Giovedì
10 dicembre
Aula C, ore 15:00

INFN PERUGIA

A.D. 1308 unipg

DIPARTIMENTO DI FISICA E GEOLOGIA

PeRAPS 2026

Patients, longitudinal data and predictive models in a rare cancer

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ALK-positive lung cancer is a success story of precision medicine: a single molecular target, highly effective drugs. Yet about half of patients relapse within five years, and it is not clear why. The disease is rare, and longitudinal collections on the same patients across every line of therapy are missing: tumour DNA in blood, radiological and histological images, clinical events, patient-reported data including environmental exposure. With data of this kind, the models available today, from foundation models for molecular profiles and images to sequence models for treatment trajectories, would make it possible to estimate for an individual patient which drug to use, in what order and when to switch.

Patients themselves can generate that data. Allkure is an open, anonymous, GDPR-compliant registry built and governed by patients: 128 members in three weeks, with no funding and no network of clinical centres,and aggregate results public. Patients are not study subjects but part of the research group: they contribute the data, take part in choosing the questions, and see the results. The seminar presents the registry, the first analyses, and the prospects for open collaboration.