https://bmcpalliatcare.biomedcentral.com/articles/10.1186/s12904-023-01168-7>

### Take home messages

- Poor communication about pain had long lasting impact
- People with conversational English may still struggle with medical technical terms, or reading labels
- Unaddressed concerns about pain medication, led some to reduce or stop prescribed medication
- Many tried alternative therapies
  - Doctors may not be aware
- Out of hours improvements would benefit all




## Intersection between ethnicity and area-based deprivation and the association with place of death: evidence from the UK Census (selected abstract)

Dr Joanna Davies (King's College London)

Read the conference abstract:

[https://spcare.bmj.com/content/14/Suppl\\_1/A33.2](https://spcare.bmj.com/content/14/Suppl_1/A33.2)

Take home points:



1. Many ethnic minority groups are more likely to die in hospital than white British people, this is not fully explained by differences in age, deprivation, language or cause of death.
2. The intersection between ethnicity and other factors is important.
3. Where possible, using self-identified ethnicity data, and nuanced categories of ethnicity are essential for understanding inequalities.

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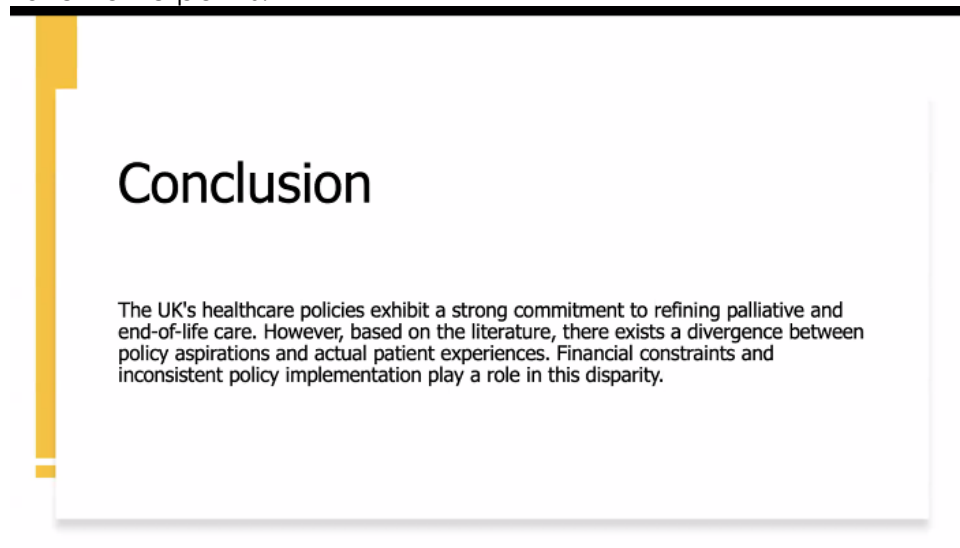
## Evaluating the Impact of Healthcare Policies on the Delivery of Palliative and End-of-Life Care in the UK (selected abstract)

Laima Khan (University of Oxford)

Read the conference abstract:

[https://spcare.bmj.com/content/14/Suppl\\_1/A18.2](https://spcare.bmj.com/content/14/Suppl_1/A18.2)

Take home points:



### Conclusion

The UK's healthcare policies exhibit a strong commitment to refining palliative and end-of-life care. However, based on the literature, there exists a divergence between policy aspirations and actual patient experiences. Financial constraints and inconsistent policy implementation play a role in this disparity.

## The experiences of family carers looking after older people at home towards the end-of-life in rural and remote locations (selected abstract)

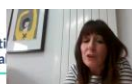
Dr Caroline Mogan (Liverpool John Moores University)

Read the conference abstract:

[https://spcare.bmj.com/content/14/Suppl\\_1/A19.1](https://spcare.bmj.com/content/14/Suppl_1/A19.1)



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### Take Home Messages...

Older people in rural areas may delay or avoid specialist care because of the challenges created by distance. This can impact on their outcome.

Having an awareness of "rural culture" and language barriers is important at the end-of-life

We must acknowledge the value of volunteer led services

There is an urgent need to co-design models of sustainable health and social care for older people in rural areas in the last year of life

## Acknowledgements

Many thanks to the speakers for sharing their work at the Marie Curie Research Conference 2024.

**If you have any questions, please contact the Research Team at Marie Curie:**

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