Experience of recording recurrence and progression in the Netherlands Cancer Registry

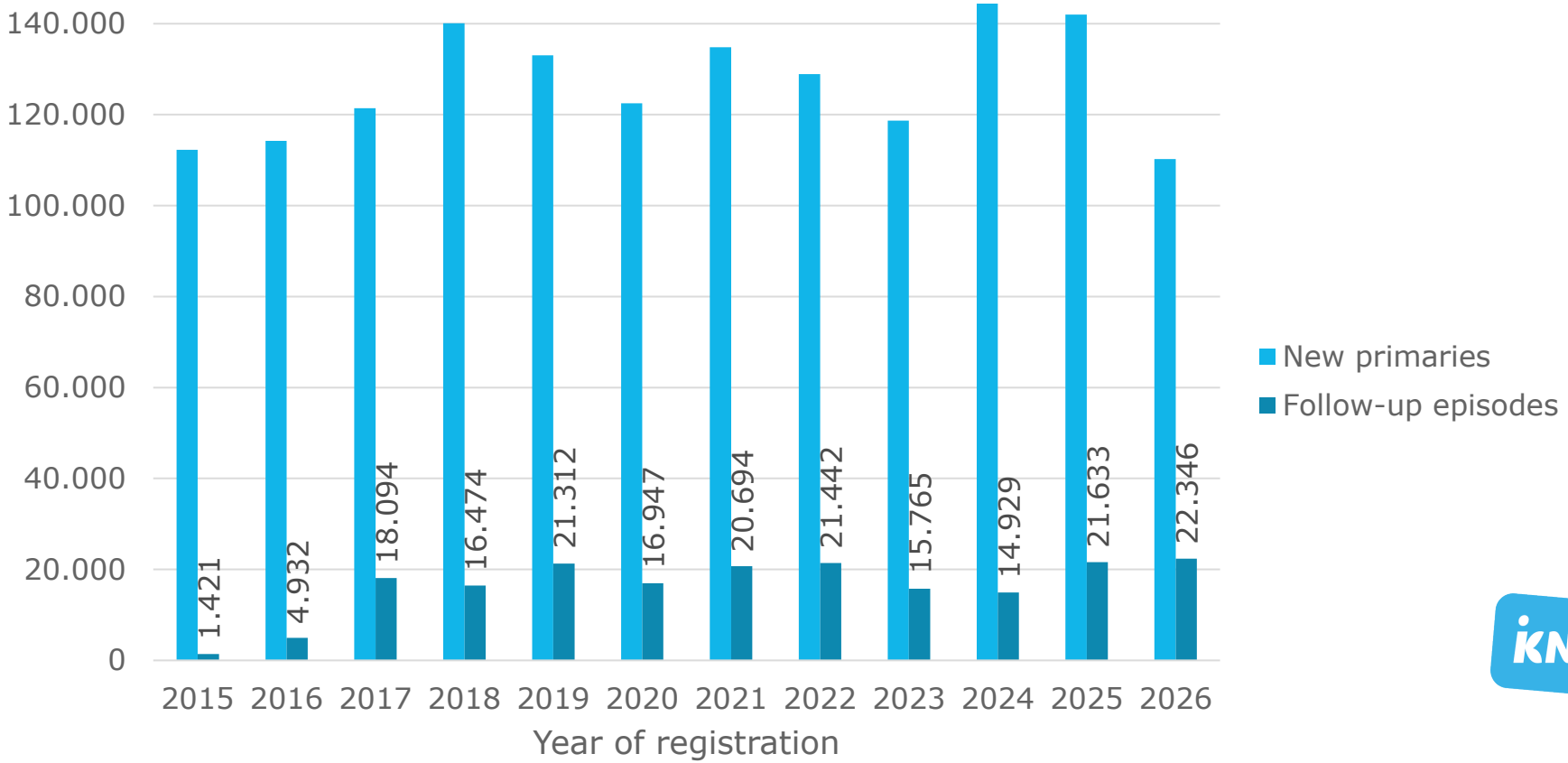


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Disease episodes

- We started with the registration of disease episodes in 2015, when a new registration application for the cancer registry was introduced
- Before 2015 we did not register disease episodes, but we did have several (regional) site-specific follow-up projects, mostly aimed at calculating recurrence rates after surgery (colon/rectum, bladder, breast)
- As of 2015, the number of follow-up projects gradually increased, but we still do not cover all tumour types. Besides, many studies are not nation-wide or only focussed on one specific treatment (e.g. 'all CCL-patients treated with ibrutinib')
- National recurrence or progression rates not yet available

Number of registered episodes in the Netherlands Cancer Registry



Registration capacity

- Depending on the type of cancer a smaller or larger proportion of all cancers do not receive tumour-reductive therapy, which means you do not have to do follow-up for these patients
- An estimated 10-15% of all incident solid cancers has a recurrence
- Progression rates not known from the NCR (and very different for different treatments), but clinical interest in progression rates is growing, especially if new expensive drugs are concerned
- If you have limited capacity you could focus on recurrence only for one or more tumours sites or progression after a specific systemic treatment

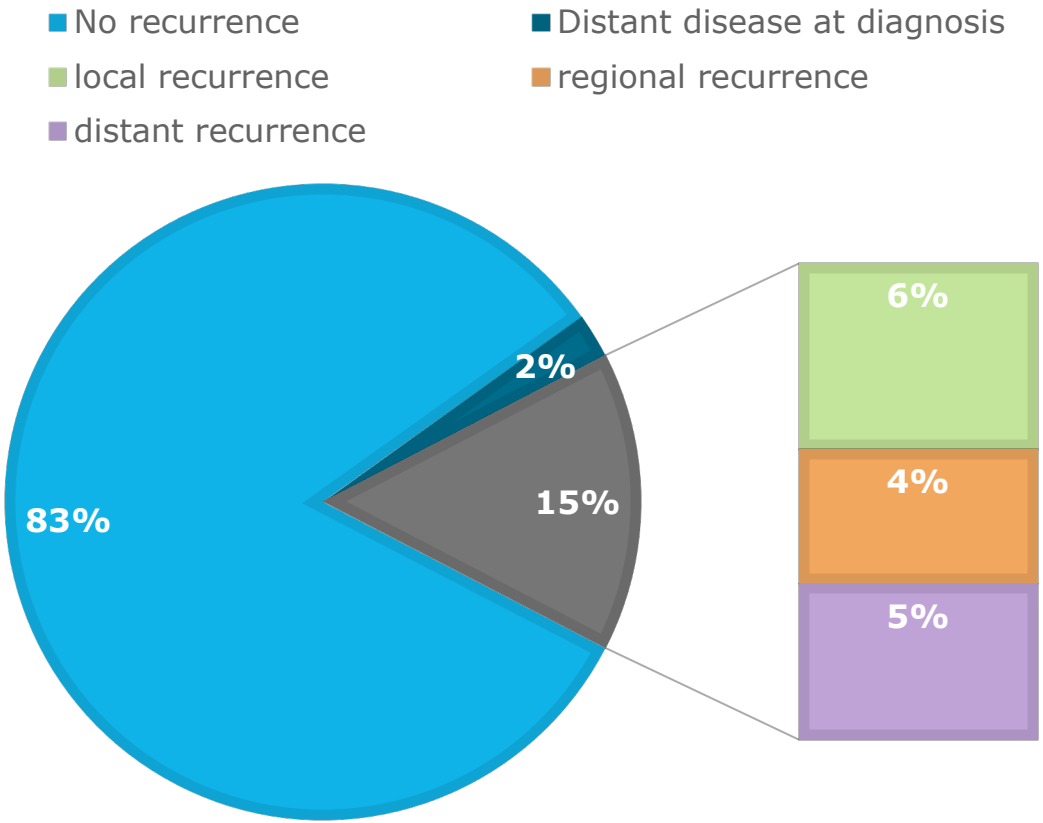
Registration capacity

- More and more patients have more than two treatment episodes
- The number of patients with multiple treatment lines is expected to increase further in the coming years
- If you want to collect them all, this increases the resources that you need
- An example is multiple myeloma, but also in metastatic breast cancer or metastatic melanoma >2 treatment lines are not uncommon.

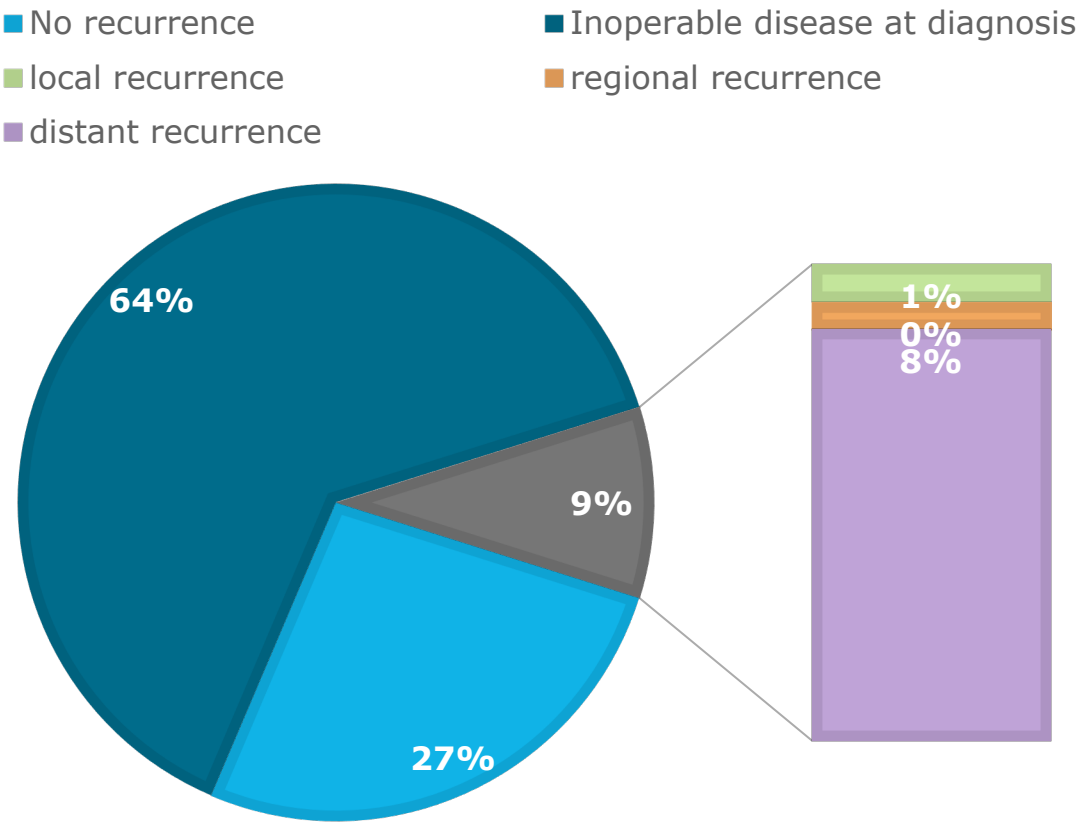
Notification

- Recurrence or progression is not notified as such to the Netherlands Cancer Registry
- A part of them are pathologically confirmed and if that is the case, the registry receives a pathology notification; pathological confirmation is high in locoregional recurrences of for example breast of head & neck cancer
- If there is no pathology (around half of all distant metastasis) other sources are needed; this may include notifications of surgery, systemic treatment or radiotherapy (at place in one third of the Dutch hospitals)
- For the other hospitals or when a patient did not receive treatment we need other sources or active follow-up

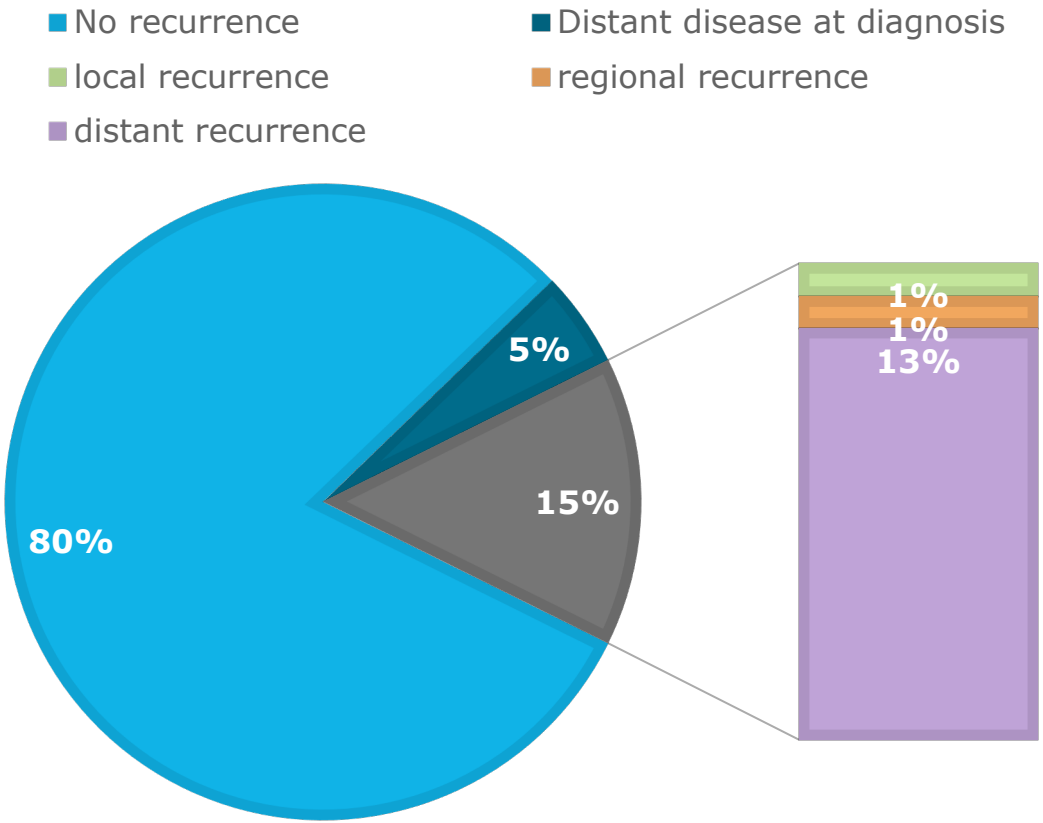
Number of first recurrences: head & neck



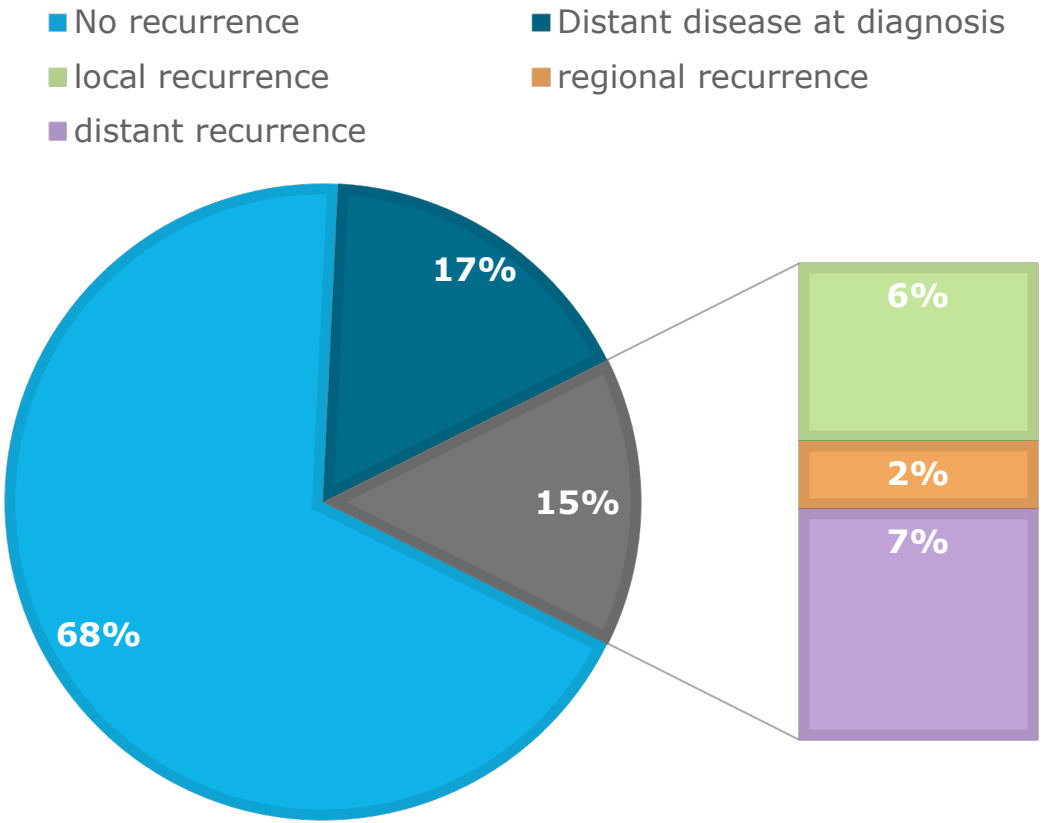
Number of first recurrences: oesophagus/stomach



Number of first recurrences: breast



Number of first recurrences: female genitals



Future plans

- Automatic notifications
- Registration of nation-wide recurrence data for low incidence cancers
- Registration of recurrence data for aselective cohorts for high incidence cancers
- Second line treatments for progressive cancers
- Therapy-based cohorts for third and subsequent lines

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