CancerWatch

Survey results on
RECURRENCE – PROGRESSION - TRANSFORMATION

Workshop
ENCR Recommendations on Recording Recurrence, Progression and Transformation Episodes
23 October 2026

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CANCER REGISTRY
REGISTER RAKA
SLOVENIJA

CancerWatch project

- **a Joint Action** supporting **Europe's Beating Cancer Plan**
- Start: September 1 2025, 36 months duration; coordinated by the Norwegian Institute of Public Health
- primary goal: **improve the quality and timeliness of cancer registry data collected by the members of European Network of Cancer Registries (ENCR)**

CancerWatch will:

- Help registries capture richer, faster data using digital innovation.
- Harmonize quality standards across Europe.
- Address legal and GDPR barriers for secure data use.
- Improve survival and prevalence indicators in ECIS.
- Prepare registries for the European Health Data Space (EHDS).

Why it matters?

Cancer data in Europe vary widely in quality and timeliness—some regions lack full coverage, others face delays of over two years.

Locations



CancerWatch Survey 2026 (Task 5.1.1)

- **Designed to map PBCR across Europe**
- Developed by the **Slovenian Cancer Registry (SCR) in collaboration with WP leaders; SCR as a central coordinating body for implementation of the survey**
- A comprehensive list of PBCRs in Europe prepared by the SCR and reviewed by the regional coordinators
- A REDCap platform
- Tested by regional coordinators in pilot
- Assesses in **15 thematic sections**:
  registry operations, digitalisation, and maturity, including legal frameworks, financing, staff capacity, data flow, IT infrastructure, data quality, and dissemination practices



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CancerWatch Survey Achieves Record-Breaking 94% Response Rate Across Europe

We are proud to share that the **CancerWatch survey phase** has officially concluded, marking a significant step forward for the Joint Action. Between January 14th and February 28th, 2026, we reached out to 192 cancer registries across Europe to map the current landscape of cancer data collection and management.

A Community-Driven Success To our knowledge, this is the most extensive survey ever conducted within this community. The participation rate has exceeded all expectations:

- **Response Rate:** 94.3% (181 out of 192 registries).
- **Data Quality:** 91.1% of participants provided fully completed questionnaires.

This exceptionally high response rate is a testament to the strong engagement and readiness of European registries to evolve and collaborate. It also reflects the outstanding coordination by the **Slovenian Cancer Registry** team, who implemented the survey via the REDCap platform with the support of our regional coordinators.

Several items in the questionnaire pertinent to RECCURENCE – PROGRESSION - TRANSFORMATION

ESMO GOOD SCIENCE BETTER MEDICINE BEST PRACTICE

ESMO REAL WORLD DATA AND DIGITAL ONCOLOGY

ORIGINAL ARTICLE

Mapping population-based cancer registries in Europe: coverage, data availability, and capacity for real-world data generation

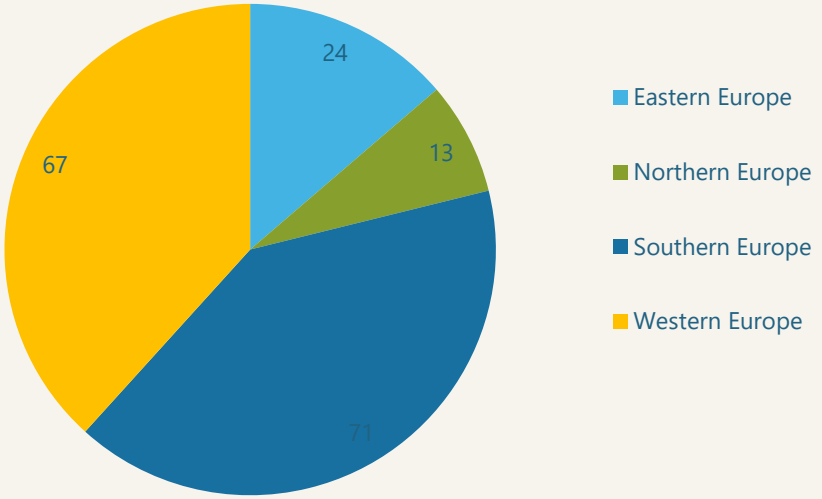
V. Zadnik[1*], A. Duratović Konjević[1], M. Jurtela[1], K. Lokar[1], N. Bric[1], T. Zagar[1], D. Petrova[2,3,4,5], M. J. Bento[6,7,8], M. D. Chirlaque[9,10], D. Coza[11], L. Daubisse-Marliac[12,13,14,15], P. Delafosse[16], G. Geleijnse[17,18], S. Guzzinati[19], M. Hackl[20], T. Hartz[21], N. Meuter[21], D. Murray[22,23], K. Staehelin[24], L. Taraszkiewicz[25], G. Ursin[19,26,27] & M. Trojanowski[25]

https://doi.org/10.1016/j.esmorw.2026.100785

CW survey 2026

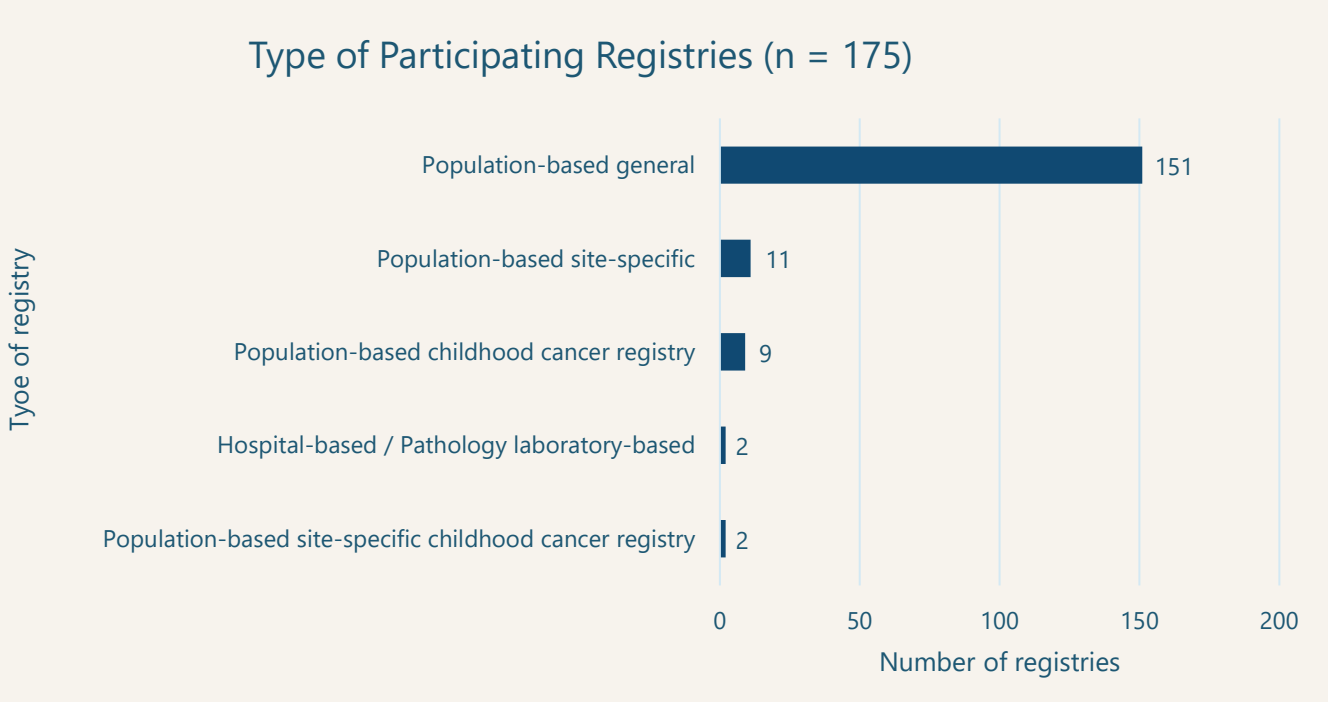


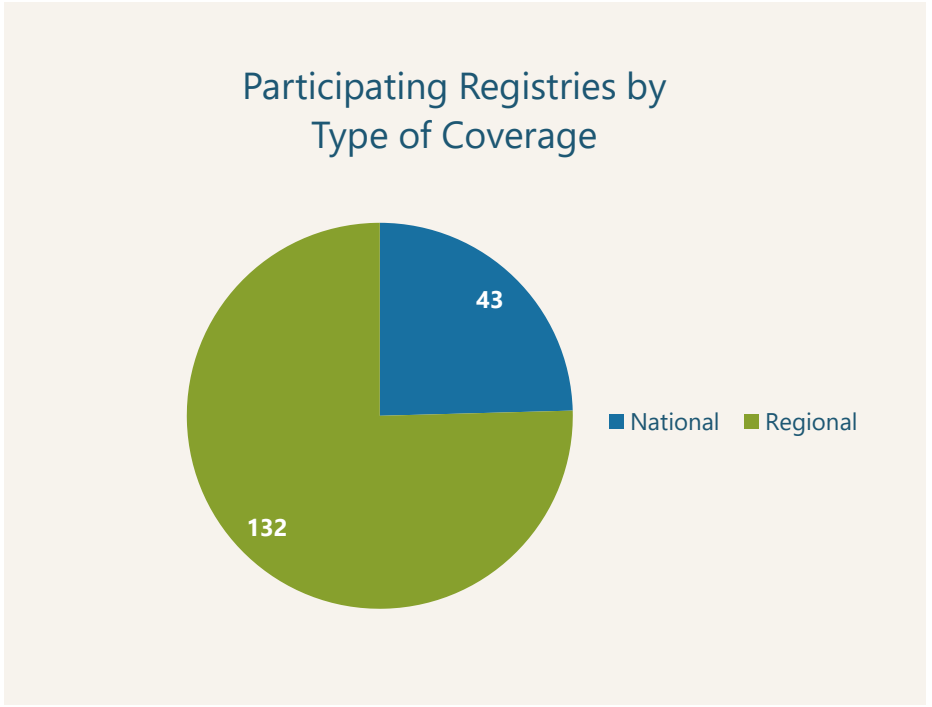
Participating PBCRs by European region (n=175)



CW survey 2026

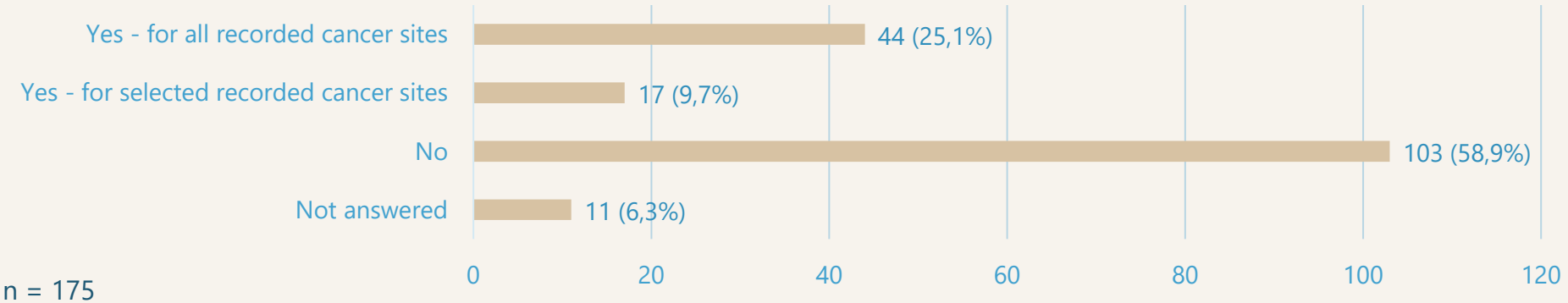
- **Q12.9.3.** Are the following outcome measures - **recurrence after disease-free interval & progression-free survival)** available at your registry?
  - Level of autonomy in independently performing estimations & reasons for that?
- **Q6.1.33.** Do you collect **date** and **site(s) of recurrence or progression on a routine basis**?
  - What information do you collect?
  - Plans & conditions for recording it in the future?
- **Q6.1.34.** Do you collect data about **type of recurrence (local, regional, distant) on a routine basis**?
  - Plans & conditions for recording it in the future?
- **Q6.1.35.** Do you collect data on **transformation episodes in haematological malignancies**?
  - Plans & conditions for recording it in the future?
- **Q7.8.** Do you follow the **ENCR recommendations** on Recording REcurrence, Progression and Transformation Episodes (2025)?





Albania, Austria, Belgium, Bosnia and Herzegovina, Croatia, Cyprus, Czechia, Denmark, England (UK), Estonia, Faroe Islands, Finland, France & French Overseas Territories, Germany, Hungary, Iceland, Ireland, Italy, Latvia, Lithuania, Luxembourg, Malta, Moldova, Montenegro, Netherlands, North Macedonia, Northern Ireland (UK), Norway, Poland, Portugal, Romania, Serbia, Slovakia, Slovenia, Spain, Sweden, Switzerland, Turkey, Wales (UK)

Is recurrence after disease-free interval / progression-free survival available at your registry?

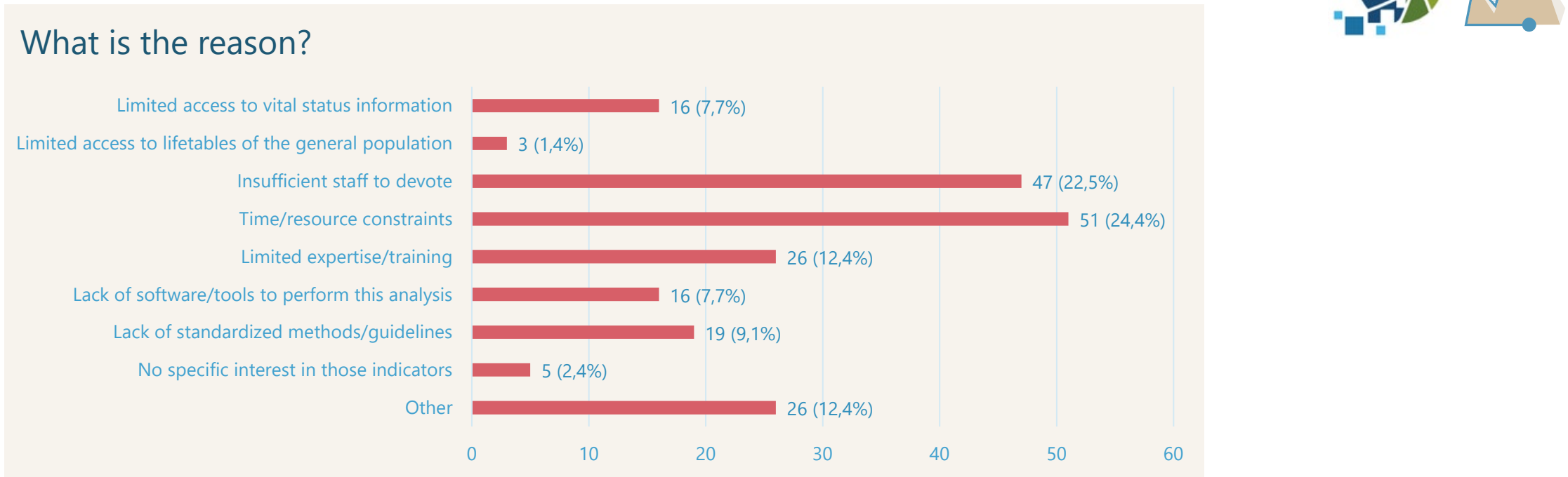


n = 175

Free-text responses for **Yes – for selected cancer sites**:

Category	n	Overview of responses
Selected cancer sites or diagnoses	**9**	• Breast cancer ×2 • Breast and colorectal cancer ×2 • Breast, ovary and rectum ×1 • Colorectal adenocarcinoma ×1 • Lymphoid malignancies ×1 • Melanoma and childhood cancers ×1 • Specific ICD-10 sites (list given) ×1
All / broadly defined sites	**4**	• All sites; reporting incomplete ×1 • All sites; registry medical staff validation required ×2 • Malignant tumours only ×1
Specific projects or cohorts	**3**	• Specific projects ×2 • Specific cohorts ×1

For those who answered **NO** for recurrence availability:

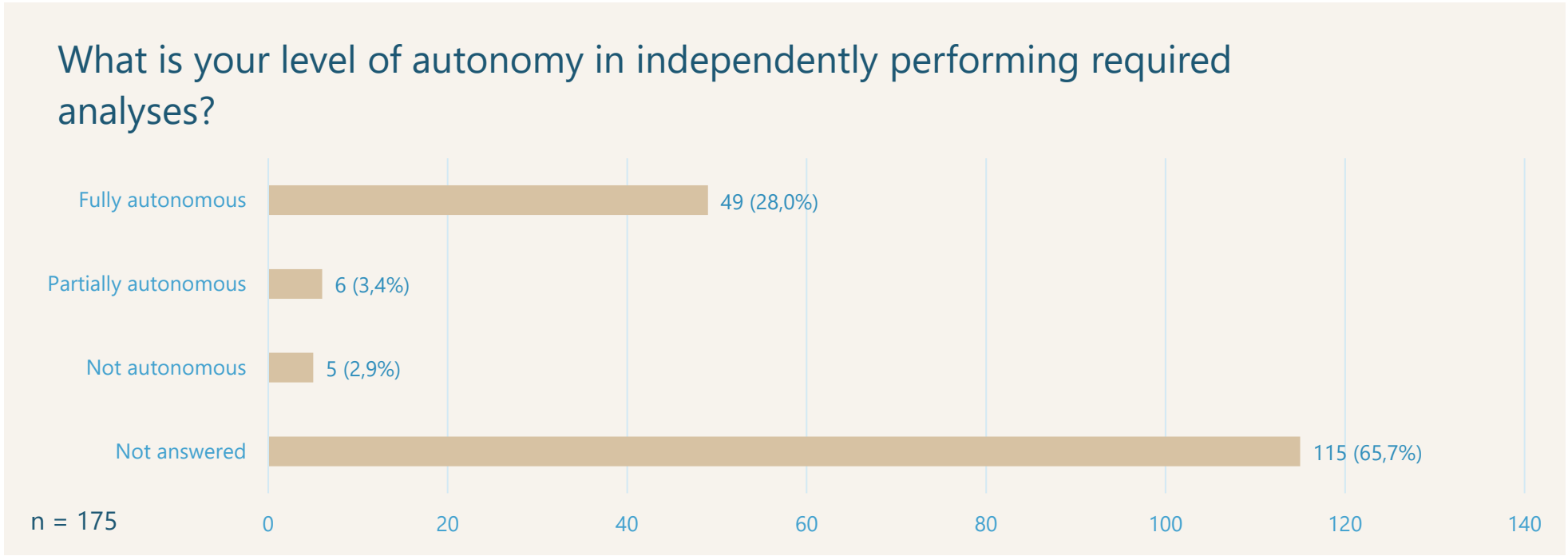


Other:

Category	n	Overview of responses
Insufficient quality, completeness or standardisation of available data	**8**	• Incomplete / insufficient clinical recurrence/progression information ×3 • Uncertain/challenging identification of recurrence/progression ×2 • Lack of standardized information ×1 • Limited information on disease-free period ×1 • Insufficient data quality ×1
Organisational, resource or legislative constraints	**3**	• Resource limitations ×1 • Legislative change required ×1 • Data handled by another national organisation ×1
Collection planned	**2**	• Planned ×2
Non-availability of baseline data	**13**	• Recurrence/progression data not collected or recorded ×6 • No or limited access to follow-up data ×4 • Not routinely recorded, not defined as variable ×2 • Registry/institution focuses on incidence and survival ×1

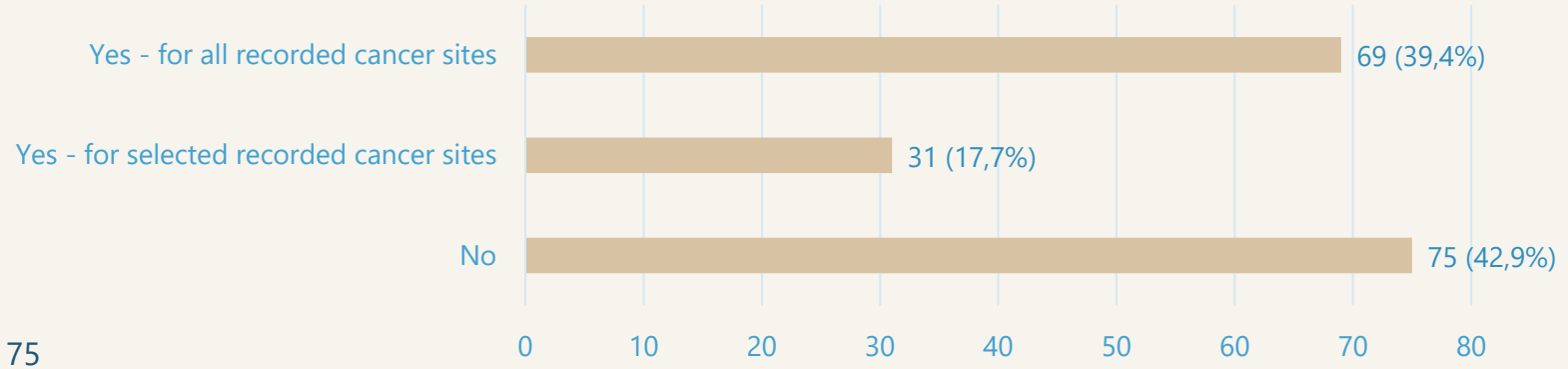
Q: 12.9.3

For those who answered **YES** for recurrence availability:



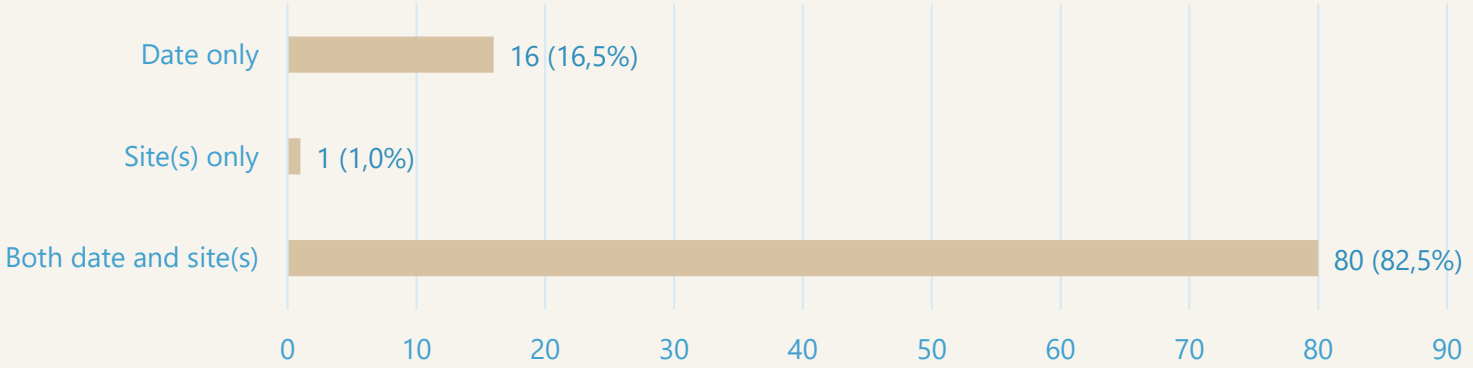
Q: 12.9.3

Do you collect **date and site(s) of recurrence or progression** on a routine basis?



n = 175

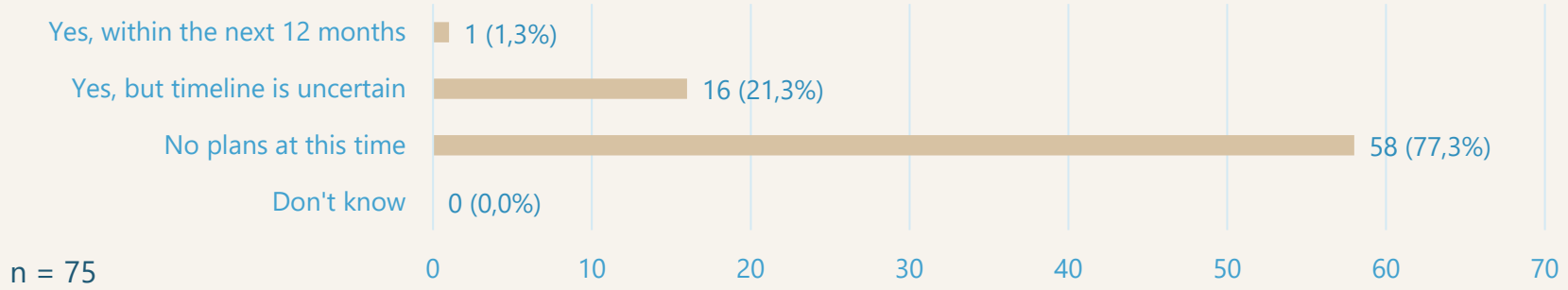
What information do you collect?



n = 97

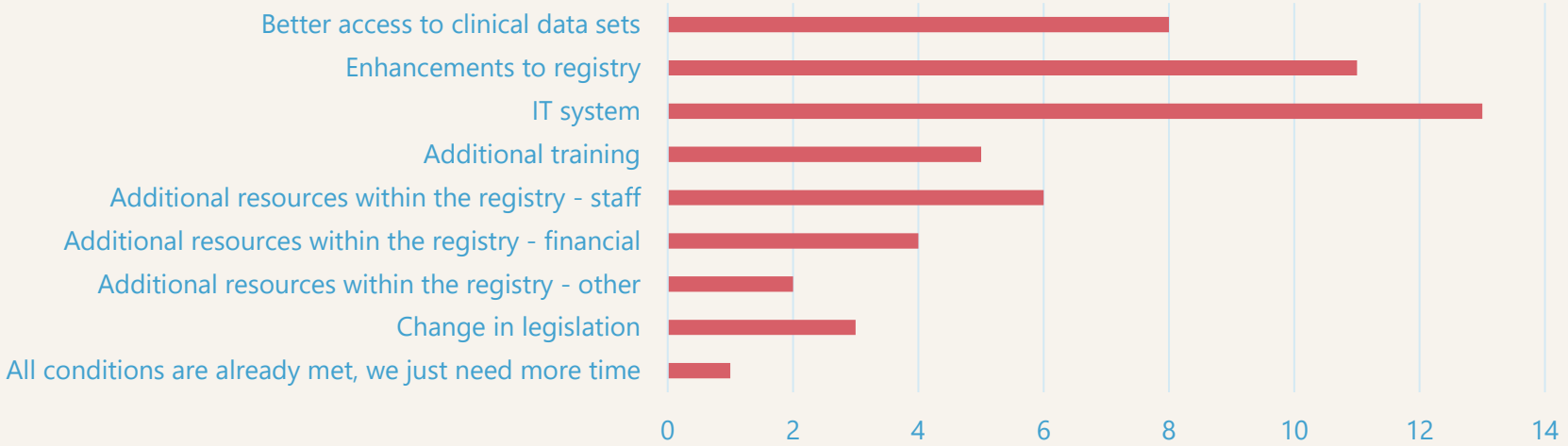
For those who answered **NO** on collection of date/site of recurrence or progression:

Are there plans to record date/site of recurrence or progression in the future?



n = 75

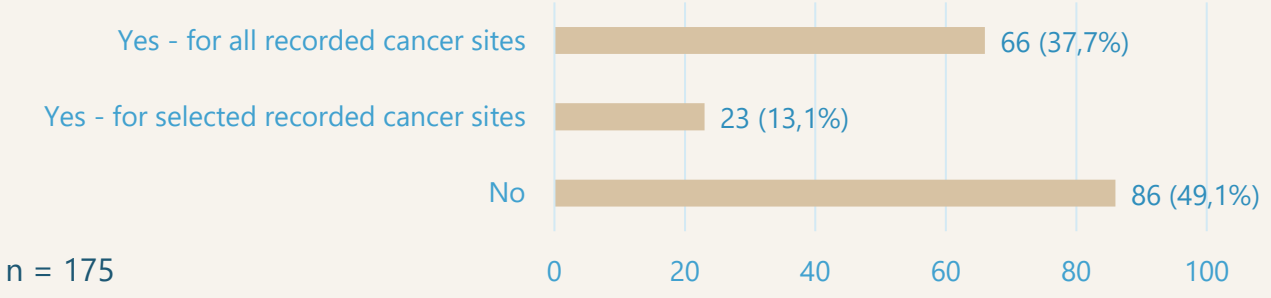
Recording of this item is conditional on:



Q: 6.1.33

Q: 6.1.34

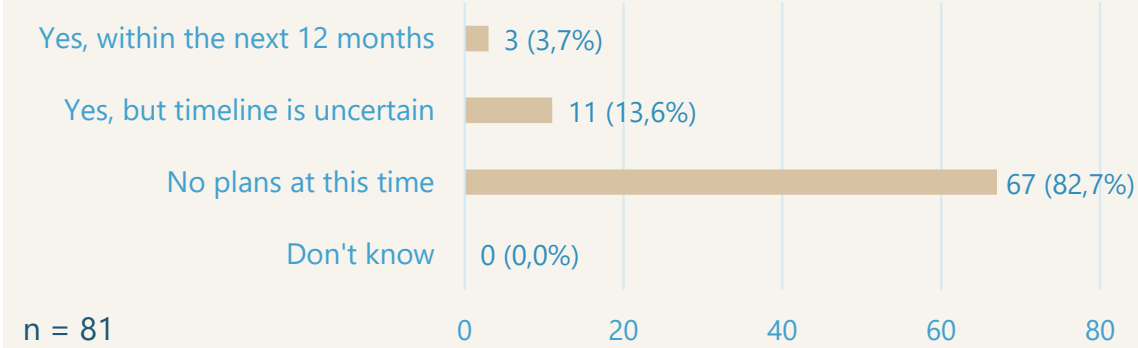
Do you collect data about type of recurrence (local, regional, distant) on a routine basis?



n = 175

NO

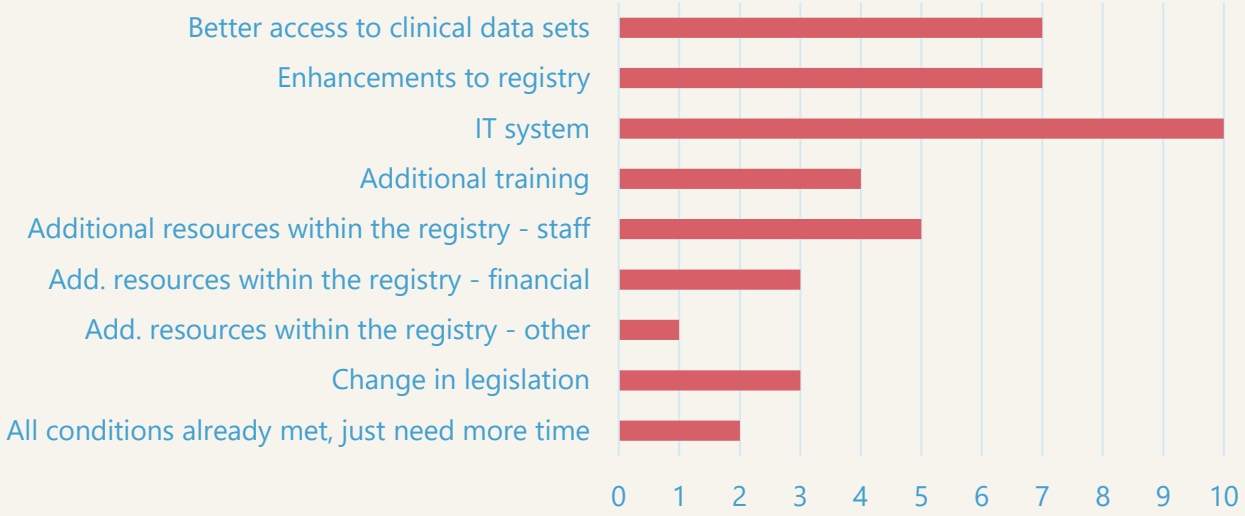
Are there plans to record type of recurrence in the future?



n = 81

YES OR DON'T KNOW

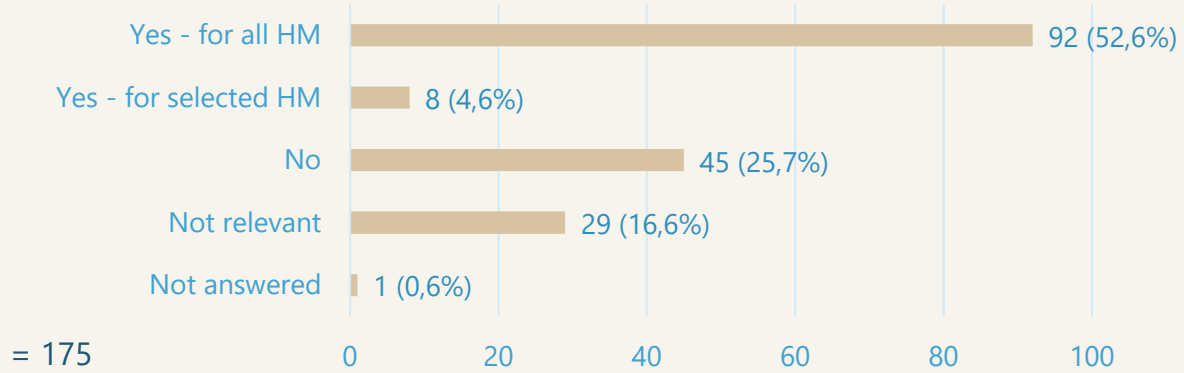
Registration of recurrence type is conditional to:



Q: 6.1.34

Q: 6.1.35

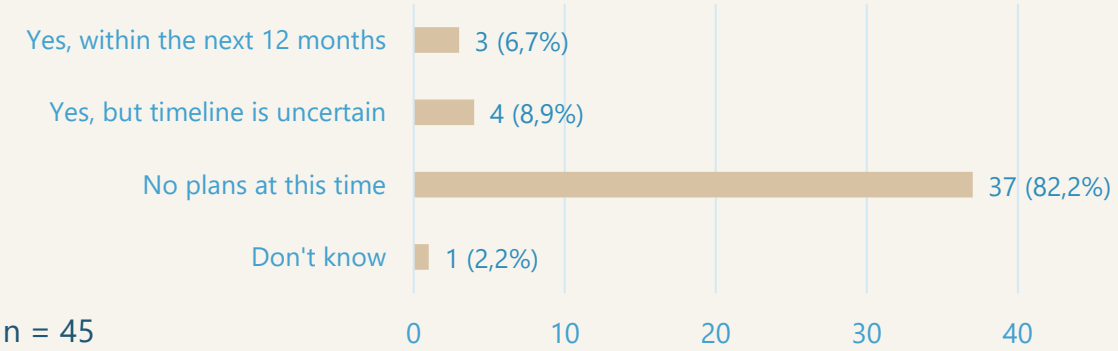
Do you collect data on tranformation episodes in haematological malignancies (HM)?



n = 175

NO

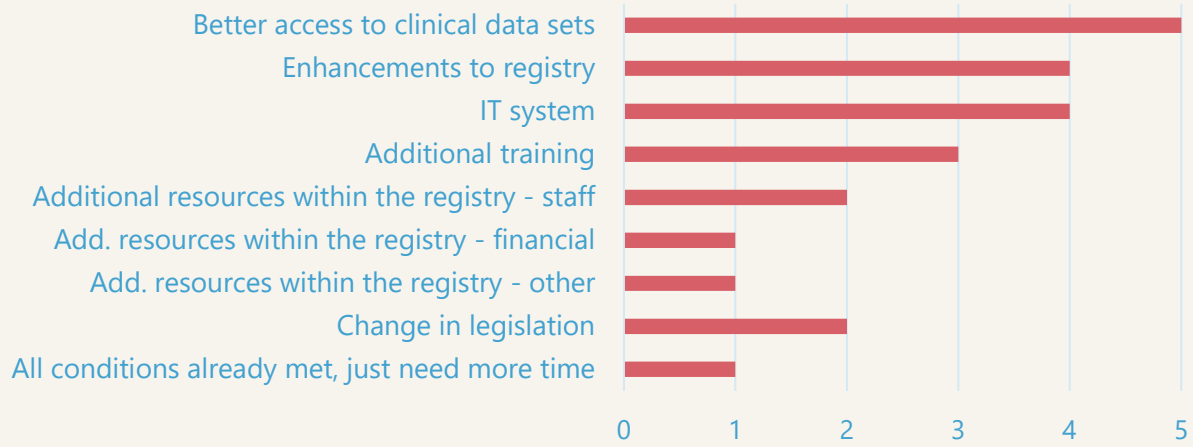
Are there plans to record this item in the future?



n = 45

YES OR DON'T KNOW

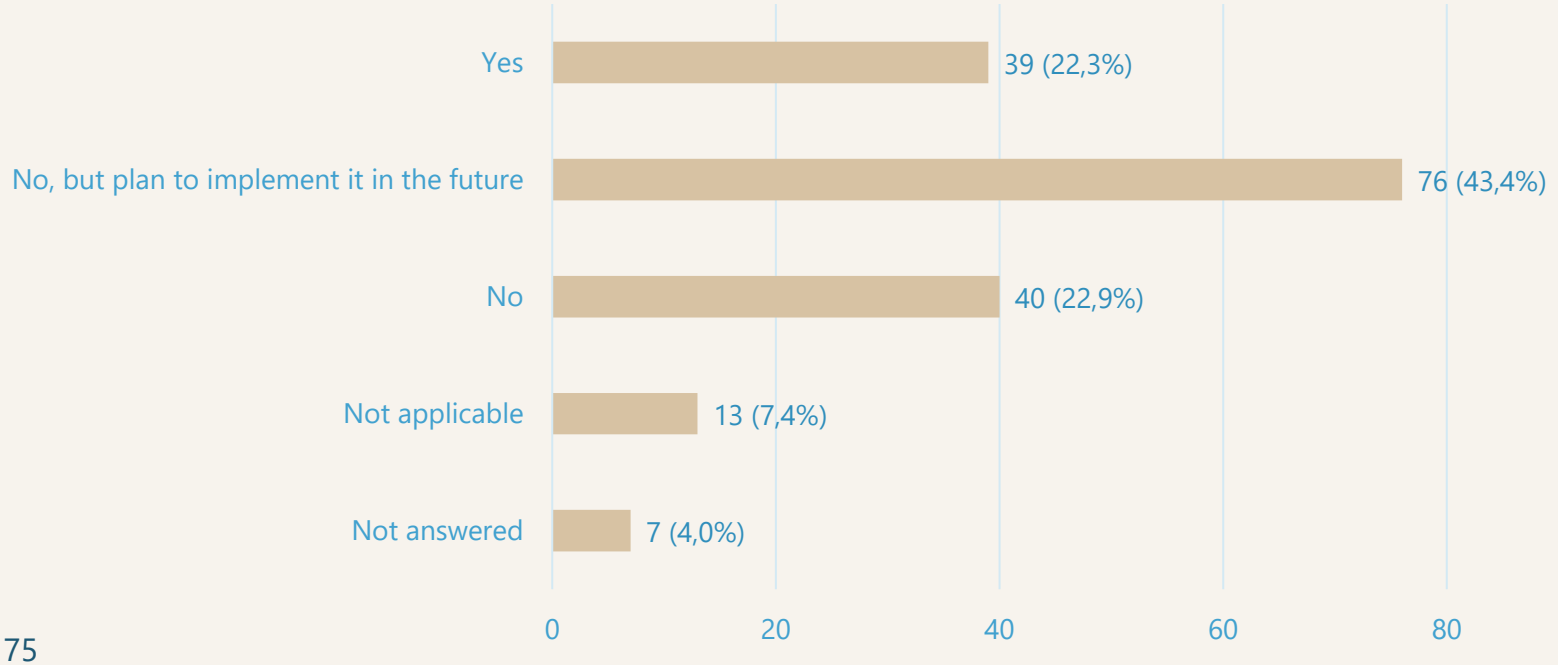
Registration of transformation episodes in HM is conditional to:



Q: 6.1.35

Q: 7.8

Do you follow the ENCR recommendations on Recording Recurrence, Progression and Transformation Episodes (2025)?



n = 175

Wrap-up: Findings of the CancerWatch survey 2026

- **34%** of responding European PBCRs record solid **cancer recurrences** (majority for all cancer sites & on the type, date & site)
- **63%** of responding European PBCRs record **transformation** episodes of haematological malignancies

Main conditions for recording this data would be:

- *IT system upgrade,*
- *better acces to clinical data,*
- *enhancement to the PBCR.*

- **22%** follow **ENCR recommendations 2025**, while **43 %** plan to do so in the future

Co-funded by the European Union

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