



Dr Nicoletta Policek, UK-CAB /EATG
Session : End of life

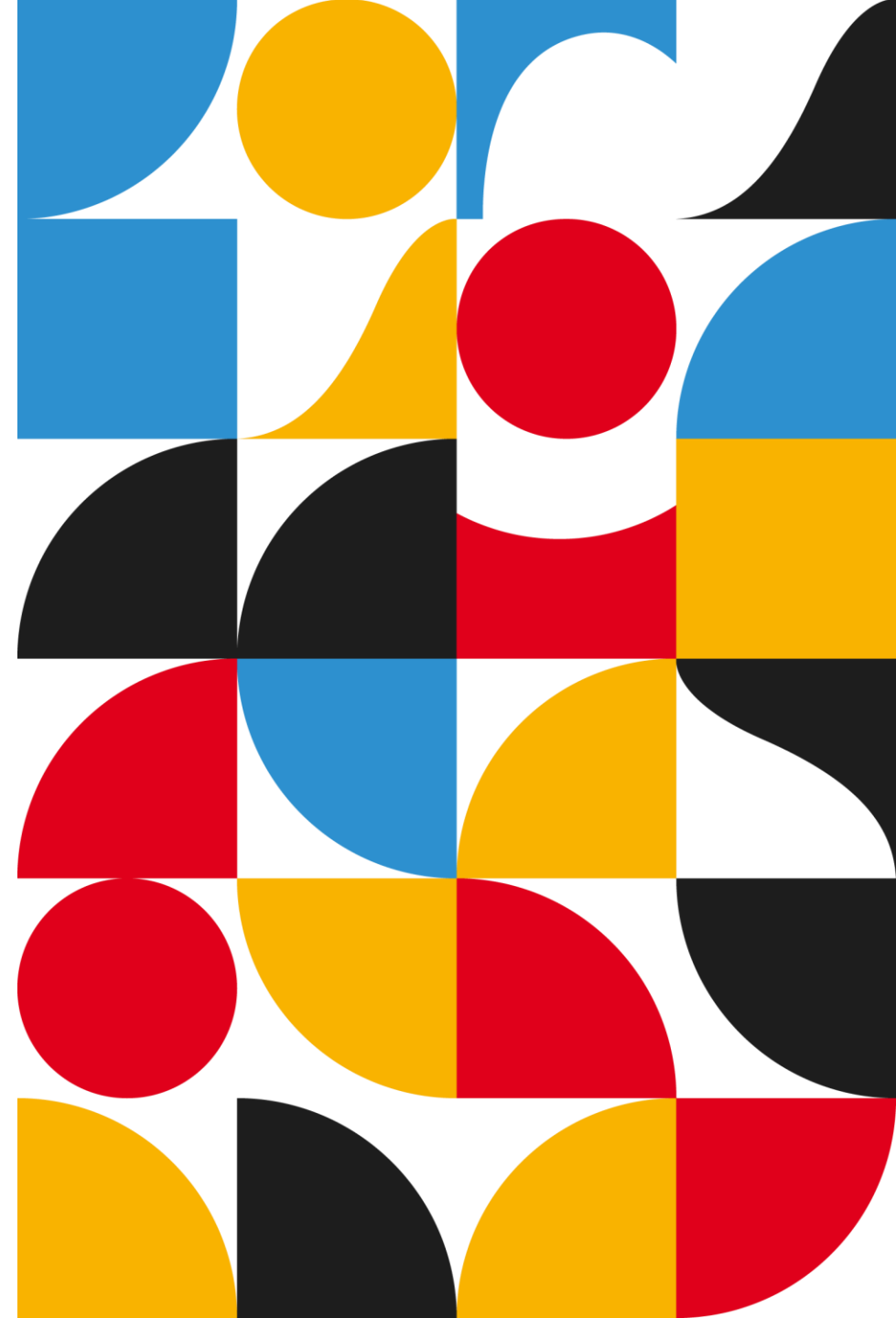
**“WE HAVE FORGOTTEN ABOUT DEATH”
END OF LIFE NARRATIVES AMONGST
OLDER AND AGEING WOMEN LIVING
WITH HIV**



OUTLINE

- **RATIONALE**
- **FEAR OF PROGRESSION (FoP) and FEAR OF DEATH (FoD)**
- **KEY THEMES FROM FOCUS GROUPS**
- **TAKE HOME MESSAGE**

Fear of progression (FoP) is a type of anxiety that results from concerns about disease progression and its consequences.



STUDY POPULATION AND DESIGN

14 WOMEN AGED BETWEEN 56 AND 71

Mean age 65 years

ETHNICITY: 8 CAUCASIAN, 6 AFRICAN CARIBBEAN DESCENT

9 SINGLE 3 MARRIED 2 WIDOWS

IN TOTAL 29 CHILDREN

LIVING WITH HIV FOR AN AVERAGW OF 30 YEARS

2 FOCUS GROUPS

MAIN THEMES FROM FOCUS GROUPS



1. FoP is widely experience by participants whereas FoD is not
2. FoD is linked to experience of loneliness
3. Death is associated with fear of physical pain
4. Trust in healthcare practitioners decreases as age increases
5. Assisted death
6. Fear of inability to afford own funeral
7. Fear of increased stigmatization

TAKE HOME MESSAGE



1. For women living with HIV FoP frames narratives about their future
2. A good quality of life as women age with HIV should be followed by a good quality of death
3. The traumatic experience that is living once told that they were going to die at young age should be acknowledged
4. The experience of poverty and the experience of loneliness and isolation frame women's narratives about their own death.
5. Eexplore health care practitioners roles in responding to patients' requests for aid in dying.

1. Legislation which supports assisted death' considering bioethical, legal, religious, cultural, and professional viewpoints.
2. Peer led and co-produced research which addresses FoP and FoD as experienced by women who are ageing with HIV.

THANK YOU



QUESTIONS ?