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Cancer research into action

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Population-Based Cancer Registries are the Pillars of Cancer Control in Europe: Ensuring Sustainability in a Changing Data Landscape

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Cancer Watch

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Strengthening Europe's Cancer Intelligence

€ 16 M
€ 13 M EC contribution

36 months
Sept 25 - Aug 28

29
Countries

92
Beneficiaries

NIPH Norwegian Institute of Public Health
Lead
Norwegian Institute of Public Health

CancerWatch

Commitment to improve Population-Based Cancer Registration

Within CancerWatch, one of our **objectives** is (1) to familiarize diverse stakeholders with population-based cancer registry (PBCR) operations, functions, expertise, and contributions to surveillance and cancer control; and (2) to start characterizing the sustainability capacity of European PBCRs and describe key barriers and opportunities.

PBCRs, the backbone of cancer control

They:

- Monitor incidence, mortality, prevalence and survival
- Evaluate screening and early-detection policies
- Expose inequalities by age, sex, socioeconomic status, and region.
- Across four quality dimensions:

Comparability | Timeliness | Validity | Completeness

Method

- Survey of European PBCRs: 162 responding registries (84% response rate) including a sustainability assessment based on the Sustainability capacity for Health Programs Model.

Figure 1. Sustainability model adapted from the Program Sustainability Assessment Tool (PSAT)

Result

Figure 2. Can you spot the misconceptions?

1 "PBCRs only provide basic incidence statistics"

MYTHS ✗

FACTS ✓

They monitor trends in incidence, mortality and prevalence to evaluate public health programs, policies and assess quality of care, survival, stage at diagnosis, and inequalities by age, sex, socioeconomic status, or geographical region.

2 "The European health data space (EHDS) will replace PBCRs"

MYTHS ✗

FACTS ✓

The EHDS will facilitate access to data but it still needs to be transformed into cancer intelligence. It also does not replace core registry functions such as case definition, quality control, national and international comparability, and indicator computation.

3 "European health records (EHRs) already have the data"

MYTHS ✗

FACTS ✓

PBCRs integrate multiple sources and ensure comparability within and across countries. EHRs are not standardized, population-based, or validated.

4 "AI will soon replace PBCRs"

MYTHS ✗

FACTS ✓

AI-supported workflows are being integrated in PBCRs. However, expert human oversight remains indispensable for case consolidation, coding rules and quality assurance. Integration of AI depends on digital infrastructure and maturity of PBCRs.

Figure 3. Sustainability capacity of European PBCRs by dimension.

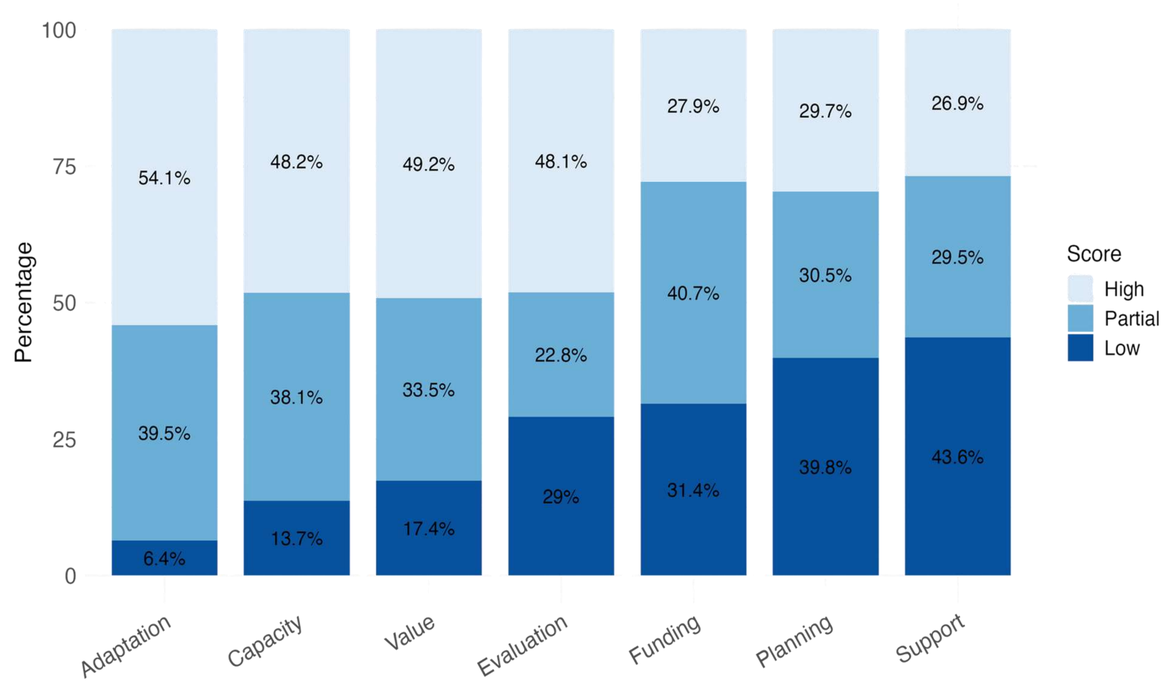
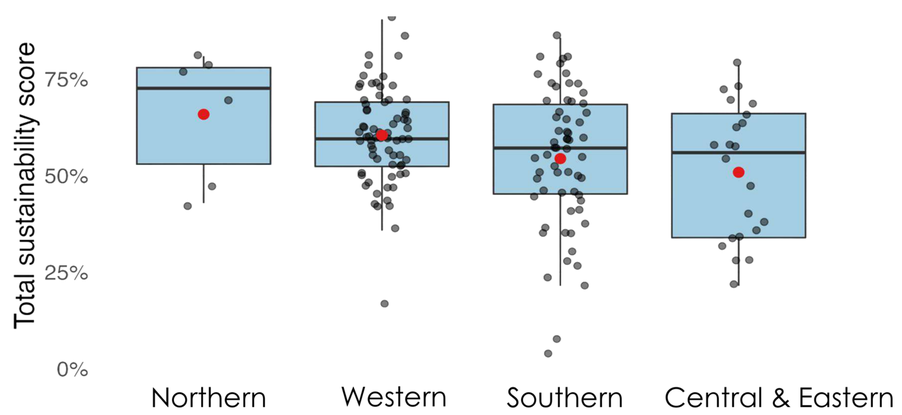


Figure 4. Total sustainability capacity scores by European region.



- **There is substantial variability in the sustainability capacity of European PBCRs across regions.**
- **The most frequent challenges include a lack of funding and insufficient institutional support, with implications for strategic planning.**
- **Strengths include strong operational and adaptive capacity, with frequent demonstration of value to stakeholders.**

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Conclusion

Europe cannot afford inaccurate, outdated, or fragmented population-based cancer data. Ensuring the sustainability and resilience of PBCRs requires coordinated support from policymakers, healthcare providers, researchers, and patient communities.

Window of opportunity

Sept 2025 — Aug 2028

36 months to shape the future of cancer intelligence in Europe

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