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EXPLAINING RARE CANCER SURVIVAL GAPS: A COMPARATIVE POLICY REVIEW OF SIX EUROPEAN COUNTRIES

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BACKGROUND

- Rare cancers comprise about 22% of all cancers in Europe and often have poorer survival due to diagnostic delay, limited expertise, and fragmented care.
- Despite EU initiatives, substantial cross-country differences persist.
- Comparative evidence linking national standardization policies and explicit care pathways to outcomes is limited.
- We analysed national policies in countries with differing rare-cancer survival in the early 2000s.
- We aimed to examine the relationship between national cancer care policies and rare-cancer survival across high-, moderate-, and low-survival countries, and to identify policy components that may contribute to the survival gap.

METHODS

- EUROCARE and RARECAREnet survival data for 2000 to 2007 (the latest) were used to stratify six countries: Germany and Italy (high), the Netherlands and Norway (moderate), and Lithuania and Bulgaria (low).
- We retrieved national policies from 2000 to 2007, or the nearest available period, from governmental, professional-society, and international sources in any language.
- Policies were grouped into four domains:
  1. rare-cancer frameworks including familial cancer syndromes as a subdomain,
  2. standardization initiatives (certification, clinical guidelines, quality monitoring),
  3. national cancer control plans or strategies,
  4. care pathway documents.
- Policies were thematically analysed based on topics of for each domain and SWOT analysis was done.

RESULTS

- **High-survival countries adopted early, comprehensive measures:**
  - ✓ Only Italy had a national policy explicitly covering rare cancers in 2001, establishing the National Network for Rare Diseases, including rare cancer referral centres with molecular and genetic diagnostic capacity.
  - ✓ Italy's 2006–2008 National Health Plan emphasized coordinated oncology care and encouraged the adoption of diagnostic-therapeutic pathways at the regional level; in some regions, time-to-treatment targets and genetic testing protocols were subsequently defined.
  - ✓ Germany's certified oncology centres for breast (2003) and colorectal (2006) cancer mandated multidisciplinary meetings, audits, and process indicators.
  - ✓ By the late 2000s, Germany also integrated BRCA testing and hereditary cancer counselling into its public insurance coverage, supporting early risk identification and preventive management.
- **Moderate-survival countries acted slightly later:**
  - ✓ The Netherlands' 2002 breast guideline defined diagnostic–treatment steps and timelines, while also including hereditary-risk assessment criteria for BRCA1/2 testing; the 2005–2010 National Cancer Control Programme reinforced quality standardization and care coordination.
  - ✓ Norway's first cancer strategy (2006) and 2007 breast guideline established pathway steps, treatment deadlines, and recommendations for genetic counselling in high-risk families.
- **Low-survival countries had fragmented approaches:**
  - ✓ Lithuania's 2003–2010 Cancer Prevention and Control Programme focused mainly on screening, with minimal service standardization and no provisions for hereditary cancer management.
  - ✓ Bulgaria's 2001–2006 National Oncological Screening Programme was limited in scope, focusing on population screening without defined pathways or genetic risk frameworks; no comprehensive national cancer plan emerged until the 2020s.

Table 1. National policy domains related to rare cancer care (2000–2007 or nearest period)

Domain	High survival		Moderate survival		Low survival	
	Germany	Italy	Netherlands	Norway	Lithuania	Bulgaria
Rare-cancer frameworks	No dedicated rare-cancer framework before 2010; national rare-disease policy developed later.	DM 279/2001 established the National Network for Rare Diseases including oncology referral centres with molecular/genetic diagnostics.	No general rare cancer–specific policy; covered under general oncology guidelines.	No dedicated general rare cancer policy until later decades.	Rare cancer framework absent; general cancer programme only.	Absent; general cancer control plan without rare-cancer component.
Policies addressing familial cancer syndromes	Integrated hereditary breast/ovarian cancer centres; BRCA testing reimbursed by public insurance; multidisciplinary management promoted (2008).	Established molecular/genetic diagnostic capacity; regional Diagnostic–Therapeutic–Assistance Pathway later incorporated BRCA testing and genetic counselling (2001; 2010s).	Included hereditary-risk assessment and referral criteria for BRCA1/2 testing; implemented via Clinical Genetics Centres (2002).	Defined criteria for BRCA testing and access to genetic counselling (2008).	National reimbursement for genetic testing introduced only in the 2020s.	Limited hospital-based genetic counselling; no national strategy or reimbursement mechanism.
Standardisation initiatives	Certification of oncology centres for breast (2003) and colorectal (2006) cancer; quality audits and indicators.	Regional quality systems integrated within national plan; AIOM guidelines issued.	NABON accreditation and multidisciplinary guideline system in early 2000s.	National standards in cancer guidelines (2007 breast cancer).	Partial standardisation via screening protocols.	Limited; hospital-based standards only.
National cancer control plans / strategies	National Cancer Plan under development (2008); earlier quality initiatives.	National Health Plan 2006–2008 integrating oncology organisation.	National Cancer Control Programme (2005).	First national cancer strategy (2006).	National Cancer Programme 2003–2010 focused on screening.	National Cancer Control Programme 2001–2006 focused on screening.
Care-pathway documents	Clinical pathways embedded within certification model.	National Health Plan 2006–2008 promoted regionally implemented diagnostic-therapeutic pathways.	2002 breast cancer guideline defined diagnostic–treatment steps and time targets.	2007 pathway guidance with defined treatment timelines.	Screening pathways only; no treatment pathways.	Screening intervals only; no diagnostic-treatment sequences.

Table 2. SWOT analysis results of national policies and rare cancer care in Europe (2000–2007 or nearest period)

STRENGTHS	WEAKNESSES
• Early policy leadership in certain countries (e.g., Italy's national networks initiative, Germany's certification system, Netherlands' early care pathway definition).	• Absence of rare-cancer–specific frameworks in most countries except Italy.
• Development of multidisciplinary oncology centres improving coordination of care.	• Fragmented policy landscape; heterogeneity between regions and across countries.
• Integration of quality indicators and process audits into national standards (Germany, Norway).	• Weak linkage between national plans and actual clinical implementation, especially in low-survival countries.
• Early inclusion of hereditary cancer considerations in a few national guidelines (Netherlands 2002, Germany 2008).	• Lack of hereditary cancer policies, counselling networks, and reimbursement structures in most countries during the study period.
• Policy learning through EU collaboration and data harmonisation (EUROCARE, RARECAREnet).	• Limited use of population-based outcomes and indicators for quality monitoring.
OPPORTUNITIES	**THREATS**
• Building pan-European frameworks linking national cancer plans with rare-cancer including hereditary cancer policies.	• Persistent survival inequality due to uneven policy uptake and implementation capacity.
• Adoption of integrated care pathways with defined time-to-treatment targets and cross-border collaboration.	• Workforce shortages and regional disparities in oncology expertise.
• Using registry-based outcome data to guide national quality standards and audits.	• Economic and political variation limiting sustainability of national initiatives.
• Integration of genetic counselling, molecular diagnostics, and multidisciplinary networks into national strategies.	• Risk of widening policy gaps between Western and Eastern Europe if harmonisation remains slow.

CONCLUSIONS

- Rare-cancer survival gaps appear linked to the timing, scope, and specificity of national policy implementation.
- Early adoption of certified multidisciplinary centres, integrated care pathways with defined time targets, and rare-cancer frameworks was associated with higher survival.
- Across six European countries, strengths were concentrated in Western Europe, where Germany and the Netherlands demonstrated early leadership through certified oncology centres, structured care pathways, and the integration of hereditary cancer considerations.

- Importantly, Italy's rare-disease framework represented a unique structural advantage with establishing national networks but suffered from regional heterogeneity.
- Norway showed growing policy coherence but slower operational uptake.
- In contrast, Lithuania and Bulgaria displayed major weaknesses due to the absence of rare-cancer and hereditary cancer policies, limited care standardisation, and insufficient workforce capacity.

- ✓ Overall, unequal policy maturity, implementation gaps, and economic constraints continued to threaten convergence toward equitable cancer outcomes across Europe.
- ✓ Embedding these elements in national strategies, with measurable indicators and routine audit, could help reduce inequalities and improve outcomes.

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ABBREVIATIONS:

AIOM: *Associazione Italiana di Oncologia Medica* (Italian Association of Medical Oncology)
DM 279/2001: *Decreto Ministeriale 18 March 2001, n. 279* (Italian Ministerial Decree)
NABON: *Nationaal Borstkanker Overleg Nederland* (National Breast Cancer Consultation Group of the Netherlands)

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Inspired by:

RARECARENet
Information Network on Rare Cancers