The Incidence and Survival of Kaposi Sarcoma Using The National Cancer Registry Data

Catarina Quaresma Dermatology Specialty Trainee St3, Royal Devon University Healthcare NHS Foundation Trust

Agnieszka Lapin Dermatology Senior Clinical Fellow, Norfolk and Norwich University Hospitals NHS Foundation Trust

Sally Vernon Get Data Out Programme, National Disease Registration Service

Agnieszka Tan Consultant in Genitourinary and HIV Medicine, Cambridgeshire Community Services NHS Trust

Zoe Venables Clinical Associate Professor and Consultant Dermatologist, Norfolk & Norwich University Hospitals NHS Foundation Trust



Kaposi sarcoma

- Angioproliferative tumour, most commonly presenting in the skin with purple patches, plaques or nodules. Mucosal and internal involvement is seen less commonly.
- Described in 1872 by Mortiz
 Kaposi, who defined the classic
 type of Kaposi sarcoma (KS) in
 several elderly men of
 European descent as a disease
 of an indolent course.¹



Kaposi sarcoma - pathogenesis

Infection with human herpes virus 8 (HHV-8) is necessary for the disease development, but insufficient on its own.²

Co-existing immunosuppression, as seen in AIDS, is required for the viral oncogenesis.²

HHV-8 immunostain provides an accurate diagnosis, distinguishing KS from other vascular tumours.

HHV-8 prevalence

High

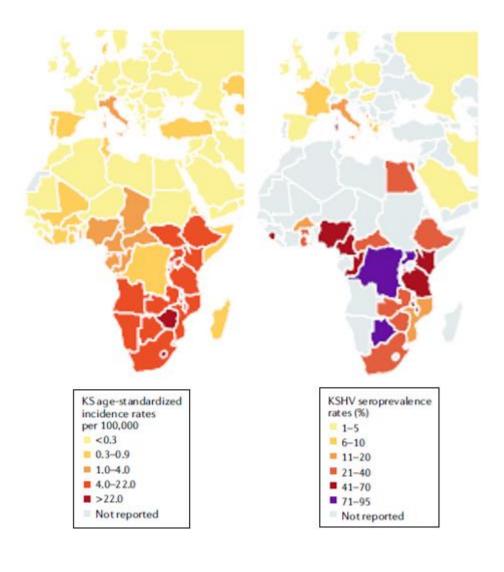
- >90% in adults
- Sub-Saharan Africa

Intermediate

- 20-30%
- Mediterranean

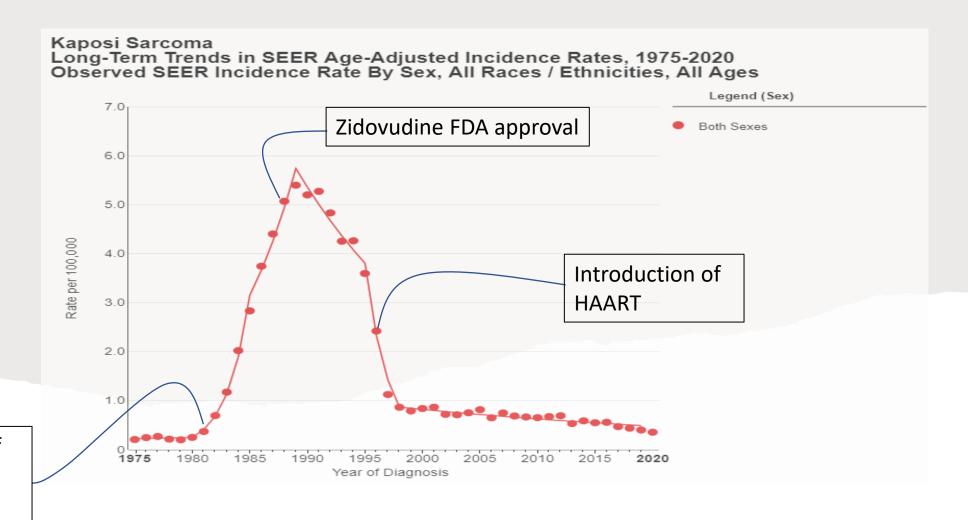
Low

- <10%
- Northern Europe, Asia, USA^{1,4}



Source: 'Kaposi Sarcoma' Cesarman et al Nat Rev Dis Primers 5, 9 (2019)

Kaposi Sarcoma Incidence



The onset of AIDS pandemic

Kaposi Sarcoma incidence in England

- Only one epidemiological study in England and Wales to date.
- 68 cases reported between 1971 and 1980
- incidence rate of 0.01 per 100,000 person-years.
- Male to female ratio was equal to 1.
- Migrants from Eastern Europe, Mediterrenean, Africa and Middle East were at higher risk of developing KS in comparison to people born in the UK.

Br. J. Cancer (1992), 66, 1135-1137

C Macmillan Press Ltd., 1992

Kaposi's Sarcoma in England and Wales before the AIDS epidemic

A.E. Grulich¹, V. Beral² & A.J. Swerdlow¹

¹Epidemiological Monitoring Unit, London School of Hygiene and Tropical Medicine; ²Imperial Cancer Research Fund Cancer Epidemiology Unit. Oxford, UK.

Summary The epidemiological features of Kaposi's Sarcoma (KS) incidence in England and Wales in the period 1971-1980 are reviewed. The epidemiology of KS in England and Wales in this period is distinct from

Get Data Out Programme

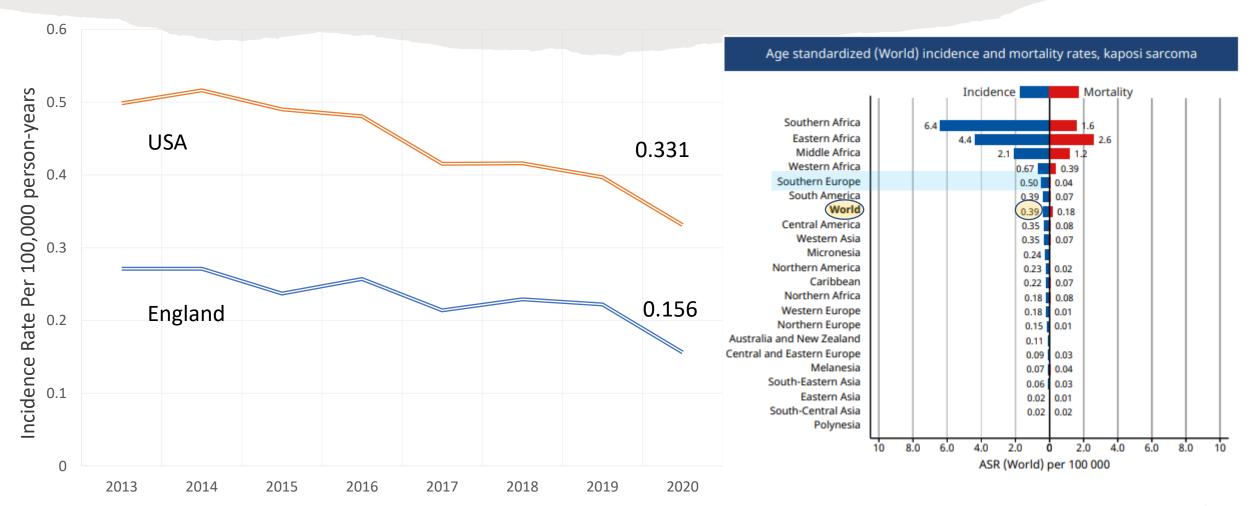
- National data from the National Disease Registration Service (NDRS) is available for 2013 – 2020 via the Get Data Out Programme.
- Only the annual figures are reported, no further division of patient groups.
- Cancer registration data is gathered for tumours coded to ICD-10 C46 (WHO) from pathology laboratories, MDTs treating patients with cancer, and death certifications.

The Get Data Out programme

AIM: Routine publication of detailed open data on small, anonymous groups of cancer patients.



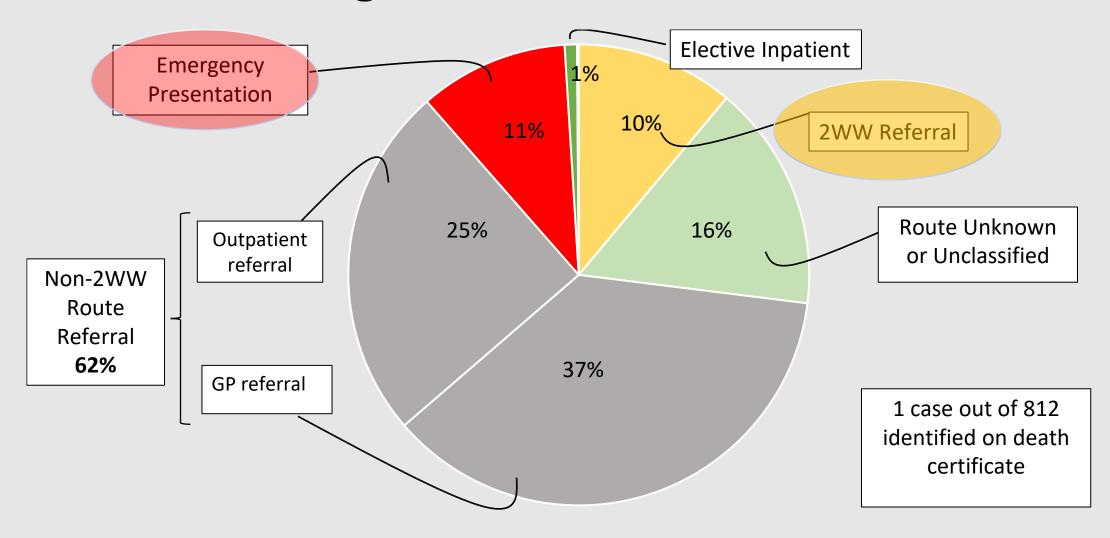
Kaposi Sarcoma incidence rate in England



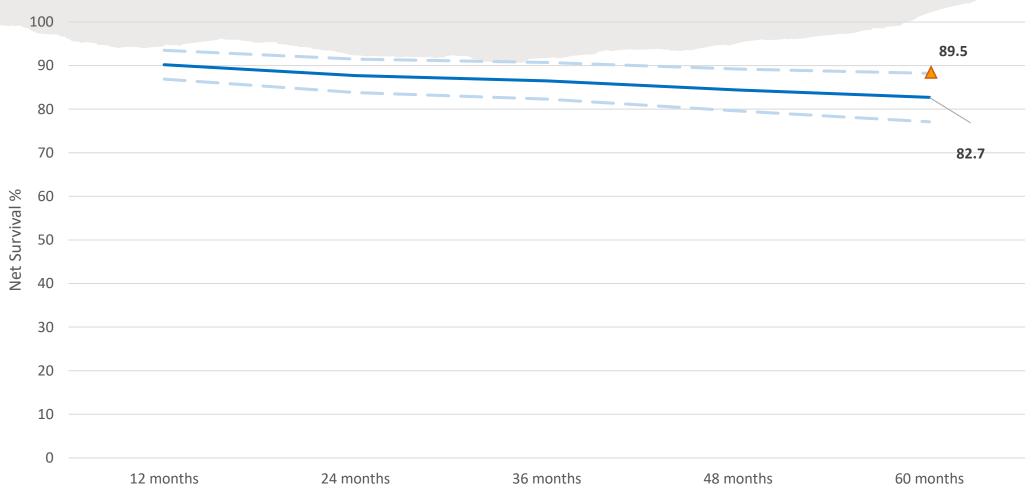
Data source:
For UK: Get Data Out Programme
For USA: Surveillance, Epidemiology, and End Results Program (SEER)

Data source: GLOBOCAN 2020; International Agency for Research on Cancer

Routes to diagnosis



Kaposi sarcoma – net survival



Conclusion

- 1. First nationally reported epidemiological data on Kaposi sarcoma since the 1980s.
- 2. More data on patients demographics and Kaposi sarcoma subtypes are needed.
- 3. 11% of cases still presented as an emergency.
- 4. The true incidence of Kaposi sarcoma is likely underreported as patients could be managed outside of a cancer setting e.g. patients living with HIV managed in GUM/HIV clinics.
 - ❖ No histological confirmation of KS
 - KS diagnosis absent on the death certificate

References

- 1. Cesarman E, Damania B, Krown SE, Martin J, Bower M, Whitby D. Kaposi sarcoma. *Nat Rev Dis Primers*. Jan 2019.
- 2. Douglas JL, Gustin JK, Moses AV, Dezube BJ, Pantanowitz L. Kaposi Sarcoma Pathogenesis: A Triad of Viral Infection, Oncogenesis and Chronic Inflammation. *Transl Biomed*. 2010.
- 3. Gottlieb G, Ragaz A, Vogel J, Friedman-Kien A, Rywlin A, Weiner E, Ackerman A. A preliminary communication on extensively disseminated Kaposi's sarcoma in young homosexual men. *The American Journal of Dermatopathology.* 1981.
- 4. Schwartz RA, Micali G, Nasca MR, Scuderi L. Kaposi sarcoma: a continuing conundrum. *J Am Acad Dermatol*. 2008.
- 5. Grulich AE, Beral V, Swerdlow AJ. Kaposi's sarcoma in England and Wales before the AIDS epidemic. *Br J Cancer.* 1992