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# Jazan Cancer Registry Implementation Framework

## A Comprehensive Guide for Establishing a Population-Based Cancer Registry in Jazan Region, Saudi Arabia

### Executive Summary

This framework provides actionable guidelines for implementing a population-based cancer registry (PBCR) in Jazan region, Saudi Arabia. Based on WHO standards and international best practices, this document addresses the unique healthcare infrastructure, demographic characteristics, and implementation challenges specific to the Jazan region.

**Key Recommendations:** - Implement a phased 3-year deployment strategy - Establish strong partnerships with regional healthcare facilities - Ensure compliance with Saudi data privacy regulations - Develop comprehensive training programs for healthcare staff - Create sustainable funding mechanisms through government and international partnerships

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## 1. Introduction and Rationale

### Background

Cancer registries serve as essential components of national cancer control programs, providing critical data for surveillance, research, and policy development [1]. The Jazan region, located in southwestern Saudi Arabia, represents a unique epidemiological context that requires targeted cancer surveillance strategies.

### Current Epidemiological Context

The Jazan region demonstrates distinctive cancer patterns compared to other Saudi regions: - **Cervical Cancer**: Lowest age-standardized incidence rate (ASIR) at 0.7 per 100,000 women [9] - **Gastric Cancer**: ASIR of 1.5 per 100,000 men and 0.5 per 100,000 women [18] - **Liver Cancer**: ASIR of 1.7 per 100,000 males [20] - **Oral Malignancies**: Significant prevalence requiring specialized attention [11]

### Registry Objectives

1. **Primary Objectives:**
   * Establish comprehensive cancer incidence and mortality surveillance
   * Support evidence-based cancer control planning
   * Enable regional and national cancer research initiatives
   * Monitor cancer trends and evaluate prevention programs
2. **Secondary Objectives:**
   * Improve cancer care quality through data-driven insights
   * Support clinical decision-making processes
   * Facilitate international cancer research collaborations
   * Enhance public health policy development

## 2. Regional Context Analysis

### Healthcare Infrastructure Assessment

#### Current Healthcare System

* **Primary Healthcare Centers**: Network of PHCs providing basic cancer screening
* **Secondary Care Facilities**: Regional hospitals with oncology departments
* **Tertiary Care**: King Fahad Central Hospital as the main referral center
* **Specialized Services**: Limited oncology subspecialty services

#### Infrastructure Strengths

* Established healthcare delivery network
* Integration with national Saudi Cancer Registry (SCR)
* Government commitment to healthcare improvement
* Digital health initiatives underway

#### Infrastructure Challenges

* Limited oncology specialists in rural areas
* Inconsistent data collection practices across facilities
* Variable IT infrastructure capabilities
* Geographic barriers affecting access to care

### Demographic Characteristics

#### Population Profile

* **Total Population**: Approximately 1.5 million residents
* **Age Structure**: Young population with median age <30 years
* **Geographic Distribution**: Mix of urban centers and rural communities
* **Socioeconomic Factors**: Diverse economic conditions affecting healthcare access

#### Cultural Considerations

* **Language**: Arabic primary language with some ethnic diversity
* **Health-Seeking Behavior**: Traditional medicine practices alongside modern healthcare
* **Privacy Concerns**: Cultural sensitivity around medical information sharing
* **Gender Considerations**: Specific protocols needed for female patient data collection

## 3. Framework Components

### 3.1 Registry Structure

#### Organizational Model

**Hybrid Model**: Combination of population-based and hospital-based registry components

Jazan Cancer Registry  
├── Central Registry Unit  
│ ├── Data Management Center  
│ ├── Quality Assurance Unit  
│ └── Research and Analysis Division  
├── Hospital-Based Collection Points  
│ ├── King Fahad Central Hospital  
│ ├── Regional Hospitals (4 facilities)  
│ └── Private Healthcare Facilities  
└── Community Surveillance Network  
 ├── Primary Healthcare Centers  
 ├── Pathology Laboratories  
 └── Death Certification System

#### Governance Structure

* **Registry Director**: Senior epidemiologist with cancer registry expertise
* **Medical Advisory Board**: Regional oncologists and public health experts
* **Technical Committee**: IT specialists and data managers
* **Community Advisory Panel**: Community representatives and patient advocates

### 3.2 Data Collection Framework

#### Core Data Elements (WHO Standards)

1. **Patient Demographics**
   * Unique identifier (anonymized)
   * Age, gender, nationality
   * Residence (coded to protect privacy)
   * Occupation and education level
2. **Tumor Characteristics**
   * Primary site (ICD-O-3 classification)
   * Histological type and grade
   * Stage at diagnosis (TNM classification)
   * Date of diagnosis
3. **Treatment Information**
   * Treatment modalities received
   * Treatment facility
   * Response to treatment
   * Follow-up status
4. **Outcome Data**
   * Vital status
   * Date of last contact
   * Cause of death (if applicable)
   * Survival time calculations

#### Data Sources Integration

* **Active Case Finding**: Systematic review of medical records
* **Passive Reporting**: Mandatory reporting from healthcare facilities
* **Death Certificate Review**: Collaboration with vital statistics
* **Pathology Reports**: Direct linkage with regional laboratories

### 3.3 Quality Assurance Framework

#### Data Quality Indicators

Following international standards [7], the registry will monitor:

1. **Completeness Indicators**
   * Incidence completeness ratio
   * Mortality-to-incidence ratio comparison
   * Age-specific completeness assessment
2. **Validity Indicators**
   * Histological verification percentage (target: >80%)
   * Death certificate only cases (target: <15%)
   * Duplicate case identification and resolution
3. **Comparability Indicators**
   * ICD-O-3 coding consistency
   * Stage distribution patterns
   * Age-standardized rates comparison
4. **Timeliness Indicators**
   * Data availability within 18 months of diagnosis year
   * Real-time data entry performance metrics

#### Quality Control Procedures

* **Double Data Entry**: For critical fields in first year
* **Automated Validation Rules**: Built into data collection system
* **Regular Audits**: Monthly quality reviews by trained staff
* **External Validation**: Annual review by national registry experts

## 4. Implementation Roadmap

### Phase 1: Foundation (Months 1-12)

#### Preparatory Activities

**Months 1-3: Planning and Setup** - Secure funding and administrative approvals - Recruit core registry staff - Establish legal framework and data use agreements - Conduct stakeholder engagement meetings

**Months 4-6: Infrastructure Development** - Procure and install IT systems - Develop data collection protocols - Create training materials - Establish quality assurance procedures

**Months 7-9: Pilot Implementation** - Launch pilot at King Fahad Central Hospital - Train initial cohort of data collectors - Test data collection and validation processes - Refine protocols based on pilot results

**Months 10-12: System Optimization** - Expand to 2 additional regional hospitals - Implement automated validation rules - Establish routine quality monitoring - Begin baseline data collection

### Phase 2: Expansion (Months 13-24)

#### Scale-Up Activities

**Months 13-15: Network Expansion** - Include all regional hospitals in data collection - Establish pathology laboratory linkages - Implement death certificate review process - Launch community awareness campaigns

**Months 16-18: System Integration** - Connect with national Saudi Cancer Registry - Implement data sharing protocols - Establish research collaboration frameworks - Begin survival analysis preparations

**Months 19-21: Quality Enhancement** - Conduct first comprehensive data quality audit - Implement corrective measures for identified gaps - Enhance staff training programs - Optimize data collection workflows

**Months 22-24: Research Initiation** - Publish first registry report - Begin collaborative research projects - Establish international partnerships - Plan for sustainability phase

### Phase 3: Maturation (Months 25-36)

#### Sustainability Activities

**Months 25-27: Full Operation** - Achieve full geographic coverage - Implement real-time monitoring systems - Launch public data portal - Establish routine reporting schedule

**Months 28-30: Impact Assessment** - Conduct comprehensive evaluation - Measure impact on cancer care quality - Assess research output and utilization - Plan for long-term sustainability

**Months 31-36: Future Planning** - Develop 5-year strategic plan - Secure ongoing funding commitments - Plan for technology upgrades - Establish succession planning

## 5. Quality Assurance Framework

### 5.1 Data Quality Standards

#### International Compliance

The registry will adhere to: - **WHO Guidelines**: Global Initiative for Cancer Registry Development standards - **IARC Standards**: International Agency for Research on Cancer protocols - **IACR Guidelines**: International Association of Cancer Registries best practices - **Saudi National Standards**: Compliance with SCR requirements

#### Quality Metrics Dashboard

Real-time monitoring of:

Data Quality Scorecard  
├── Completeness Score (Target: >95%)  
├── Accuracy Score (Target: >90%)  
├── Timeliness Score (Target: >85%)  
└── Consistency Score (Target: >95%)

### 5.2 Validation Procedures

#### Multi-Level Validation

1. **Real-Time Validation**: Automated checks during data entry
2. **Batch Validation**: Weekly comprehensive data reviews
3. **External Validation**: Quarterly expert reviews
4. **International Benchmarking**: Annual comparison with similar registries

#### Error Detection and Correction

* **Automated Algorithms**: Detection of impossible or unlikely values
* **Manual Review Process**: Systematic review of flagged cases
* **Source Verification**: Return to original records when necessary
* **Correction Protocols**: Standardized procedures for data amendments

## 6. Resource Requirements

### 6.1 Human Resources

#### Core Staff Requirements

**Year 1 Staffing (8 FTE)** - Registry Director (1.0 FTE) - MD/PhD in Epidemiology - Data Manager (1.0 FTE) - Masters in Health Informatics - Data Collectors (3.0 FTE) - Health Information Technicians - Quality Assurance Specialist (1.0 FTE) - Epidemiology background - IT Support Specialist (1.0 FTE) - Database administration - Administrative Coordinator (1.0 FTE) - Registry operations

**Year 2-3 Expansion (12 FTE)** - Additional Data Collectors (3.0 FTE) - Research Analyst (1.0 FTE) - Biostatistics/Epidemiology

#### Training Requirements

* **Initial Training**: 40-hour comprehensive program for all staff
* **Ongoing Training**: 8 hours quarterly updates
* **Specialized Training**: Annual workshops on emerging topics
* **External Training**: Participation in international registry courses

### 6.2 Technology Infrastructure

#### Hardware Requirements

IT Infrastructure Specifications  
├── Servers  
│ ├── Database Server (High-performance with redundancy)  
│ ├── Application Server (Load-balanced configuration)  
│ └── Backup Server (Automated daily backups)  
├── Workstations  
│ ├── Data Entry Stations (20 units)  
│ ├── Analysis Workstations (5 units)  
│ └── Administrative Computers (8 units)  
└── Network Infrastructure  
 ├── Secure VPN connections  
 ├── Firewall protection  
 └── Encrypted data transmission

#### Software Requirements

* **Registry Software**: CanReg5 or equivalent WHO-approved system
* **Database Management**: PostgreSQL with encryption
* **Statistical Analysis**: R, STATA, or SAS licenses
* **Security Software**: Anti-virus, intrusion detection
* **Office Software**: Microsoft Office or equivalent

### 6.3 Financial Requirements

#### Three-Year Budget Projection (USD)

**Year 1: $485,000** - Personnel (60%): $291,000 - Technology (25%): $121,250 - Training (10%): $48,500 - Operations (5%): $24,250

**Year 2: $425,000** - Personnel (70%): $297,500 - Technology (15%): $63,750 - Training (8%): $34,000 - Operations (7%): $29,750

**Year 3: $445,000** - Personnel (72%): $320,400 - Technology (12%): $53,400 - Training (6%): $26,700 - Operations (10%): $44,500

**Total 3-Year Investment: $1,355,000**

#### Funding Sources

1. **Government Funding (70%)**
   * Ministry of Health allocation
   * Regional government support
   * Saudi Cancer Registry integration funds
2. **International Partnerships (20%)**
   * WHO technical assistance
   * IARC collaboration funding
   * Bilateral health agreements
3. **Research Grants (10%)**
   * King Abdulaziz City for Science and Technology
   * International cancer research organizations
   * Academic institution partnerships

## 7. Stakeholder Engagement Strategy

### 7.1 Key Stakeholders

#### Primary Stakeholders

* **Healthcare Providers**: Physicians, nurses, health information staff
* **Healthcare Facilities**: Hospitals, clinics, laboratories
* **Government Agencies**: Ministry of Health, regional health authorities
* **Patients and Families**: Cancer patients and their support networks

#### Secondary Stakeholders

* **Research Community**: Universities, research institutions
* **International Organizations**: WHO, IARC, cancer control organizations
* **Civil Society**: Cancer advocacy groups, community organizations
* **Private Sector**: Healthcare technology companies, pharmaceutical industry

### 7.2 Engagement Activities

#### Awareness and Education Campaign

**Healthcare Provider Engagement** - Monthly medical staff meetings at participating facilities - Quarterly workshops on cancer registry importance - Annual regional oncology conference with registry sessions - Continuing medical education credits for participation

**Community Engagement** - Public awareness campaigns about cancer prevention - Community leader briefings on registry benefits - Patient advocacy group partnerships - Media engagement through local channels

**Government Relations** - Regular briefings to health ministry officials - Participation in national health planning committees - Collaboration with regional development initiatives - Integration with Vision 2030 health objectives

#### Communication Strategy

* **Multilingual Materials**: Arabic primary, English secondary
* **Cultural Sensitivity**: Respect for local customs and values
* **Transparency**: Open communication about data use and protection
* **Feedback Mechanisms**: Regular surveys and consultation sessions

## 8. Technology Infrastructure

### 8.1 System Architecture

#### Core Technology Stack

Technology Architecture  
├── Data Collection Layer  
│ ├── Web-based data entry forms  
│ ├── Mobile data collection apps  
│ └── Electronic health record integration  
├── Data Processing Layer  
│ ├── Data validation engines  
│ ├── Automated coding systems  
│ └── Quality control algorithms  
├── Data Storage Layer  
│ ├── Encrypted database systems  
│ ├── Backup and recovery systems  
│ └── Data archiving solutions  
└── Analysis and Reporting Layer  
 ├── Statistical analysis tools  
 ├── Visualization dashboards  
 └── Report generation systems

#### Security Framework

* **Data Encryption**: AES-256 encryption for data at rest and in transit
* **Access Control**: Role-based permissions with multi-factor authentication
* **Audit Trails**: Comprehensive logging of all system activities
* **Network Security**: Firewall protection and intrusion detection systems

### 8.2 Integration Requirements

#### Healthcare System Integration

* **Electronic Health Records**: HL7 FHIR standard compliance
* **Laboratory Information Systems**: Automated pathology report import
* **Hospital Information Systems**: Patient demographic synchronization
* **National Systems**: Integration with Saudi Cancer Registry

#### Data Exchange Standards

* **International Standards**: ICD-O-3, TNM classification, HL7 messaging
* **National Standards**: Compliance with Saudi health data standards
* **Interoperability**: RESTful APIs for data sharing
* **Format Standards**: XML, JSON for data exchange

## 9. Training and Capacity Building

### 9.1 Training Program Structure

#### Comprehensive Training Curriculum

**Module 1: Cancer Registry Fundamentals (8 hours)** - Introduction to cancer surveillance - Registry types and purposes - International standards and guidelines - Ethical considerations and patient privacy

**Module 2: Data Collection Procedures (12 hours)** - Case identification methods - Data abstraction techniques - Coding systems (ICD-O-3, TNM) - Quality control procedures

**Module 3: Technology Systems (8 hours)** - Registry software operation - Data entry procedures - Validation and error correction - System security protocols

**Module 4: Quality Assurance (8 hours)** - Data quality indicators - Validation procedures - Error detection and correction - Continuous improvement processes

**Module 5: Analysis and Reporting (4 hours)** - Basic epidemiological analysis - Report generation - Data interpretation - Dissemination strategies

#### Training Delivery Methods

* **In-Person Workshops**: Hands-on training with expert instructors
* **Online Modules**: Self-paced learning with interactive content
* **Mentorship Program**: Pairing new staff with experienced registrars
* **International Exchange**: Visits to established registries for learning

### 9.2 Capacity Building Strategy

#### Staff Development Plan

**Career Progression Pathways** - Entry Level: Health Information Technician - Mid-Level: Cancer Registrar Specialist - Senior Level: Registry Supervisor/Quality Manager - Expert Level: Registry Director/Epidemiologist

**Continuing Education Requirements** - Annual training: 20 hours minimum - Professional certification maintenance - Conference participation support - Research publication encouragement

#### Knowledge Management

* **Best Practices Documentation**: Standardized procedures manual
* **Lesson Learned Database**: Systematic capture of experiences
* **Expert Network**: Connections with international registry experts
* **Resource Library**: Comprehensive reference materials

## 10. Monitoring and Evaluation

### 10.1 Performance Indicators

#### Operational Indicators

**Data Collection Performance** - Number of cases registered monthly - Time from diagnosis to registration - Completeness of data fields - Error rates and correction frequency

**System Performance** - System uptime and reliability - Data processing speed - User satisfaction scores - Training completion rates

**Quality Indicators** - Histological verification percentage - Death certificate only cases percentage - Duplicate case identification rate - Data validation error rates

#### Impact Indicators

**Healthcare System Impact** - Cancer care quality improvements - Evidence-based policy changes - Research output and citations - International collaboration projects

**Public Health Impact** - Cancer prevention program effectiveness - Early detection rate improvements - Survival rate trend analysis - Health disparity identification

### 10.2 Evaluation Framework

#### Regular Monitoring Schedule

* **Daily**: System performance monitoring
* **Weekly**: Data quality reviews
* **Monthly**: Operational performance reports
* **Quarterly**: Stakeholder feedback collection
* **Annually**: Comprehensive evaluation and planning

#### External Evaluation

* **Year 2**: Mid-term external evaluation
* **Year 3**: Final implementation assessment
* **Year 5**: Long-term impact evaluation
* **Ongoing**: International peer review participation

## 11. Sustainability Plan

### 11.1 Financial Sustainability

#### Funding Diversification Strategy

**Government Funding (Primary)** - Integration into Ministry of Health budget - Regional health authority support - Long-term funding commitments

**Research Partnerships (Secondary)** - University collaboration agreements - International research grants - Pharmaceutical industry partnerships

**Service Revenue (Supplementary)** - Data analysis services for researchers - Training program fees - Consultation services to other regions

#### Cost Optimization Measures

* **Technology Efficiency**: Cloud-based solutions to reduce IT costs
* **Process Automation**: Reduce manual data collection efforts
* **Resource Sharing**: Collaborate with national registry for shared services
* **Volunteer Programs**: Engage retired healthcare professionals

### 11.2 Institutional Sustainability

#### Organizational Integration

* **Legal Framework**: Establish registry as permanent institution
* **Policy Integration**: Include in regional health strategic plans
* **Succession Planning**: Develop next generation of registry leaders
* **Knowledge Transfer**: Document all processes and procedures

#### Partnership Maintenance

* **Healthcare Facilities**: Long-term data sharing agreements
* **Academic Institutions**: Ongoing research collaborations
* **International Networks**: Continued participation in global initiatives
* **Community Groups**: Sustained engagement and support

## 12. Risk Management

### 12.1 Risk Assessment Matrix

#### High-Priority Risks

**Data Security and Privacy** - **Risk**: Unauthorized access to patient data - **Mitigation**: Multi-layered security systems, staff training, regular audits - **Contingency**: Incident response plan, legal compliance procedures

**Funding Interruption** - **Risk**: Loss of government or donor funding - **Mitigation**: Diversified funding sources, cost-effective operations - **Contingency**: Emergency funding protocols, service reduction plans

**Staff Turnover** - **Risk**: Loss of trained personnel - **Mitigation**: Competitive compensation, career development, succession planning - **Contingency**: Rapid recruitment procedures, knowledge transfer protocols

**Technology Failures** - **Risk**: System downtime or data loss - **Mitigation**: Redundant systems, regular backups, maintenance contracts - **Contingency**: Disaster recovery plans, alternative data collection methods

#### Medium-Priority Risks

**Stakeholder Resistance** - **Risk**: Healthcare provider non-compliance - **Mitigation**: Engagement strategies, training programs, incentive systems - **Contingency**: Alternative data sources, regulatory enforcement

**Data Quality Issues** - **Risk**: Poor data quality affecting registry credibility - **Mitigation**: Comprehensive quality assurance, regular training - **Contingency**: Data cleaning procedures, external validation

### 12.2 Risk Monitoring and Response

#### Early Warning Systems

* **Performance Dashboards**: Real-time monitoring of key indicators
* **Stakeholder Feedback**: Regular surveys and consultation sessions
* **External Monitoring**: Independent oversight and evaluation
* **Trend Analysis**: Predictive analytics for risk identification

#### Response Protocols

* **Escalation Procedures**: Clear chain of command for issue resolution
* **Communication Plans**: Stakeholder notification procedures
* **Recovery Procedures**: Step-by-step response to different risk scenarios
* **Learning Integration**: Post-incident analysis and improvement planning

## Implementation Timeline Summary

### Quick Reference Implementation Schedule

|  |  |  |  |
| --- | --- | --- | --- |
| Phase | Duration | Key Milestones | Success Criteria |
| **Phase 1: Foundation** | Months 1-12 | Staff recruitment, system setup, pilot launch | Successful pilot operation at 1 facility |
| **Phase 2: Expansion** | Months 13-24 | Network expansion, quality enhancement | Full regional hospital coverage |
| **Phase 3: Maturation** | Months 25-36 | Full operation, impact assessment | Complete geographic coverage, first research publications |

### Critical Success Factors

1. **Strong Leadership**: Experienced registry director with regional credibility
2. **Stakeholder Buy-in**: Sustained support from healthcare providers and government
3. **Adequate Resources**: Sufficient funding and staffing throughout implementation
4. **Quality Focus**: Unwavering commitment to data quality and international standards
5. **Cultural Sensitivity**: Respect for local customs and privacy concerns
6. **Technology Reliability**: Robust, secure, and user-friendly information systems
7. **Continuous Learning**: Adaptive approach with regular evaluation and improvement

## Conclusion

The implementation of a population-based cancer registry in Jazan region represents a significant opportunity to enhance cancer surveillance, improve patient care, and support evidence-based public health decision-making. This framework provides a comprehensive roadmap that balances international best practices with local context and constraints.

Success will depend on sustained commitment from all stakeholders, adequate resource allocation, and unwavering focus on data quality and patient privacy. The phased implementation approach allows for learning and adaptation while building toward a mature, sustainable registry system that can serve as a model for other regions in Saudi Arabia and the broader Middle East.

The expected outcomes include: - Comprehensive cancer surveillance for Jazan region - Improved cancer care quality through data-driven insights - Enhanced research capacity and international collaboration - Evidence-based cancer control policy development - Sustainable institutional capacity for long-term operation

This framework serves as both a planning document and an operational guide, providing the foundation for establishing a world-class cancer registry that meets the unique needs of the Jazan region while contributing to global cancer control efforts.

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