

Rare cancers are not well captured in many health information systems

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Conclusion:

- An international strategy is required → improve the identification of rare cancers, with standardised diagnostic protocols → ensure patients receive optimal surveillance strategies, treatments, and access to clinical trials.

Introduction:

- Cancer is Rare cancers comprise ~22% of cancers, affecting ~4 million people in the EU.
- a leading cause of death.
- There is no consensus definition;
- RARECARENet (Surveillance of Rare Cancers in Europe) provides data for selected rare cancers using the international classification of diseases for oncology with an incidence rate <6/100,000 per person years.
- Several inherited diseases increase a person's predisposition to developing cancer.

Methods:

- The latest dataset was downloaded from RARECARENET (2000-2007) with incidence in the USA (2009-2013) obtained from DeSantis *et al.*, (2017).
- Cancers within the NI Cancer Registry were carefully evaluated to optimally capture rare cancers from 2014-2018, including genetic diagnoses.
- Comparative analyses were conducted.

Aim:

- To generate rare cancer statistics for Northern Ireland (NI) and compare with international datasets.

Results:

- ✓ Rare cancers account for >25% of all cancers in NI
- ✓ Significant variation in survival statistics at 5 years
 - ✓ e.g. Rare female breast cancer has 90% survival versus 13% for rare thoracic cancers
- ✓ Rare cancers are associated with socioeconomic deprivation (Table 1)

- ✓ Selected rare cancers have higher incidence and prevalence in particular countries
- ✓ Rare cancers are rarely designated as 'rare cancer' within healthcare records

Table1. socio-economic deprivation and rare cancer incidence in NI

2017 SOA-based deprivation quintile	Crude incidence rate per 100,000 person years (Confidence interval)	Standardised incidence ratio compared to NI (CI)
1 (Least deprived)	137.9 (90.6 - 98.1)	94.3
2	128.4 (91.0 - 98.5)	94.7
3	128.4 (92.5 - 100.1)	96.3
4	136.1 (99.0 - 106.9)	102.9
5 (Most deprived)	140.1 (110.1 - 119.3)	114.6
Northern Ireland*	134.0	

Fig1. rare epithelial cancer of head and neck

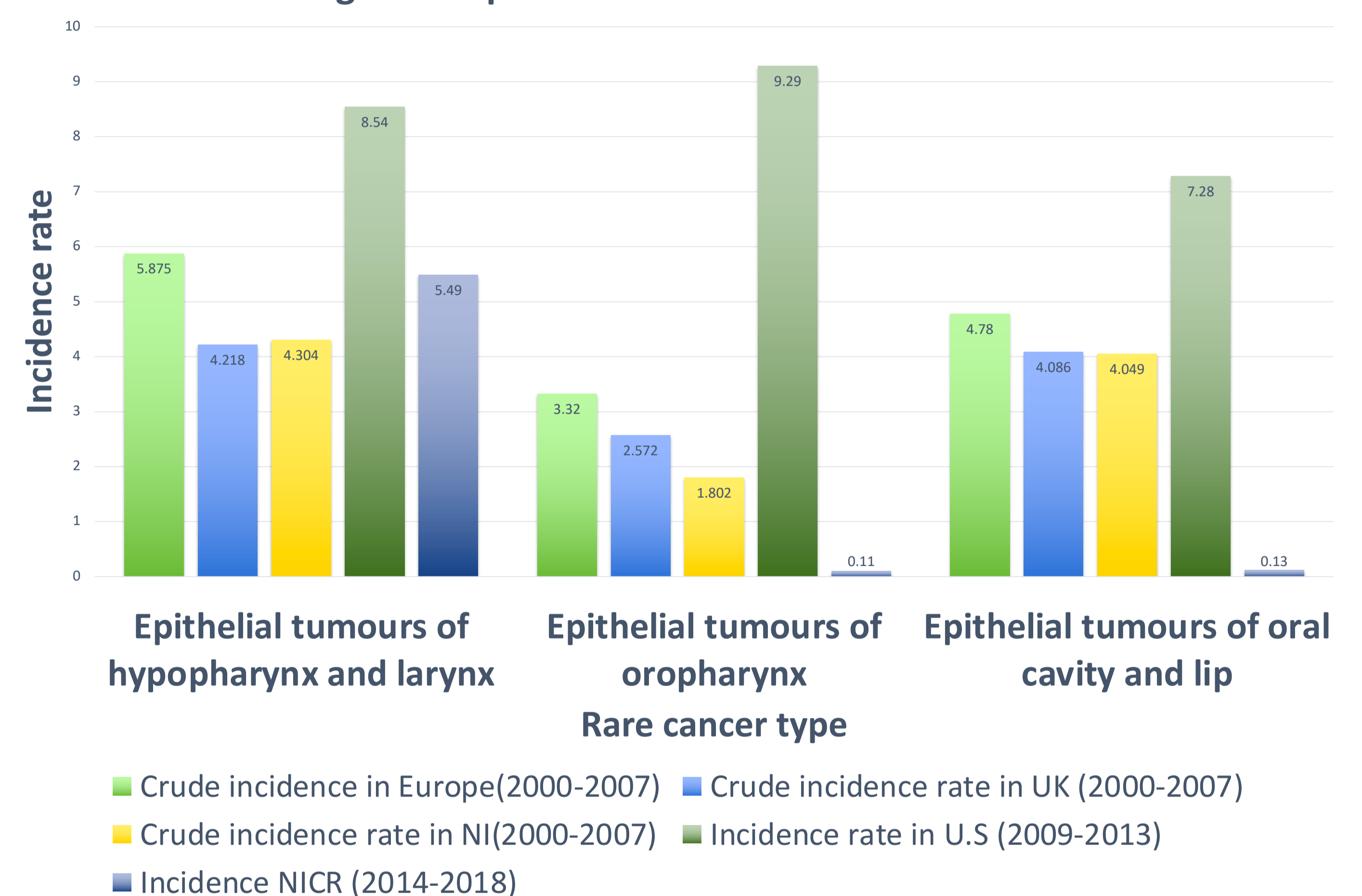
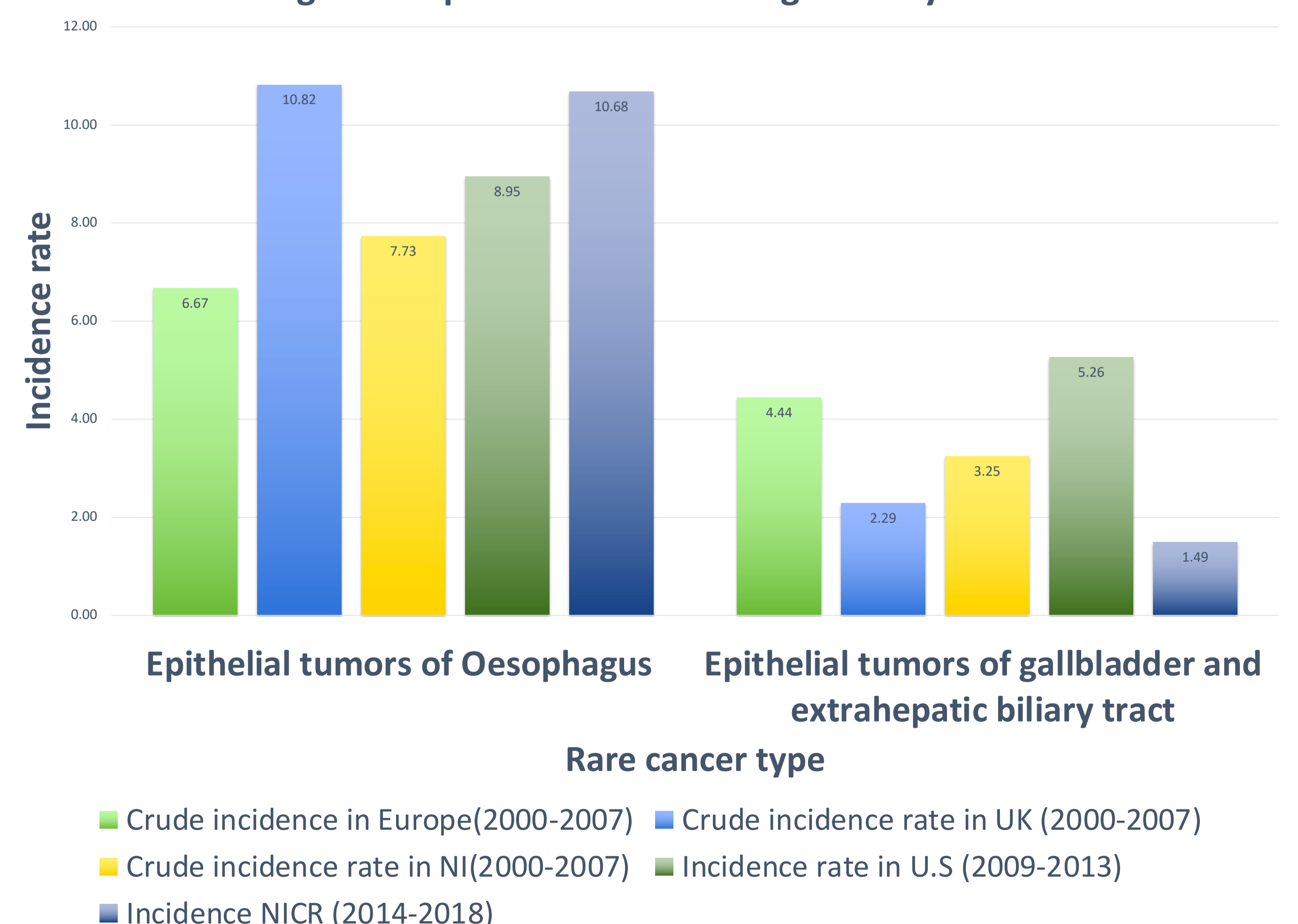


Fig2. rare epithelial cancer of digestive system



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