HTA Austria
Austrian Institute for
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GmbH

Oncological Breast Cancer Care in Selected European Countries

Cross-sectoral cancer care models

Final report

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A&D	Accreditation and Designation
ADT	Arbeitsgemeinschaft Deutscher Tumorzentren e.V/ Association of German Tumour Centres
AIHTA	Austrian Institute for Health Technology Assessment
AIs	Aromatase inhibitors
AJCC	American Joint Committee on Cancer
AML	Acute myeloid leukemia
ASIH	Advanced Health Care in the Home/Avancerad sjukvård i hemmet
ASV	Outpatient specialised care/ambulante spezialfachärztliche Versorgung
AWMF	Association of the Scientific Medical Societies in Germany/ Arbeitsgemeinschaft der Wissenschaftlichen Medizinischen Fachgesellschaften
BCR	Belgian Cancer Registry
BCS	Breast-conserving surgery
BCT	Breast-conserving therapy
BKRG	Federal Cancer Registry Data Act/Bundeskrebsregisterdatengesetz
BMASGK	Federal Ministry of Social Affairs, Health, Care and Consumer Protection/ Bundesministerium für Arbeit, Soziales, Gesundheit und Konsumentenschutz
BMI	Body mass index
BNHO	Professional Association of Outpatient Haematologists and Oncologists/ Berufsverband der niedergelassenen Onkologen und Hämatologen
BSN	Citizen Service Number
B-ZK	Federal Target-Based Governance Agreement/Bundes-Zielsteuerungsvertrag
C	Organ cancer centre
CC	Cancer Centre
CCC	Comprehensive Cancer Centre
CCN	Comprehensive Cancer Network
CCP	Cancer Care Pathway/Cancer Patient Pathway
CDA	Clinical Document Architecture
C-HPD	Centralised Healthcare Provider Index
C-MPI	Centralised Master Patient Index
COP	in cooperation
CPR	Central Person Register
CT	Computed tomography
DBCG	Danish Breast Cancer Cooperative Group
DBCG	Danish Breast Cancer Group
DCIS	Ductal carcinoma in situ
DCR	Danish Cancer Registry
DEGRO	German Society for Radiation oncology/Deutsche Gesellschaft für Radioonkologie
DEXA	Dual-Energy X-ray Absorptiometry
DFS	Disease-free survival
DGGG	German Society for Gynaecology and Obstetrics/ Deutsche Gesellschaft für Gynäkologie und Geburtshilfe
DGHO	German Society for Haematology and Medical Oncology

DGP	German Society for Palliative Medicine/Deutsche Gesellschaft für Palliativmedizin
DGS	German Society for Pain Medicine/Deutsche Gesellschaft für Scherzmedizin
DHA	Digital health application
DHT	Digital health technology
DKG	German Cancer Society/Deutsche Krebsgesellschaft,
DKH	German Cancer Aid/Deutsche Krebshilfe
DMP	Disease Management Programme
EBM	Physician’s fee scale of the SHI
ECCO	European CanCer Organisation
ECIBC	European Commission Initiative on Breast Cancer
EHR	Electronic health record
ELGA	Elektronische Gesundheitsakte/Austrian EHR
ENCR-JRC	European Network of Cancer Registries – Joint Research Centre
EPA	Electronic patient file/elektronische Patientenakte
ER	Oestrogen receptor
ERQCC	Essential Requirements for Quality Cancer Care
ESMO	European Society for Medical Oncology
EU	European Union
EUREF	European Guidelines on Breast Cancer Screening
EUSOMA	European Society of Breast Cancer Specialists
FTE	Full-time equivalent
G-BA	The Federal Joint Committee/Gemeinsamer Bundesausschuss
GDL	Health care provider/Gesundheitsdienstleister
GDP	Gross domestic product
GDPR	General Data Protection Regulation
GEKID	Society of Epidemiological Cancer Registries in Germany/Gesellschaft der epidemiologischen Krebsregister in Deutschland
GEP	Gene expression profiling
GKV-Spitzenverband	National Association of Statutory Health Insurance Fund/ Spitzenverband der Gesetzlichen Krankenversicherung
GP	General practitioner
HER2	Human epidermal growth factor receptor 2
HIE	Health Information Exchange
HIS	Health information system
HIS	Hospital information system
HR	Hormone receptor
HRQoL	Health-related QoL
IAEA	International Atomic Energy Agency
IARC	International Agency for Research on Cancer
IBC	Invasive breast cancer
ICHOM	International Consortium for Health Outcomes Measurement
ID	Patient identifier
IKNL	Integraal Kankercentrum Nederland
JA	Joint Action

KBV	Federal Association of Statutory Health Insurance Physicians/ Kassenärztliche Bundesvereinigung
KCE	Belgian Health Care Knowledge Centre
KFRG	Cancer Screening and Registry Act/Krebsfrüherkennungs- und -registergesetz
KHVVG	Hospital Care Improvement Act/Krankenhausversorgungsverbesserungsgesetz
KOK	Oncological Nursing and Paediatric Nursing Conference/ Konferenz Onkologischer Kranken- und Kinderkrankenpflege
KV	Association of Statutory Health Insurance Physicians/Kassenärztliche Vereinigung
LFS	Li-Fraumeni syndrome
LGF	State health funds/Landesgesundheitsfonds
LKF	Austrian DRG System/Leistungsorientierte Krankenanstaltenfinanzierung
LL	Leitlinie
M	Metastasis
MDS	Minimum data set/Minimaldatensatz
MDT	Multidisciplinary team
MRI	Magnetic resonance imaging
mRNA	Messenger RNA
MTR	Medical technologists for radiology
MVP	My Care Plan in Cancer Care/Min vårdplan
N	Lymph nodes
NABON	National Breast Cancer Counselling Service/ Nationaal Borstkanker Overleg Nederland)
NCP	National Cancer Plan
NCR	Netherlands Cancer Registry
NCS	National Cancer Strategy
NIZP PZH-PIB	National Institute of Public Health – National Institute of Hygiene Poland
NKBC	National Quality Registry for Breast Cancer
NKR	National Cancer Registry/Nationaal Kankerregister
NRC	National Cancer Registry
NRS	National Registry for Pain Rehabilitation
NSSC	Non-specific severe symptoms and signs of cancer
OAS	Overall survival
OECD	Organisation for Economic Co-operation and Development
OECI	Organisation of European Cancer Institutes
ONKA	Associated oncology centres/Assoziierte onkologische Versorgung
ONKS	Specialist centres/Onkologischer Schwerpunkt
ONKZ	Oncology reference centres/Onkologisches Zentrum
ÖSG	Austrian Structural Plan for Healthcare/Österreichischer Strukturplan Gesundheit
ÖZK	Austrian Certification Commission/Österreichische Zertifizierungskommission
PAM50	Microarray 50
PET	Positron emission tomography
PFS	Progression-free survival
PHI	Private health insurance
PICC	Peripherally inserted central catheter

PICo	Problem, Interest, Context
PKV-Verband	Association of Private Health Insurers
PR	Progesterone receptor
PROFILES	Patient-Reported Outcomes Following Initial Treatment and Long-term Evaluation of Survivorship
PROM	Patient-reported outcome measures
PROMs	Patient-reported outcomes
QoL	Quality of life
QR	Quality registry
QS	Qualitätssicherung
RCC	Regional Cancer Centres
RIVM	National Institute for Public Health and the Environment
RIVM-CPS	RIVM's Centre for Population Screening
RIZIV-INAMI	National Institute for Health and Disability Insurance
RKKP	Danish Regions Clinical Quality Program
RQ	Research question
RRP	Recovery and Resilience Plan
SALAR	Swedish Association of Local Authorities and Regions
SDM	Shared decision-making
SGB V	Fifth Book of the German Social Code/Sozialgesetzbuch V
SHI	Social Health Insurance
SHI	Social health insurance
SPECT	Single Photon Emission Computed Tomography
SLNB	Sentinel lymph node biopsy
SLNE	Sentinel lymph node adenectomy
SONCOS	Dutch Foundation for Oncological Collaboration
SRPC	Swedish Registry of Palliative Care
T	Tumour
TNM	Tumour node metastasis
VIKZ	Vlaams Instituut voor Kwaliteit van Zorg
WHO	World Health Organisation
WINHO	Scientific Institute of the BHNO/ Wissenschaftliches Institut der Niedergelassenen Hämatologen und Onkologen
ZfKD	Centre for Cancer Registry Data/Zentrum für Krebsregisterdaten

Executive Summary

Introduction

cross-sectoral care models essential to improve resource efficiency & establish consistent care pathways

The incidence and prevalence of cancer, especially breast cancer, have risen significantly in Austria and other European countries, placing substantial strain on Austria's healthcare system. Given the hospital-centred nature of cancer care in Austria, this trend will lead to increased costs and pressure on hospital resources. Exploring alternative, cross-sectoral care models is essential for reducing inpatient burden and improving resource efficiency.

overview of breast cancer care models in 6 European countries

This report provides insights into cancer care models from six European countries: Austria, Germany, Denmark, Sweden, the Netherlands, and Belgium. It compares healthcare infrastructures, service provision, and professions across the breast cancer patient journey, with the goal of identifying promising practices and challenges to enhance Austria's cancer care.

Methods

literature search & expert consultations

mapping of "patient journeys", infrastructures & care coordination

The study included a literature search, expert consultations, and data synthesis. It mapped the breast cancer patient journey and analysed healthcare infrastructures, services, and coordination across countries, distinguishing between inpatient, hospital outpatient clinics, outpatient, external, and home treatment settings. Consultations with 17 experts across six countries provided in-depth insights. Data on cancer epidemiology and healthcare expenditures were collected from national and international sources.

Results

3 stylised models of breast cancer care across countries

The analysis revealed diverse approaches to breast cancer care. Some countries use centralised specialist models, while others adopt decentralised or network-based care. In all countries, patients are identified via screening programs, GP referrals, or incidental findings. Different healthcare infrastructures are available and utilised in the examined countries. The results indicated that there are three primary approaches available in the six examined countries:

centralised specialist model: care in a limited number of certified centres

- *Centralised Specialist Model:* Breast cancer care is provided in a limited number of certified centres with strict volume and quality standards, ensuring that complex cases are handled by experienced specialists (e.g., Austria, Denmark, Belgium).

decentralised model: integration of outpatient care

- *Decentralised Model:* Care is distributed across a larger number of certified hospitals including specialist oncological outpatient care where national standards maintain quality, allowing many patients to access services closer to home (e.g., Germany).

network-based model: specialist centres collaborate with regional hospitals & home-care teams

- *Network-based Model:* Centralised specialist centres collaborate with regional hospitals and home-care teams, enabling high-complexity treatments at specialist centres while coordinating follow-ups and less complex cases across multiple local facilities (e.g., The Netherlands, Sweden).

These models vary in centralisation and specialisation but share the common goal of ensuring high-quality care through regulation, certification, and collaboration. Each country adopts a model aligned with its cancer strategy and healthcare infrastructure, often blending elements of different care models to suit specific needs and resources, as these models are not mutually exclusive.

model elements are non-mutually exclusive → countries blend elements of each care model

Discussion and Conclusion

The findings highlight the complexity of balancing centralisation and decentralisation in cancer care. Countries are adopting innovative approaches, such as home-based treatments and nurse-led care, to meet rising demand. However, workforce shortages and fragmented data systems present significant challenges.

innovative approaches such as home-treatment & nurse-led care to meet rising demand & optimise resource use

Optimising Austria's cancer care will require a balance between centralised, decentralised, and network-based models while addressing workforce shortages and enhancing data integration. Continuous adaptation, investment in skilled professionals, and cross-sectoral coordination are essential for delivering high-quality, accessible, and efficient breast cancer care in Austria.

balance between centralisation & decentralisation, adequate workforce endowment & qualification & data integration essential

Zusammenfassung

Einleitung

In den letzten Jahren sind Inzidenz und Prävalenz von Krebserkrankungen, insbesondere von Brustkrebs, sowohl in Österreich als auch in anderen europäischen Ländern deutlich gestiegen. Dieser Trend stellt das österreichische Gesundheitssystem vor erhebliche Herausforderungen, insbesondere in Verbindung mit der derzeit bestehenden krankenhauszentrierten Krebsversorgung. Zu den Konsequenzen zählen steigende Kosten und eine ineffiziente Nutzung von Kapazitäten.

steigender Trend bei Inzidenz & Prävalenz von Krebserkrankungen

Die Erforschung und Implementierung alternativer, sektorübergreifender Modelle der Krebsversorgung ist daher von entscheidender Bedeutung, um die Belastung der stationären Versorgung zu verringern und eine effiziente Nutzung der verfügbaren Ressourcen sicherzustellen.

sektorübergreifende Versorgungsmodelle für mehr Effizienz & konsistente Versorgungspfade

Dieser Bericht bietet einen umfassenden Überblick über Krebsversorgungsmodelle und sektorübergreifende Ansätze in sechs europäischen Ländern: Österreich (AT), Deutschland (DE), Dänemark (DK), Schweden (SE), den Niederlanden (NL) und Belgien (BE). Es werden die jeweilige Gesundheitsinfrastruktur, die medizinische Leistungserbringung sowie die beteiligten Berufsgruppen entlang der „Patient Journey“ in diesen Ländern analysiert. Der Fokus liegt dabei auf der Brustkrebsversorgung, um einen Einblick in alternative Modelle und sektorübergreifende Ansätze zur Krebsversorgung im europäischen Vergleich zu geben.

Überblick der Brustkrebsversorgungsmodellen in 6 europäischen Ländern

Methoden

Der vorliegende Bericht folgte einem schrittweisen Ansatz, bestehend aus einer strukturierten Literaturrecherche, Expert*innenkonsultationen und einer Datenanalyse. Die „Patient Journey“ von Brustkrebspatientinnen wurde abgebildet, und die Gesundheitsinfrastrukturen, medizinischen Leistungen sowie die Versorgungskoordination in den jeweiligen Ländern wurden untersucht. Folgende Gesundheitsinfrastrukturen wurden unterschieden: stationäre Versorgung/Krankenhaus (mind. eine Krankenhausübernachtung), Krankenhausambulanz (ohne Übernachtung), extramurale/niedergelassene Versorgung, externes Labor/Radiologie/Strahlentherapiezentrum, Behandlung zu Hause (Home Treatment). Eine vergleichende Analyse identifizierte Unterschiede in den Versorgungsmodellen.

strukturierte Literatursuche & Expert*innen-konsultationen

Überblick von „Patient Journeys“, Infrastrukturen & Koordinierung der Versorgung

Die Literaturrecherche fokussierte sich auf relevante Publikationen, politische Dokumente und Expert*inneninformationen. Insgesamt wurden 86 Expert*innen aus acht Ländern kontaktiert, von denen sich 17 (aus sechs Ländern) zu virtuellen oder schriftlichen Konsultationen bereit erklärten, um länderspezifische Einblicke zu gewähren. Daten zur Krebsepidemiologie, zu Gesundheitsausgaben und zur Leistungserbringung wurden aus nationalen und internationalen Quellen erhoben.

86 Expert*innen kontaktiert & final 17 aus 6 Ländern befragt

Ergebnisse

Die Untersuchung zeigte diverse Ansätze zur Organisation der Brustkrebsversorgung in den sechs untersuchten Ländern. Einige Länder haben zentralisierte Spezialistenmodelle, andere setzen auf dezentralisierte oder netzwerkbasierte integrierte Versorgungsansätze. Es wurden Unterschiede in der Nutzung von stationären, ambulanten, extramuralen und häuslichen Versorgungsangeboten für Diagnostik, Therapie, Patientinnenbegleitung („patient support“) und Nachsorge beobachtet.

unterschiedliche Ansätze aber auch Gemeinsamkeiten in der Organisation der Brustkrebsversorgung

Identifizierung der Patientinnen

In allen untersuchten Ländern werden Patientinnen über organisierte Screening-Programme, Überweisungen durch Hausärzt*innen (Allgemeinmediziner*innen) oder zufällige Befunde während der Diagnostik für andere Erkrankungen identifiziert. Die Screening-Programme sind gut etabliert, wobei Frauen vorwiegend im Alter von 40 bis 75 Jahren zu regelmäßigen Mammografien eingeladen werden.

identifizierte Länder haben ähnliche Identifikationsstrategien

Diagnose

Die Länder unterscheiden sich in der Nutzung von Gesundheitsinfrastrukturen für diagnostische Verfahren. Klinische Untersuchungen, Blutentnahmen und genetische Analysen werden überwiegend in Krankenhausambulanzen durchgeführt, während in einigen Ländern auch externe Labore eingebunden sind. Bildgebende Diagnostik und Stadieneinteilung erfolgen vorwiegend in Krankenhausambulanzen und teilweise in externen radiologischen Zentren. Biopsien werden in der Regel in Krankenhausambulanzen durchgeführt; einige Länder beziehen hierfür ebenfalls externe radiologische Zentren ein.

Einbindung von einzelnen spitalsambulanz-externen Labors & radiologischen Zentren in einigen Ländern

Therapiemanagement und Therapieoptionen

Multidisziplinäre Tumorboards, sogenannte „Multidisciplinary Team Conferences“, die für die Therapieplanung verantwortlich sind, finden überwiegend in Krankenhausambulanzen statt; in Deutschland werden zusätzlich niedergelassene Onkolog*innen einbezogen. Geriatrische Assessments, Knochendichtemessungen und intravenöse Infusionen werden in der Regel in Krankenhausambulanzen oder im stationären Setting durchgeführt.

generell spitalsambulante „Multidisciplinary Team Conferences“ für Therapieplanung verantwortlich

Operationen wie brusterhaltende Eingriffe und Mastektomien erfolgen typischerweise stationär, in einigen Ländern werden sie jedoch auch in Krankenhausambulanzen angeboten. Lediglich Schweden führt diese Operationen ausschließlich ambulant durch. Strahlentherapie wird hauptsächlich in Krankenhausambulanzen erbracht, während medikamentöse Tumortherapien sowohl in Krankenhausambulanzen und niedergelassenen Praxen als auch in einigen Ländern im Rahmen von Home-Treatment verabreicht werden.

Brust-OPs vorwiegend stationär, aber auch spitalsambulant

medikamentöse Therapien spitalsambulant, niedergelassen & auf Home-Treatment-Basis

Patientinnenbegleitung und Nachsorge

Psychoonkologische Betreuung, Fertilitätsberatung und genetische Beratung werden größtenteils in Krankenhausambulanzen angeboten; einige Länder beziehen zusätzlich niedergelassene Praxen ein. Klinische Sozialarbeit und Entlassungsplanung erfolgen über eine Kombination aus Krankenhausambulanzen, stationärer Behandlung und niedergelassenen Praxen.

Beratungsangebote im spitalsambulanten Setting

Sozialarbeit auch niedergelassen

Die Angebote in der Nachsorgephase („Survivorship Care“) und Palliativversorgung variieren stark: Einige Länder bieten eine Mischung aus Home Treatment, Krankenhausambulanzen und stationären Einrichtungen an, während andere sich stärker auf niedergelassene oder stationäre Versorgung konzentrieren. Brustrekonstruktionsoperationen werden überwiegend stationär durchgeführt; in einigen Ländern werden hierfür auch Krankenhausambulanzen genutzt.

Nachsorgephase („Survivorship Care“) & Palliativversorgung variieren stark

Diskussion

Die Ergebnisse verdeutlichen die Komplexität der Ausgewogenheit zwischen Zentralisierung und Dezentralisierung der Krebsversorgung, um eine qualitativ hochwertige, zugängliche und effiziente Versorgung sicherzustellen. Die Länder erproben innovative Ansätze wie Home Treatment und von Pflegekräften (z. B. „Nurse Practitioners“) geleitete Versorgung, um dem steigenden Bedarf an Krebsbehandlungen gerecht zu werden. Fachkräftemangel und Einschränkungen bei der sektorübergreifenden Datenintegration stellen jedoch weiterhin erhebliche Herausforderungen dar.

Ausgewogenheit zwischen Zentralisierung & Dezentralisierung, angemessene Personalbesetzung sowie Qualifizierung & Datenintegration unerlässlich

Identifizierte Versorgungsmodelle

Die untersuchten Länder verfolgen drei Modelle zur Organisation der Brustkrebsversorgung, die unterschiedliche Stärken und Herausforderungen aufweisen. Diese Modelle spiegeln verschiedene Grade an Zentralisierung und Spezialisierung wider, verfolgen jedoch alle das Ziel, eine qualitativ hochwertige Versorgung durch Regulierung, Akkreditierung und kollaborative Netzwerke sicherzustellen. Jedes Land richtet sich nach einem dieser Modelle, basierend auf der nationalen Krebsstrategie und der bestehenden Gesundheitsinfrastruktur. Viele Länder kombinieren jedoch auch Elemente aus verschiedenen Modellen, um ihren spezifischen Gesundheitsbedürfnissen und Ressourcen gerecht zu werden.

3 Modelle der Brustkrebsversorgung in den identifizierten Ländern

- *Zentralisierte Fachärzt*innenmodelle (AT, BE, DK):* Diese Modelle bündeln die Brustkrebsversorgung in einer begrenzten Anzahl hochspezialisierter, meist akkreditierter Zentren, die strengen Mindestmengenanforderungen unterliegen. Ziel ist es, durch Regulierung und Zertifizierung hohe Qualitätsstandards zu gewährleisten. Dieser Ansatz kann jedoch die gleichmäßige Zugänglichkeit beeinträchtigen, insbesondere in unterversorgten Regionen.

zentralisiertes Fachärzt*innenmodell: Versorgung in einer begrenzten Anzahl von zertifizierten Zentren

- *Dezentralisierte Versorgung (DE):* In diesem Modell wird die Versorgung auf eine größere Anzahl von Krankenhäusern verteilt, wobei strenge Zertifizierungssysteme die Qualitätskontrolle sicherstellen, insbesondere bei Operationen und der Versorgungskoordination. Dieser Ansatz kann die Bequemlichkeit und Effizienz erhöhen, erfordert jedoch eine starke Koordination, um die Qualität durchgängig zu gewährleisten.

dezentralisiertes Modell

- *Netzwerkbasierte integrierte Versorgung (NE, SE):* Dieser Ansatz kombiniert zentralisierte Fachärzt*innenzentren mit dezentralen Elementen, indem hochspezialisierte Behandlungen in Zentren angeboten werden und weniger komplexe Fälle in regionalen Krankenhäusern und ambulanten Einrichtungen versorgt werden. Interdisziplinäre Zusammenarbeit und flexible Akkreditierungsstandards ermöglichen dabei verschiedene Versorgungsebenen innerhalb des Netzwerks.

netzwerkbasierte integrierte Versorgung: Fachzentren arbeiten mit regionalen Krankenhäusern und häuslichen Pflegeteams zusammen

Jedes Modell bringt spezifische Vor- und Nachteile mit sich. Zentralisierte Fachärzt*innenmodelle sichern hohe Qualitätsstandards, können jedoch die Zugänglichkeit einschränken. Dezentralisierte Modelle erleichtern den Zugang und fördern Effizienz, erfordern jedoch eine enge Koordination zur Qualitätssicherung (QS). Netzwerkbasierte integrierte Versorgung strebt an, die Vorteile beider Ansätze zu vereinen; für eine erfolgreiche Umsetzung sind jedoch effektive sektorübergreifende Zusammenarbeit und Datenintegration entscheidend.

Modelle haben verschiedene Vor- & Nachteile (bspw. Zugänglichkeit versus Effizienz versus Qualität)

Fachkräftemangel und sektorübergreifende Datenintegration

Der Fachkräftemangel, insbesondere bei spezialisierten Pflegekräften, stellt eine erhebliche Herausforderung für die Ausweitung neuer Versorgungsmodelle wie Home Treatment und von Pflegekräften geleitete Kliniken dar. Die Bewältigung dieser Personalengpässe wird entscheidend sein für Länder, die eine verstärkt ambulante und sektorübergreifende Krebsversorgung anstreben.

Ausweitung der sektorübergreifenden Versorgung auch abhängig vom verfügbaren Personal

Auch fragmentierte elektronische Patient*innenakten-Systeme über stationäre und niedergelassene Sektoren hinweg behindern eine umfassende Datenintegration und den effizienten Informationsaustausch. Der nahtlose Zugang zu Patient*innendaten ist jedoch entscheidend, um die Kontinuität der Versorgung sicherzustellen, die klinische Entscheidungsfindung zu unterstützen und eine Qualitätsüberwachung zu ermöglichen. Die Entwicklung interoperabler elektronischer Patientenakten-Systeme und Datenaustauschprotokolle sollte daher für Gesundheitssysteme, die die sektorübergreifende Koordination verbessern möchten, höchste Priorität haben.

fragmentierte elektronische Patient*innenakten-Systeme beschränken sektorübergreifenden Informationsaustausch

Limitationen

Bei der Interpretation der Ergebnisse dieses Berichts zur Brustkrebsversorgung und sektorübergreifenden Modellen in Europa sind einige Einschränkungen zu beachten:

Limitationen:

Die Fokussierung auf Brustkrebs, insbesondere in Bezug auf Österreich, könnte die Gesamtsituation der Krebsversorgung nicht vollständig widerspiegeln. Österreich weist in der Brustkrebsversorgung hohe Standards auf, die durch Datenerhebung und Zertifizierung der Brustkrebszentren unterstützt werden. Dies könnte Herausforderungen in weniger zertifizierten Krebsbereichen verdecken, was auch in anderen Ländern der Fall sein kann.

Brustkrebsversorgung als Fallbeispiel für gesamte Krebsversorgung nicht repräsentativ

Zudem bestehen Unterschiede in der Verfügbarkeit von Literatur zwischen den Ländern. Die umfangreichen Informationen und das etablierte Zertifizierungssystem in Deutschland könnten zu einer verzerrten Darstellung führen, während in anderen Ländern vergleichbare Informationen begrenzter sind. Sprachbarrieren könnten ebenfalls relevante Dokumente ausgeschlossen haben. Auch die Expert*innenkonsultationen, die zentral für den Bericht waren, könnten limitierend sein, da pro Land nur zwei Expert*innen beteiligt waren.

unterschiedliche Verfügbarkeit von Infos aus identifizierten Ländern & sprachliche Barrieren; repräsentative Auswahl der Expert*innen-Perspektiven war eine Herausforderung

Schlussfolgerung

Übergang zu dezentralisierten oder netzwerkbasierten Modell könnte Druck auf Krankenhausressourcen mindern & gleichzeitig die Patient*innenautonomie stärken & Versorgungsqualität verbessern

Der Bericht betont die Bedeutung, Krankenhausbehandlungspraktiken an die spezifischen Anforderungen des jeweiligen Gesundheitssystems anzupassen. Länder mit zentralisierten Fachärzt*innenmodellen, wie Österreich, könnten von einer schrittweisen Integration niedergelassener Versorgung und Home Treatment Angeboten profitieren. Ein Übergang zu einem stärker dezentralisierten oder netzwerkbasierten Modell könnte den Druck auf Krankenhausressourcen mindern und gleichzeitig die Patient*innenautonomie und Versorgungsqualität stärken. Dies erfordert jedoch eine sorgfältige Planung, um die notwendige Infrastruktur und das qualifizierte Personal für eine sichere und hochwertige Versorgung außerhalb des Krankenhauses bereitzustellen.

adäquate Personalausstattung essenziell

Der Fachkräftemangel, insbesondere bei Pflegekräften, stellt dabei eine erhebliche Herausforderung dar, da der Erfolg integrierter oder netzwerkbasierter Modelle von ausreichend geschultem Personal abhängt, um die Betreuung auch in ländlichen Regionen sicherzustellen.

Zertifizierung wesentlicher Faktor für Versorgungsqualität

Einige Länder orientieren sich zunehmend an zentralisierten Fachärzt*innenmodellen, um Qualität und Sicherheit in der Versorgung zu fördern. Die Zertifizierung von Krebszentren spielt hierbei eine wesentliche Rolle, um hohe Versorgungsstandards zu gewährleisten. Erfahrungen zeigen jedoch, dass eine umfassende Koordination über verschiedene Fachdisziplinen und Sektoren hinweg notwendig ist, um konsistente Versorgungspfade zu erhalten.

sektorübergreifende Netzwerke stärken potenziell Versorgungssicherheit & reduzieren Ineffizienzen

Integrierte, netzwerkbasierte und zentralisierte Fachärzt*innenmodelle bieten Vorteile, indem sie die Zusammenarbeit und Koordination verbessern. Dies kann dazu beitragen, Ineffizienzen zu reduzieren und die Versorgungsqualität sowie -effizienz zu steigern. Der Ausbau sektorübergreifender Netzwerke kann zudem die Versorgungssicherheit insbesondere in unterversorgten Regionen stärken.

österreichische Herausforderungen → z. B.: Fachkräftemangel, Versorgungsstandards sichern, sektorübergreifende Zusammenarbeit

Österreich steht vor der Herausforderung, sein zentralisiertes Fachärzt*innenmodell mit der wachsenden Nachfrage nach ambulanter Versorgung und Home-Treatment in Einklang zu bringen. Gleichzeitig gilt es, den Fachkräftemangel zu bewältigen und hohe Versorgungsstandards durch spezialisierte und zertifizierte Zentren sicherzustellen. Der zukünftige Weg für Österreich könnte ein stärker integrierter Ansatz sein, der die sektorübergreifende Zusammenarbeit fördert und sicherstellt, dass Patientinnen rechtzeitig Zugang zu einer wirksamen Krebsbehandlung haben – sei es im Krankenhaus, in der Ambulanz oder zu Hause.

1 Background

1.1 Introduction

Over the past decade, Austria has seen a significant rise in cancer incidence and prevalence, particularly in breast cancer, which remains the most common type, with 81,174 cases reported in 2018. In 2020, breast cancer accounted for 28% of all female cancer cases [1, 2]. The increase in numbers is attributable to multiple factors, including demographic ageing, improved survival rates, extended life expectancy, environmental factors and the expansion of screening programmes [2, 3].

steigende Brustkrebsinzidenz & Prävalenz in Österreich (AT)

The Austrian Federal Ministry of Labour, Social Affairs, Health and Consumer Protection (BMASGK, Bundesministerium für Arbeit, Soziales, Gesundheit und Konsumentenschutz) projects a 39% increase in cancer cases by 2030 compared to 2014, resulting in approximately 457,700 cancer patients, or 4.9% of the population [4]. This growth is expected to further strain the healthcare system, with current per capita cancer care costs in Austria exceeding the European Union (EU) average (€ 440 vs. € 326 in 2018) [2]. Despite efforts to expand outpatient services, Austria's healthcare system remains heavily hospital-centred, with 30% of the health care budget allocated to inpatient care compared to the EU average of 28%. The high density of acute care beds (5.84 per 1,000 inhabitants vs. the EU average of 3.94) instead of close-to-home care models is another factor that reflects this focus on hospital-based care [5-7]. However, this hospital-centred approach complicates the transition to more cost-effective, outpatient-based care [6].

kontinuierlicher Anstieg der Krebsfälle → steigende Kosten

AT derzeit ausgeprägte Krankenhauszentrierung der onkologischen (onkolog.) Versorgung

The rising public health care services costs from 2000 to 2020 have outpaced overall economic growth. In particular, the development of the Austrian DRG System ("Leistungsorientierte Krankenanstaltenfinanzierung", LKF) points in oncology has shown a marked increase, with the volume of LKF points more than tripling between 2010 and 2019, whereas non-oncology sectors saw more moderate growth [4]. Although the National Cancer Framework Programme ("Nationales Krebsrahmenprogramm") recognises the need for efficient resource use, Austria faces challenges in implementation due to fragmented financing responsibilities between federal and state governments and other stakeholders, including Social Health Insurance (SHI) funds. Furthermore, the National Cancer Framework Programme lacks binding measures for efficient resource use and transparent resource allocation. Efficiency criteria are mainly applied to national screening programmes, focusing on cost-effective interventions only when all other, more efficient measures, including primary prevention, have been exhausted [2].

mehr als dreifacher Anstieg der LKF Punkte im onkolog. Sektor (zw. 2010-2019)

AT fragmentiertes Finanzierungsverantwortung zwischen Bund & Ländern

Given these challenges, there is a growing need to explore alternative models of cross-sectoral cancer care that can reduce the burden on inpatient services, ensure efficient and target-oriented resource use, and improve patient outcomes. Cross-sectoral care, which integrates various aspects of health care delivery across different sectors, offers potential solutions by shifting towards more outpatient-focused services. The report aims to provide an overview of optional cancer care models and cross-sectoral care approaches from other European countries, with a focus on breast cancer care.

Überblick Krebsversorgungsmodelle & sektorübergreifende Versorgungsansätze ausgewählter europäischer (EU) Länder

1.2 Organisation of Health Care in Austria

The Austrian healthcare system exhibits considerable complexity and fragmentation due to its federalist structure. Responsibilities are divided between the federal government and the nine federal states (Bundesländer), with additional self-governing bodies such as social insurance [6]. Financing of the Austrian healthcare system is sourced from social insurance funds (~44%), taxes (~30%), and private co-payments (~26%) (Figure 1-1). Generally, no formal gatekeeping system is in place, allowing patients unrestricted access to health care services [6, 8].

fragmentiertes & komplexes Gesundheitssystem

kein Gatekeeping-System

In Austria, the highest health care utilisation rate (33.8%) occurs in inpatient settings (Figure 1-1). The integrated planning, management, and funding of public and private non-profit acute care hospitals are the responsibility of federal state health funds (Landesgesundheitsfonds, LGF), established through a healthcare reform in 2005. Each of the nine federal states has its own LGF, which consolidates various funding sources, including contributions from the federal states and municipalities, to cover operational losses ("Betriebsabgangsdeckungen") of inpatient care facilities. Non-profit hospitals constitute over half of Austria's hospital facilities (~55%) and provide 79.4% of hospital beds. In contrast, for-profit hospitals comprise about 44% of facilities and provide 20.6% of hospital beds [6, 8].

höchste Inanspruchnahme des Gesundheitswesens im Spitalsbereich (33,8 %)

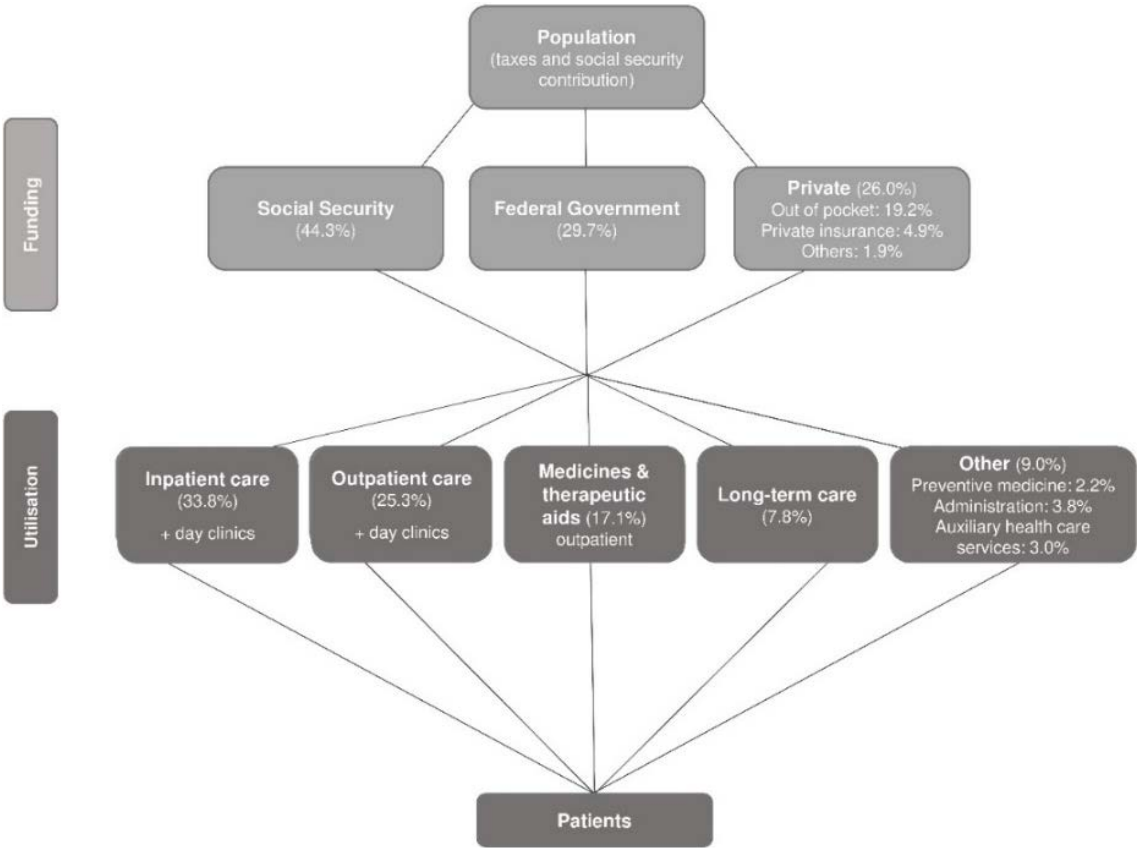


Figure 1-1: Financial organisation of the Austrian healthcare system (adapted from Wild [2009] and Bundesministerium für Soziales and Gesundheit and Pflege und Konsumentenschutz [2019], own depiction)

1.2.1 Organisation of Cancer Care in Austria – Reforms & Policies

10 österreichische Gesundheitsziele → Rahmen für nationale Gesundheitspolitik bis 2032

In recent years, two significant policy developments have been initiated to enhance population health, overcome fragmented responsibilities, and to improve financing arrangements through collaborative planning, decision-making, and funding. Firstly, the adoption of the 10 Austrian Health Targets in 2012 established a comprehensive framework guiding national health policy and reforms until 2032. Developed through extensive stakeholder participation and grounded in a Health in All Policies approach, these targets are endorsed by the federal government and aim to increase Austria's healthy life expectancy by two years [6, 10].

2013: Einführung der Bundes-Zielsteuerungskommission (B-ZK) als höchstes Entscheidungsorgan im Gesundheitswesen

Secondly, introducing the target-based health governance system in 2013 created the Federal Target-Based Governance Commission (Bundes-Zielsteuerungskommission, B-ZK) as the supreme decision-making body for the health system. This commission brings together federal government officials, state representatives, and statutory health insurance funds to agree on common goals and objectives formalised in Federal Target-Based Governance Agreements, with corresponding agreements at the state level. This system aims to enhance coordination and policy coherence while respecting the constitutional division of powers and responsibilities [6].

2014: Nationaler Krebsrahmenplan umfasst sechs strategische Ziele

Aligned with these governance reforms, the National Cancer Framework Programme, adopted in 2014, serves as Austria's overarching cancer prevention, detection, and treatment policy instrument, implemented across all health system sectors. The Programme is driven by six strategic goals, each supported by several operative goals [11]:

- Reduction of cancer incidence in the population through prevention/health promotion.
- Reduction of cancer mortality and prolonged survival of patients through evidence-based and early detection, diagnosis, and treatment.
- Improvement or maintenance of a high quality of life for cancer patients in all phases of the disease, as well as for relatives and caregivers.
- Equal access to all care structures, as well as innovation and progress for the population, regardless of age, gender, origin, or socio-economic background.
- High-quality data and improved evidence-based information for decision-making.
- Promotion of cancer research across all areas.

eine Priorität des Krebsrahmenprogrammes: Ausbau der Palliativversorgung

The National Cancer Framework Programme set goals to expand palliative care, monitor its uptake, and train health professionals. Thus, over the last 15 years, expanding end-of-life care has been a priority. Between 2004 and 2006, a multi-tier framework for adult end-of-life care was established, followed by a similar framework for younger patients in 2013. These frameworks, part of the Joint Structural Plan for Health, include inpatient palliative units, hospice units, day-hospice centres, and mobile teams, providing 492 beds [12]. Cancer patients are the majority, with 72% in long-term care and 88% in inpatient units. Additionally, a 2012 rehabilitation plan aims to support mental, physical, social, and vocational recovery for cancer survivors [2, 13].

Currently, the Austrian National Cancer Framework Programme is being updated to address present and future needs in cancer care. The revision incorporates international recommendations and focuses on filling existing gaps. Key areas include health promotion, early detection, high-quality diagnostics and treatment, oncological rehabilitation, and palliative care [2].

derzeit: Überarbeitung des Krebsrahmenprogrammes

Since 2009, an Oncology Advisory Board has been established to advise the Minister of Health on cancer prevention and care and the Programme's implementation. This board comprises policymakers, health care providers, payers, government departments and HTA agencies, and representatives of patient organisations. Since the inception of the National Cancer Framework, the Board has monitored progress and published biannual reports [2, 14].

seit 2009 Beratung des Gesundheitsministerium durch Onkologiebeirat

1.2.2 Austrian Cancer Care Infrastructures

The quality criteria for oncology care in Austria include interdisciplinary collaboration among specialities such as geriatrics, palliative care, psychology, and transfusion medicine. Additionally, multiprofessional teams involve physiotherapy, dietetics, psycho-oncology, and sexual medicine. Process quality is ensured by interdisciplinary tumour boards, which determine diagnostic and treatment plans. These boards are adapted to local conditions, require immediate patient registration and discussion post-diagnosis, and mandate further discussions when multiple treatment options exist. Only physicians with proven expertise are allowed to conduct tumour therapies and procedures, and the hospital management designates specific departments for oncology services, adhering to defined quality and safety criteria.

Qualitätskriterien onkolog. Versorgung: Interdisziplinäre Zusammenarbeit, multiprofessionelle Teams, Tumorboards für Diagnostik & Therapie

In addition to these structured processes, public awareness and support services play a critical role in the overall oncology care framework in Austria. Generally, public awareness concerning cancer is primarily promoted by private non-profit organisations such as the Austrian Cancer Aid Organisation (Österreichische Krebshilfe). Early detection efforts involve opportunistic screening by health care providers and a coordinated screening program managed by social health insurance (SHI) through contracts with screening centres. Treatment primarily occurs at state-funded hospitals and is complemented by care from specialists in private practice reimbursed by SHI. In addition to these roles, the Austrian Cancer Aid Organisation operates 63 counselling centres staffed with professionals who provide support to patients and families. Their services include psycho-oncology, nutritional guidance, assistance with social and legal matters, sexual health education related to cancer, and communication support for parents of children with cancer. The Austrian Cancer Aid Organisation also offers financial aid to cancer patients experiencing economic hardship [2].

Aufklärung & Beratung: unterstützt durch österreichische Krebshilfe

Behandlung: hauptsächlich in staatlich finanzierten Krankenhäusern (KH) + Fachärzt*innen

Three tiers of cancer care

Cancer treatment in Austria follows a three-tier system outlined in the National Cancer Framework Programme. It aims to reduce mortality, increase survival through early detection and treatment, and maintain high quality of life for patients and their caregivers. Specialised cancer treatment is provided through the Joint Structural Plan for Health, with three tiers of care [15]:

- Oncology reference centres (Onkologisches Zentrum, ONKZ).
- Specialist centres (Onkologischer Schwerpunkt, ONKS).
- Associated oncology centres (Assoziierte onkologische Versorgung, ONKA).

Krebsbehandlung basiert auf dreistufigem System:

ONKZ: Onkologisches Zentrum,
ONKS: onkologischer Schwerpunkt,
ONKA: assoziierte onkologische Versorgung

Oncology reference centres (Onkologisches Zentrum, ONKZ)

An ONKZ is primarily located in a tertiary care hospital. It includes all essential interdisciplinary team specialities ("tumour board") and most oncology subspecialties, such as a centre for internal oncology and haematology, as well as a radiotherapy unit equipped with teletherapy and brachytherapy facilities. According to the Austrian Structural Plan for Healthcare (Österreichischer Strukturplan Gesundheit, ÖSG), an ONKZ is responsible for the following services [15]:

ONKZ:
KH der Zentralversorgung inkl. Zentrum für internistische Onkologie & Hämatologie & Radioonkologie

- Complex therapeutic procedures.
- Diagnostics and therapies require high interdisciplinary collaboration.
- Complicated systemic therapies and treatments for high-risk patients.
- Rare malignancies.

Additionally, an ONKZ has the following characteristics:

zusätzliche Kriterien ONKZ → klin. Forschung, Verpflichtung zur Ausbildung, regionale Koordinationsfunktion

- Conducting clinical research, including clinical trials (also in prevention and early detection measures).
- Commitment to training.
- Regional coordination within and across specialities.
- Accessibility: within 120 minutes.
- Service area: at least 500,000 inhabitants.

Erreichbarkeit: 120 min.
Einzugsbereich: ≥500.000 Einwohner*innen (EW)

The Austrian hospital system has 14 ONKZ located in 17 state-funded hospitals [4, 15].

Specialist centres (Onkologischer Schwerpunkt, ONKS)

An ONKS can only be maintained by a hospital providing specialised care. It includes the speciality areas designated within the interdisciplinary team ("tumour board") and additional oncology subspecialties, at least surgery and gynaecology, including a focus on internal oncology and haematology and a radiotherapy unit in close proximity. Specialist centres also possess the following characteristics [15]:

ONKS:
KH mit Schwerpunktversorgung inkl. Schwerpunkt für internistische Onkologie & Hämatologie (IONKS) & in räuml. Nähe → Radioonkologie

- Diagnosis and treatment of oncological diseases corresponding to the provided speciality areas, excluding diagnostic and therapeutic procedures reserved for oncology reference centres.
- Conducting clinical trials.
- Commitment to training.
- Ensuring collaboration with an oncology reference centre.
- Regional coordination within and across specialities.
- Accessibility: within 60 minutes.
- Service area: at least 300,000 inhabitants.

Erreichbarkeit: 60 min.
Einzugsbereich: ≥300.000 EW

The Austrian hospital system has 26 state-funded hospitals with an ONKS.

Associated oncology centres (Assoziierte onkologische Versorgung, ONKA)

An ONKA is characterised by the following specifics [4, 15]:

ONKA: assoziiertes Angebot für internistische Onkologie & Hämatologie (IONKA): Fachabteilung für Innere Medizin

- Associated services for internal oncology and haematology: Department of Internal Medicine.
- Diagnosis, therapies, and follow-up in coordination with cooperating ONKZ and/or ONKS; emergency care.

- Mandatory involvement of patients in a tumour board of an ONKZ or ONKS; establishing a dedicated "tumour board" requires mandatory cooperation with ONKZ and/or ONKS.

In the Austrian hospital system, 33 state-funded hospitals maintain an ONKA [4]. For oncological treatments in sanatoria, compliance with the ONKA requirements is mandatory. This includes the prerequisite that patients must be presented to a tumour board before treatment. The tumour board's recommendations must be meticulously documented in the patient's medical records [15].

33 öffentliche KHs mit ONKA

Furthermore, as a prerequisite for high-quality service provision, specialised diagnostic experts must be available at the respective location as presented in Table 1-1. Thus, ONKZ offer the most comprehensive in-house diagnostic services, including advanced specialties like clinical immunology, microbiology, pathology, and genetics. ONKS centres provide a similar range of services but may require collaboration with external partners for certain specialties, while ONKA centres have the least comprehensive diagnostic equipment, heavily relying on partnerships with other centres for specialised services [15].

ONKZ → umfassendsten internen Dienstleistungen; ONKS → ähnl. Leistungsspektrum, Zusammenarbeit mit ext. Partnern; ONKA: auf ext. Zusammenarbeit angewiesen

Table 1-1: Availability of diagnostic specialities in the three tiers of cancer care according to Bundesministerium für Soziales et al. [2023]

Diagnostic specialities	Levels of Care		
	ONKZ	ONKS	ONKA
Clinical immunology	x	COP	-
Clinical microbiology	x	COP	-
Clinical pathology and molecular pathology	x	x	COP
Medical genetics	COP	-	-
Medical and chemical laboratory diagnostics	x	x	x
Radiology	x	x	x

Abbreviations: COP …in cooperation, ONKA … Associated oncology centres (Assoziierte onkologische Versorgung), ONKS … Specialist centres (Onkologischer Schwerpunkt), ONKZ … Oncology reference centres (Onkologisches Zentrum)

In terms of health care staff and equipment, ONKZ centres are fully staffed with specialists, including internal oncology and radiotherapy experts, and are equipped with advanced facilities like PET/CT and intensive care units (ICU). ONKS centres have similar staffing but may need to consult external specialists and have fewer resources, often requiring cooperation for specific equipment. ONKA centres typically operate with essential internal oncology staff during the day and depend on cooperation for most advanced diagnostic tools and specialised care, such as stem cell transplantation and radiotherapy [15].

ONKZ-Zentren vollständig mit Fachpersonal besetzt

ONKS & ONKA auf ext. Zusammenarbeit/ Kooperationen angewiesen

Table 1-2: Availability of health care staff and equipment in the three tiers of cancer care, Bundesministerium für Soziales et al. [2023]

Staff & Equipment	**Levels of Care**		
	ONKZ	**ONKS**	**ONKA**
Hospital management			
Internal oncology: medical director	specialist in internal medicine with additional specialisation in oncological care/rehabilitation (own hospital unit)	specialist in internal medicine with additional specialisation in oncological care/rehabilitation	specialist in internal medicine with additional specialisation in oncological care/rehabilitation
Stem cell transplantation (SZT): director & deputy	specialist in internal medicine with additional specialisation in oncological care/rehabilitation with at least 2 years' experience at SZT centre		
Hospital staff			
Specialist in internal medicine with additional specialisation in oncological care/rehabilitation	day shift; on call: night, weekend, and public holiday (daily medical round)	day shift; on call: night, weekend, and public holiday[1] (daily medical round)	day shift
Specialist in radiotherapy-radiation oncology	day shift	day shift or a consulting specialist	-
Psycho-oncological care specialist	day shift	≥1 but dependent on the # of cancer patients	
DGKP with further training in oncological care and DGKP with further training/specialisation in 'hospice and palliative care'	>1 per unit dependent on the number of cancer patients	recommended	
Specialist in internal medicine with additional specialisation in oncological care/rehabilitation with at least 2 years' experience at SZT centre	day shift; on call: night, weekend, and public holiday	-	
DGKP with corresponding experience	7/24	-	
Equipment			
Oncological hospital outpatient clinic	x	x	-
Intensive care unit (ICU)	2 ICU	1 ICU	intermediate Care Unit
Dialysis/hemofiltration	x	COP	COP
Pain management	x	x	x
Magnetic resonance imaging	x	COP	COP
Scintigraphy (Sentinel)	x	COP	COP
SPECT if PET/CT is not available	x	COP	COP
PET/CT	x	COP	COP
Cytology, histology, immunohistochemistry etc.	x	COP	COP
Frozen section examination	x	x	COP
Infection diagnostics	COP	-	-
Drug-Monitoring	COP	-	-
Centralised cytostatic preparation	x	COP	COP

Staff & Equipment	**Levels of Care**		
	ONKZ	**ONKS**	**ONKA**
Specialised genetic diagnostics	COP		
Genetic counselling	x	COP	COP
Transfusion medicine facility	x	COP	COP
Oncological rehabilitation	COP		
Palliative and/or hospice facility	COP		
Breast cancer care			
Digital mammography unit with stereotactic unit	x	COP	COP
Magnetic resonance imaging with stereotactic unit	x	COP	COP

Notes:

[1] *also via a medical specialist in training*

Abbreviations: *COP … in cooperation, DGKP … Qualified health care and nursing staff (Diplomierte Gesundheits- und KrankenpflegerInnen), ONKA … Associated oncology centres (Assoziierte onkologische Versorgung), ONKS … Specialist centres (Onkologischer Schwerpunkt), ONKZ … Oncology reference centres (Onkologisches Zentrum), PET/CT … Positron Emission Tomography/Computed Tomography, SPECT … Single Photon Emission Computed Tomography*

Certification of breast health centres

In 2009, Austrian professional societies involved in breast cancer care established requirements and metrics for certifying breast health centres ("Brustgesundheitszentren"). Nowadays, the Austrian Certification Commission (Österreichische Zertifizierungskommission, ÖZK) oversees the certification process. Currently, there are 31 certified breast health centres in Austria. In addition to breast health centres, the ÖZK also certifies treatment sites for abdominal cancer in women, known as centres for gynaecological tumours ("Zentren für Gynäkologische Tumore") [16].

seit 2009 österreich. Zertifizierungskommission (ÖZK)

31 zertifizierte Brustkrebszentren

A breast health centre can be certified as either a single-site facility ("Zentrumseinrichtung") or as part of a network with affiliated partners. An affiliated partner is not an independent breast centre and can only be certified in conjunction with a single-site facility (Figure 1-2). The number of patients in all affiliated centres must not exceed the number in the single-site facility. However, the term "Brustgesundheitszentrum" can be used by both the single-site facility and affiliated partners [16, 17].

Brustgesundheitszentrum Zertifizierung → einzelne Zentrumseinrichtung ODER Teil eines Netzwerks mit angeschlossenen Partnern

In general, a breast health centre is an interdisciplinary unit for diagnosing, treating, and researching breast cancer, formed by collaborating with various specialities (Figure 1-2]). These centres provide the expertise, infrastructure, and personnel for high-quality care. The interdisciplinary network includes surgical, medical, and radiation oncology, pathology, radiology, nuclear medicine, psycho-oncology, physiotherapy, plastic-reconstructive surgery, nursing, social work, pastoral care, and data management [17].

Brustgesundheitszentrum → interdisziplinäre Einheit zur Diagnose, Behandlung & Erforschung von Brustkrebs, die durch die Zusammenarbeit versch. Fachrichtungen

Core service providers are those specialities participating in the "tumour board" and responsible for patient diagnosis and treatment, including [17]:

- Imaging Diagnostics (Radiology/Nuclear Medicine).
- Surgical Therapy.
- Radiation Oncology.
- Pathology.
- Medical Tumour Therapy.

beteiligte Fachrichtungen des Tumorboards

The mentioned disciplines are prerequisites for independent breast health centres, whereas affiliated partners must provide at least "surgical therapy" and "diagnostics" (Figure 1-2) [17].

angeschlossenen Brustgesundheitszentren müssen mind. chirurgische Therapie & Diagnostik anbieten

The interdisciplinary "tumour board" is the centrepiece of the breast health centre. All core service providers must participate, ensuring consistent quality standards for all patients. The breast health centre must also demonstrate treatment quality by benchmarking with other centres to offer improvement opportunities. All patient data is documented in a dedicated database for quality assurance, and the results are included in the publicly available annual report of all certified centres, which is essential for the certification process [17].

Qualitätssicherung (QS) durch Dokumentation der Patientinnendaten

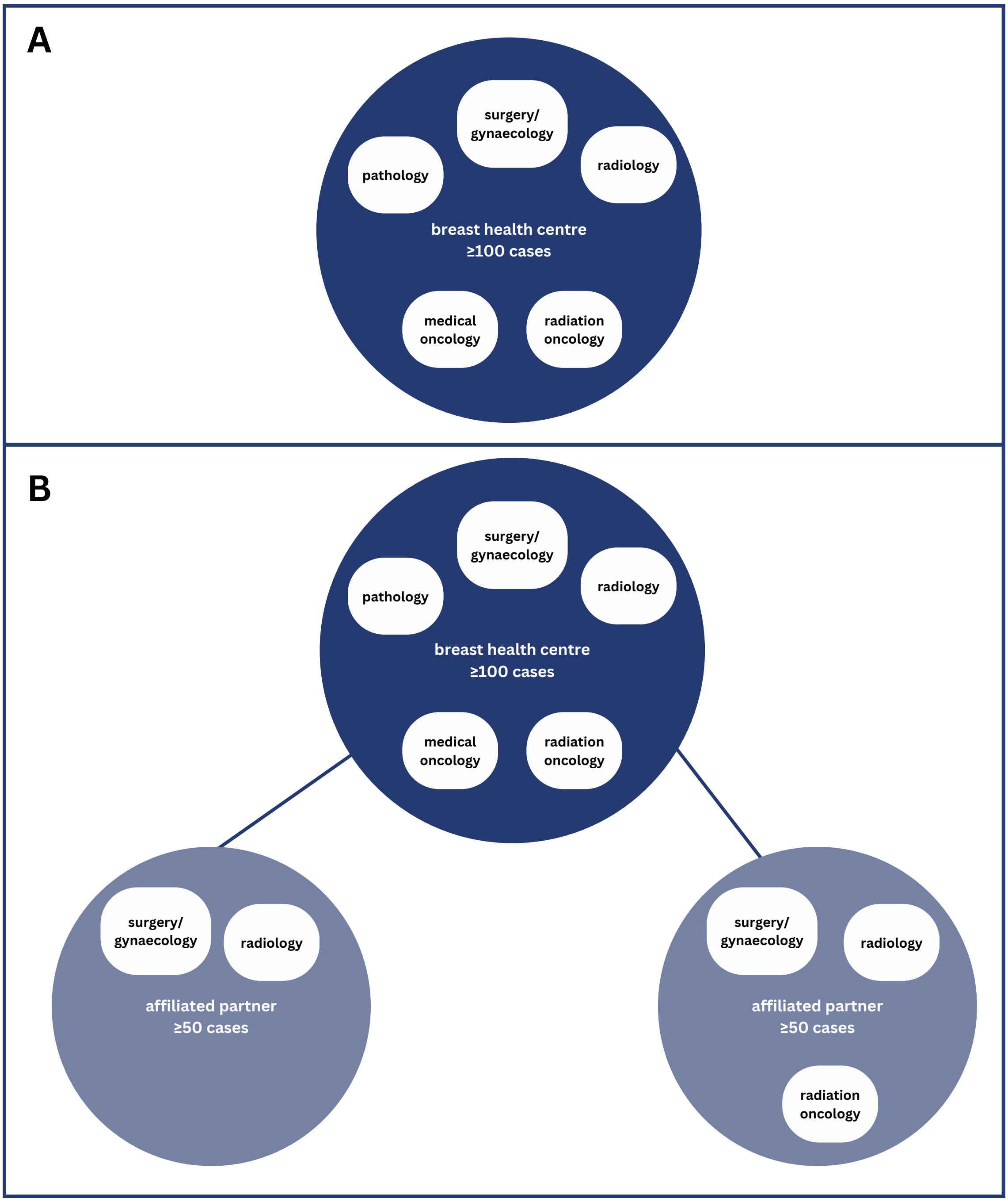


Figure 1-2: Requirements of independent sites (A) and affiliated partners (B) of breast health centres in Austria (adapted from Österreichische Zertifizierungskommission [2022], own depiction)

In 2022, over 5,300 breast cancer cases were treated in certified breast health centres (Figure 1-3). According to Statistics Austria, currently, 5,700 patients per year are diagnosed with breast cancer in Austria. Thus, the majority of all breast cancer patients in Austria are treated in a certified breast health centre accredited by the ÖZK [18].

5.300 Patientinnen (Pat.) in zertifizierten Einrichtungen behandelt (2022)

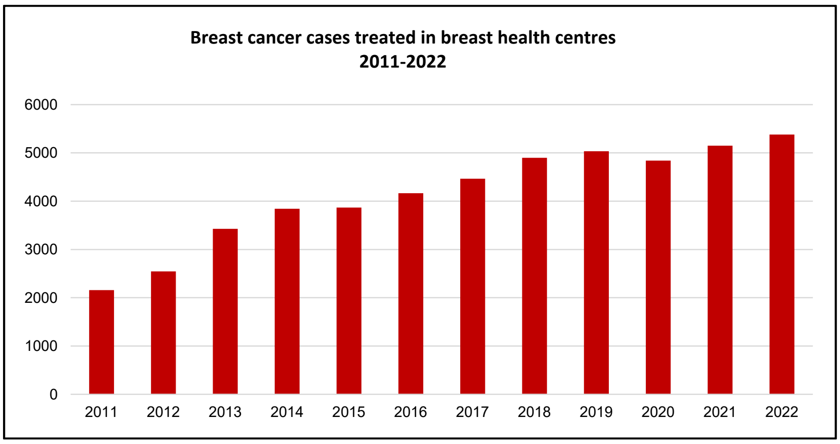


Figure 1-3: Breast cancer cases treated between 2011 and 2022 in Austrian breast health centres (adapted from Österreichische Zertifizierungskommission [2022], own depiction)

The German Cancer Society (Deutsche Krebsgesellschaft, DGK) provides an additional certification option for Austrian cancer centres. Currently, 33 health care centres are certified by the DKG in Austria for different cancer entities such as breast, skin, lung and prostate cancer [19]. Detailed information on the DKG certification can be found in Chapter 4.2.3 on the DKG Certification Criteria and Requirements for Breast Cancer Centres.

Zertifizierung in AT auch durch Deutsche Krebsgesellschaft (DKG) möglich

1.3 European Cancer Policies & Certification Systems

In 2006, European Guidelines introduced specific criteria known as the “critical mass” for breast units to establish optimal operational standards. According to these guidelines, each breast unit should manage a minimum of 150 newly diagnosed cases of primary breast cancer annually, spanning all ages and stages. Additionally, the guidelines recommend that each specialised breast surgeon within these units perform at least 50 breast surgeries per year. Furthermore, it is stipulated that each unit should have at least two specialised breast surgeons who devote at least half of their professional time to breast diseases and perform primary surgeries on 50 newly diagnosed cancers per year. While these guidelines are not legally binding, they have encouraged initiatives in various member states to adhere to these standards [20, 21].

2006 European Guideline: Brustkrebseinheiten → ≥150 neu diagnostizierte Fälle

spezialisierte Brustchirurg*innen: ≥50 Brustoperationen (OPs) pro Jahr

In 2015, The European Commission Initiative on Breast Cancer (ECIBC) was established which aims to enhance health and reduce disparities by improving and standardising breast cancer services across Europe. ECIBC has developed evidence-based breast cancer screening and diagnosis recommendations that are accessible online. It also provides a repository of national and international breast cancer care guidelines called the ‘Guidelines Platform’. In spring 2021, ECIBC launched the Manual for Breast Cancer Services, outlining 86 evidence-based quality and safety requirements for breast cancer management, with some translated into quality indicators detailed in the report [22].

European Commission Initiative on Breast Cancer (ECIBC, 2015): Verbesserung der Brustkrebsvorsorge, Handbuch (2021) mit 86 Qualitätsanforderungen

In 2021, Europe's Beating Cancer Plan was presented, underscoring the Commission's commitment to establish a European (EU) Network connecting recognised National Comprehensive Cancer Centres in each member state by 2025. The Cancer Plan aims to ensure that by 2030, 90% of eligible patients have access to such centres [23].

EU-Krebsplan (2021): 90 % der Pat. Zugang zu Versorgung in National Comprehensive Cancer Centres (CCCs) bis 2030

1.3.1 European Society of Breast Cancer Specialists (EUSOMA)

The European Society of Breast Cancer Specialists (EUSOMA) was established following the European Breast Cancer Conference held in Florence in 1998 in response to the growing need for standardised breast cancer care across Europe. A working group was tasked with developing guidelines to ensure high-quality specialist breast services. This effort culminated in the publication of "Requirements of a Specialist Breast Unit" in 2000, which set forth the standards necessary for effective breast cancer units across Europe [24, 25].

European Society of Breast Cancer Specialists (EUSOMA) → Leitlinienentwicklung für hochwertige Versorgung

EUSOMA's guidelines aim to ensure consistent, high-quality care for breast cancer patients across Europe. These guidelines consider critical factors such as [24, 25]:

Kritische Faktoren der Krebsversorgung

- Centre size and capacity.
- Core team composition and qualifications.
- Available facilities.
- Range of services provided.

Updated Guidelines and Requirements

In 2020, EUSOMA updated its guidelines, "The Requirements for a Specialist Breast Centre" in collaboration with the European Society for Medical Oncology (ESMO) and with support from the European CanCer Organisation (ECCO). This update is part of the Essential Requirements for Quality Cancer Care (ERQCC) program and emphasises multidisciplinary approaches and patient-centred pathways. The main requirements for breast cancer centres, as defined in the 2020 update, are categorised into organisational structure, patient management, and quality control and are outlined below [24, 26].

Anforderungen an ein spezialisiertes Brustzentrum → Fokus auf multidisziplinäre Ansätze & pat.-zentrierte Pfade

Organisational and Structural Requirements

Organisatorische & strukturelle Anforderungen: → Dokumentation in Brustkrebszentren

- **Breast Centre Documentation:** A formal document must describe the organisation of the breast centre in compliance with national regulations, detailing its integration within the broader cancer care network.
- **Critical Mass and Case Volume:**
  - Minimum of 150 newly diagnosed early breast cancer cases and 50 metastatic cases annually.
  - Minimum caseloads are specified for core multidisciplinary team (MDT) members, including radiologists, surgeons, oncologists, and breast care nurses.

→ Mindestfallzahlen

- **Screening Coordination:** Coordination with population-based screening programs to ensure quality and continuity of care for screen-positive cases. Diagnostic assessment of screen-detected findings should be conducted within the breast centre.

→ Koordinierung des Screenings

Patient Management and Multidisciplinary Approach

Pat.-Management & multidisziplinärer Ansatz:

- **Patient Pathway and Protocols:** Centres must develop a patient pathway detailing steps from diagnosis to follow-up, including advanced disease and palliative care, based on evidence-based protocols reviewed annually.

→ Pat.-Pfade & -protokolle:

- **MDT Conferences:**
  - Weekly MDT conferences to discuss diagnostic, preoperative, and postoperative cases, as well as metastatic cases.
  - Mandatory attendance includes radiologists, pathologists, oncologists, surgeons, nurses, and data managers.
  - At least 95% of early and locally advanced cases and 50% of metastatic cases must be discussed.

→ Multidisziplinarische Team (MDT)-Konferenzen

- **Communication and Patient Engagement:**
  - Diagnosis and treatment plans must be communicated to patients face-to-face, with shared decision-making supported by breast care nurses and psycho-oncologists.
  - Treatment should commence within 4-6 weeks from diagnosis, with follow-up care managed within the breast centre. However, this can also be conducted externally, with data feedback to the centre.

→ Kommunikation & Pat.-Beteiligung

- **Patient Information and Advocacy:**
  - Clear verbal and written information on diagnostic and treatment options available in all major languages.
  - Information on support groups and patient rights must be provided.

→ Pat.-Information & Pat.-Anwaltschaft

Quality Control and Research

Qualitätskontrolle & Forschung:
→ Qualitätskontrolle & Datenmanagement

- **Quality Control and Data Management:**
  - Maintain a database of all breast cancer patients, monitoring compliance with quality indicators and using data for scientific research.
  - Corrective actions must be implemented if minimum standards are not met.
  - Centres should monitor outcomes such as local recurrence rates annually and engage in external benchmarking.

→ Bildung & Forschung

- **Education and Research:**
  - Contribute to local, national, or international education by organising at least one teaching course per year.
  - Participate in clinical and translational research, aiming to enrol at least 5% of patients in clinical trials annually.

EUSOMA 2020-Positionspapier
→ MDT Mitglieder:

Radiolog*innen, Röntgenassistent*innen, …

In addition, the EUSOMA 2020 position paper defines specific caseload requirements for core MDT members involved in breast cancer care [26]:

- **Breast Radiologist:**
  - 1,000 mammographic exams annually (5,000 for those in centralised screening programs).
  - 200 breast ultrasounds and 50 MRI studies.
  - 50 breast-guided interventions annually.
- **Breast Radiographer:** 1,000 mammograms per year.

- **Breast Pathologist:**
  - 50 preoperative samples and 50 primary breast cancer resections per year.
  - Reporting on 25 metastatic breast surgical specimens annually.
- **Breast Surgeon:** 50 primary breast surgeries per year.
- **Breast Medical Oncologist:**
  - 50 early-stage and 25 metastatic breast cancer patients treated annually.
- **Breast Radiation Oncologist:** 50 early-stage breast cancer patients treated per year.
- **Breast Cancer Nurse:** 50 early-stage and 25 metastatic breast cancer patients cared for annually.

… Patholog*innen, Chirurg*innen, Onkolog*innen, Strahlenonkolog*innen, Krankenschwester/pfleger

1.3.2 Organisation of European Cancer Institutes (OECI)

Since 1979, the Organisation of European Cancer Institutes (OECI) has been dedicated to ensuring equitable access to high-quality cancer care through MDTs, integrating cancer research and innovation into patient care pathways, and prioritising patient-centred care. In 2002, an Accreditation and Designation (A&D) Programme was introduced that aims to establish a robust quality system that covers cancer diagnosis, treatment, education, and research within cancer centres using OECI standards, indicators, and peer review processes [27, 28].

Organisation of European Cancer Institutes (OECI) → Akkreditierungsprogramm seit 2002

Unlike regulatory and mandatory quality assessment programs, the OECI A&D Programme is a voluntary initiative uniquely designed to support cancer centres globally. The programme incorporates leading global quality standards. Peer reviews are conducted by specialists in cancer care and research from OECI-accredited centres, and site visits are overseen by directors of OECI cancer centres, ensuring thorough evaluation and continuous improvement. The OECI offers three types of designation, each emphasising multidisciplinary expertise and high-quality cancer care [27]:

- OECI Cancer Centre (CC).
- OECI Comprehensive Cancer Centre (CCC).
- OECI Comprehensive Cancer Network (CCN).

OECI-Programm: Globale Qualitätsstandards, Peer-Reviews durch Expert*innen,

3 Zertifizierungstypen:

→ Krebszentrum (CC)
→ CCC
→ Comprehensive Cancer Network (CCN)

Currently, 19 CCs, 34 CCCs, and two CCNs have been accredited mainly in European countries (except one centre in Chile), with an additional 26 centres undergoing accreditation. All OECI-accredited CCs must meet the following criteria [27]:

- Have a clear organisational structure with effective governance.
- Provide a wide range of high-quality cancer diagnostics and personalised care.
- Foster a culture of continuous learning and improvement in care quality.

CC: n=19
CCCs: n=34
CCNs: n=2

Additionally, OECI-accredited CCCs must demonstrate [27]:

- Advanced infrastructure, expertise, and innovation in cancer research, spanning translational, clinical, and basic sciences.
- Establish strong links with universities and research institutes or have a university partnership.
- Maintain extensive international networking capabilities.

CCCs → fortgeschrittene Infrastruktur, Expertise & Innovation, Zusammen-arbeit mit Universitäten, umfassende internationale Vernetzung

Recently, the European Commission approved the new Joint Action (JA) EUnetCCC, which will be launched in November 2024 for a 4-year duration. This initiative builds on JA CraNE and aims to establish a unified European network of CCCs. Led by the German Cancer Society and the National Institute of Public Health – National Institute of Hygiene in Poland (NIZP PZH-PIB), the focus will be on implementing CCCs across all EU states, advancing care standards, capacity building, feasibility testing, and developing sustainability recommendations [29].

Aufbau eines einheitlichen Netzwerkes von CCCs in der EU

Besides the A&D Programme from the OECI and EUSOMA, accreditation processes for breast cancer centres are established and managed individually by each European Member State. Consequently, the specific requirements for existing breast cancer infrastructures are detailed in the respective chapters of each country.

Akkreditierung von Brustkrebszentren auch auf Länderebene möglich

1.4 Project Objectives and Research Questions

1.4.1 Objectives and Scope

The project aims to identify cross-sectoral care models for breast cancer patients in selected European countries, including Germany, Belgium, Sweden, Denmark, and the Netherlands. Specifically, it will investigate the health care infrastructures supporting female breast cancer patients across different healthcare systems. Additionally, the project will explore the locations of medical service provision and the professional groups' roles in each country. Finally, based on these insights, the project will develop generic and country-specific patient journeys.

primäre Ziele: Übersicht & Vergleich von Brustkrebsversorgungsstrukturen in Europa & Identifizierung von sektorübergreifenden Versorgungsmodellen

1.4.2 Non-Objectives

The project does not aim to …

- Consider patient pathways and medical service provision for specific breast cancer indications.
- Conduct a guideline synopsis.
- Perform a systematic assessment of the (relative) effectiveness of medical treatments within the respective health care infrastructures (outpatient versus inpatient sector) concerning clinical endpoints or care effectiveness within the healthcare system.
- Develop a cancer care plan for Austrian breast cancer patients.

Nicht-Ziele: Untersuchung von spez. Brustkrebsindikationen, Durchführung einer Leitliniensynopse, Wirksamkeit der med. Leistungen in bestimmten Gesundheitsstrukturen, Entwicklung eines Krebsversorgungsplans

1.4.3 Research Questions

The following research questions (RQ) are answered:

3 Forschungsfragen:

- **RQ1:** What breast cancer care infrastructures are available in selected European countries (Austria, Germany, Scandinavian countries, the Netherlands, and Belgium)? What are the primary locations for medical service provision, and what roles do professional groups play in each healthcare system?

Brustkrebsversorgung in Österreich & ausgewählten EU-Ländern

- **RQ2:** What are the essential medical services in a breast cancer patient journey, and how can they be categorised?

& generische „Patient Journey“

- **RQ3:** How does breast cancer care in Austria differ from that in selected European countries in terms of health care infrastructures, involved professions, and available medical services across inpatient, outpatient, and ambulatory care settings? What cross-sectoral care models are employed in these countries?

& Ländervergleich
& Identifizierung von sektorübergreifenden Versorgungsmodellen

2 Methodology

A step-by-step approach was employed to address the three research questions:

- Conducting a structured, iterative hand search to identify relevant countries, publications, and expert contacts, utilising a Population, Interest, and Context (PICo) analysis (sections 2.1 and 2.3).
- Identification and analysis of breast cancer care guidelines (section 2.2).
- Illustration of a generic breast cancer journey based on identified literature with verification by health care experts of the respective countries through consultations (section 2.2).
- Collection of health care characteristics from prioritised countries through expert consultations and a self-designed questionnaire (sections 2.4.1 and 2.4.2).
- Presentation of a descriptive and illustrative overview of each prioritised country's breast cancer patient journey and the health care infrastructures used, based on literature and expert consultations (section 2.5).
- Comparative analysis of the collected information and narrative synthesis of cross-sectoral care models across selected European countries (section 2.6).

Stufenweiser Ansatz: (Abschnitte 2.1-2.6)

→ iterative Handsuche (PICo)

→ Leitlinienanalyse

→ Illustrierung eines Brustkrebs „Patient Journeys"

→ Expert*innen-befragungen

→ deskriptiver Länderüberblick

→ vergleichende Analyse sektorübergreifender Versorgungsmodelle

2.1 PICo Analysis

Zielgruppe, Interesse & Kontext

The following Problem, Interest, and Context (PICo) scheme guided the report, from identifying relevant literature to obtaining information on cross-sectoral cancer care and infrastructures in selected EU countries through expert consultations.

Table 2-1: PICo analysis

Problems	■ Increasing cancer prevalence and incidence ■ Hospital-centred cancer care in Austria ■ Identifying cross-sectoral care models of selected European countries
Interest	Describing health care infrastructures, medical service provision, and involved professions: ■ RQ1: Breast cancer care and service provision in Austria and in selected EU countries. ■ RQ2: Development of a breast cancer patient journey. ■ RQ3: Comparison of identified care structures, involved professions, and medical services provided between Austria and selected EU countries to identify cross-sectoral care models. *The project **does not** aim to (i) consider patient pathways and medical service provision for specific breast cancer indications, (ii) provide a guideline synopsis, (iii) perform a systematic assessment of the (relative) effectiveness of medical treatments within the respective care structures (extramural versus intramural) regarding clinical endpoints or the care effectiveness within the healthcare system, and (iv) develop a care plan for Austrian breast cancer patients.*
Context	Austrian healthcare context & selected EU countries
Language	No restriction
Publication Type	All types of publication

Abbreviations: EU … European Union, PICo … Problem, Interest, Context, RQ … research question

2.2 Development of a Breast Cancer Patient Journey

Brustkrebs "Patient Journey" → basierend auf evidenz-basierten Leitlinien (LL)

Identifizierung von kritischen Phasen

In order to address research question 2, we systematically developed the breast cancer patient journey by consulting several evidence-based breast cancer guidelines. These guidelines, encompassing national and international recommendations, provide comprehensive insights into the stages of breast cancer care, from diagnosis to follow-up. The initial step involved a thorough review of these guidelines to identify the critical phases in a breast cancer patient's journey, including diagnosis, therapy options, therapy management, patient support mechanisms, and follow-up care. This information was then synthesised into a generic patient journey model that reflects the typical decision points a breast cancer patient encountered.

Modellentwicklung: externe Validierung durch klinische Expert*innen

To ensure the model's clinical relevance and accuracy, it was developed in close collaboration with a practising oncologist, who provided expert input on medical service provision and the roles of health care professionals at each stage of the journey. Following the development of the initial model, it was further refined through a series of expert consultations. These consultations involved a diverse team, including oncologists, surgeons, radiologists, and oncology nurses, who reviewed the patient journey for comprehensiveness and accuracy.

visuelle Darstellung der medizinischen Leistungen in jeder Phase der Brustkrebsbehandlung (mittels Canva)

The final patient journey is illustrated in Figure 3-1, which visually represents the pathway and highlights the various medical services a breast cancer patient encounters at each stage. The illustration was created using Canva (https://www.canva.com/), an online graphic design platform facilitating medical information's visual organisation and presentation. Moreover, a descriptive overview of this journey was prepared, further elaborating on the current standard of care, as well as the molecular pathogenesis and natural course of breast cancer.

2.3 Literature Search, Country Selection, and Expert Contacts

Iterative Suche zur Identifikation von Ländern mit sektorübergreifender Brustkrebsversorgung & vergleichbaren Gesundheitssystemen:

AT, Germany (DE), Denmark (DK), Finland (FI), Sweden (SE), Netherlands (NL), Norway (NO), Belgium (BE)

To address research questions 1 and 3, we initially conducted an iterative search to identify countries with potential cross-sectoral breast cancer care infrastructures as well as those with comparable healthcare systems, specifically countries with SHI systems. This search consisted of two steps. First, we performed an exploratory search to identify eligible countries and gather information on their health care infrastructures. Based on these findings, and in exchange with the authorities having requested the need for this analysis and the internal reviewer (CW), the following countries were initially prioritized:

- Austria
- Germany
- Denmark
- Finland
- Sweden
- The Netherlands
- Norway
- Belgium

In the second step of the iterative search, we identified expert contacts in each country and conducted expert consultations based on a formerly prepared guideline (see section 2.4.2). This approach aimed to deepen our understanding of cross-sectoral cancer care infrastructures and the general healthcare system characteristics in the prioritised countries. Additionally, the experts were asked to provide any policy documents, national and international reports, and relevant international literature on their country. Furthermore, based on a snowball system, additional publications and resources were identified through the recommendations from the consulted experts.

Identifizierung von Expert*innenkontakten & anschließende Konsultationen

politische Dokumente & relevante nationale/ internationale Literatur

Relevant publications and documents for each country were grouped in the reference management software EndNote X20. Detailed information regarding expert contacts and their responses was systematically tabulated in a separate document.

Gruppierung der Literaturauswahl in Endnote

2.4 Data Collection, Questionnaire and Expert Consultation

2.4.1 Basic Country-Specific Data

The following healthcare system information and breast cancer care-related data were collected and tabulated for six selected EU countries using information by the Organisation for Economic Co-operation and Development (OECD):

Informationen aus Berichten der Organisation for Economic Co-operation and Development (OECD)

Table 2-2: Healthcare information and breast cancer-related data of selected EU countries

Epidemiology	Health care expenditures & Inpatient care
▪ Life expectancy at birth (years) (OECD country health profile 2023) ▪ Population aged 65 and over (OECD country health profile 2023) ▪ Cancer incidence – Breast cancer: per 100,000 and new cases absolute values ▪ Cancer mortality – Breast cancer: per 100,000 or absolute values ▪ Five-year net survival rate	▪ Health expenditures as a % of gross domestic product (GDP) ▪ Total cost of cancer (EUR per capita purchasing power parity) (OECD cancer profile) ▪ Direct costs of cancer care ▪ Health expenditures for the inpatient sector ▪ Acute bed number per 1,000 beds

Abbreviations: GDP … Gross domestic product, OECD … Organisation for Economic Co-operation and Development

2.4.2 Questionnaire and Expert Consultations

Questionnaire

To complement the information identified during the initial search, we contacted experts from prioritised European countries and asked if they would be willing to participate in an expert consultation through a virtual meeting or on a written basis. We designed a questionnaire that guided the consultation.

Expert*innenkonsultation → virtuell oder schriftlich

Befragungsleitfaden:

The questionnaire included questions in the following two domains with subdomains:

allgemeine Informationen über die Organisation der (Brust-)Krebsversorgung

- General information on the organisation of (breast) cancer care.
  - General overview of cancer care infrastructure, responsibilities, and competencies across care sectors.
  - Specific cancer care infrastructures in the outpatient setting.
  - Electronic system for health records, cancer and quality registries.
  - Coordination of cross-sectoral care.
  - Initiatives for outpatient cancer care.

Entscheidungsfindung bei der Krebsbehandlung & Ort der Leistungserbringung

- Cancer care decision-making and place of health care provision.
  - Place of care provision and professions involved.
  - Shared decision-making and advance care planning.
  - Information on digital health technologies (DHTs).
  - Home treatment (immunotherapy and chemotherapy).
  - Missing information on involved professions and relevant services.
  - Use of correct definitions and taxonomy.

Definition der Orte der Leistungserbringung

The complete questionnaire can be found in the Appendix document, whereby the included locations of health care provision were defined as follows:

→ KH (≥1 Übernachtung)

- *Inpatient setting/hospital:* a patient is admitted to a hospital for at least one overnight stay.

→ Spitalsambulanz (ohne KH-Übernachtung)

- *Hospital outpatient clinic:* a medical facility located within a hospital that provides various health care services to patients who do not require an overnight stay.

→ extramuraler Bereich

- *Outpatient setting:* any medical facility located outside the hospital, such as family, gynaecology, radiotherapy clinics or outpatient oncology practices.

→ externes Labor

- *External laboratory:* an independent laboratory located outside of the hospital.

→ externe Radiologie

- *External radiology:* an independent radiology centre located outside the hospital.

→ externes Strahlentherapiezentrum

- *External radiotherapy centre:* an independent radiotherapy centre located outside the hospital.

→ Behandlung zu Hause "Home Treatment"

- *Home treatment:* health care services provided to patients in their own homes rather than in a hospital or other medical facility.

Expert Consultations

86 Expert*innen & Gesellschaften kontaktiert, 17 Teilnehmer*innen aus 6 Ländern

Expert*innen-Konsultationen:
virtuell: n=11
schriftlich: n=6

We contacted 86 clinical experts and societies from the eight prioritised countries (Austria: n=13, Belgium: n=5, Denmark: n=7, Finland: n=6, Germany: n=21, Netherlands: n=20, Norway: n=3, Sweden: n=13). Of these, 17 experts from six European countries responded and agreed to participate in online consultations conducted through virtual meetings or in writing. In a minority of cases (n=6/17), the questionnaire or selected questions were completed exclusively in written form. To comprehensively understand the current health care landscape for breast cancer patients in the respective country, we consulted a diverse group of health care professionals, including cancer care nurses, nurse practitioners (Netherlands), oncologists, and breast cancer surgeons. Additionally, we engaged with cancer societies and, where available, breast cancer societies in each country.

The clinical expert consultations were recorded with the consent of the respective expert for internal documentation and deleted after extracting the information. The insights gathered during these consultations were accurately compiled into structured questionnaire tables. These questionnaires were then finalised and sent to each expert for verification to ensure the accuracy of the collated data.

Informationen in Fragebogentabellen erfasst anschließende Überprüfung durch Expert*innen

2.5 Data Preparation and Description

The gathered information from the clinical expert consultations was prepared separately for each country in a continuous narrative text. The publications and documents on breast cancer care identified during the iterative search and the expert consultations have been incorporated into the written text. A patient journey was described and illustrated for each country by adapting the externally validated Figure 3-1. Non-English language sources were translated using DeepL (www.deepl.com) as well as Google Translate (https://translate.google.com/) and processed in the body text.

Erstellung von länderspezifischen "Patient Journeys"

Übersetzung nicht-englischer Quellen mit DeepL & Google Translate

2.6 Analysis of the Information and Country Comparison

To answer research question 3, we performed a narrative synthesis of the results of the country overview and compared the existing health care structures, professions, and medical service provision across the selected countries. In a further step, we identified the main differences in (breast) cancer care between countries focusing on involved health care professions and cross-sectoral care infrastructures. The differences were described narratively and illustrated.

Forschungsfrage 3 → narrative Synthese, Vergl. der Gesundheits-strukturen & -berufe, Identifikation von sektorübergreifende Infrastrukturen

2.7 Quality Assurance of the Report

As part of quality assurance, the report was reviewed by an internal reviewer (CW) and two external reviewers (KS; JB). The external reviewers were asked to assess the following quality criteria:

- **Technical correctness:** Is the report technically correct (evidence and information used)?
- Does the report **consider the latest findings** in the research area?
- **Adequacy and transparency of method:** Is the method chosen adequate for addressing the research question, and are the methods applied transparently?
- **Logical structure and consistency of the report:** Is the report's structure consistent and comprehensible?
- **Formal features:** Does the report fulfil formal criteria of scientific writing (e.g. correct citations)?

The AIHTA considers external peer review by scientific experts from different disciplines a quality assurance method of scientific work. The responsibility for the report content lies with the AIHTA.

Begutachtung durch 1 interne Reviewerin & 2 externe Reviewer*innen

3 Results: Breast Cancer Patient Journey

The patient journey of breast cancer patients comprises a total of 26 different medical services, categorised into diagnostic procedures, therapy management and treatment, as well as patient support and follow-up care. This comprehensive journey is illustrated in Figure 3-1 and is described narratively in the following chapters.

Brustkrebs "Patient Journey" beinhaltet 26 medizinische Leistungen

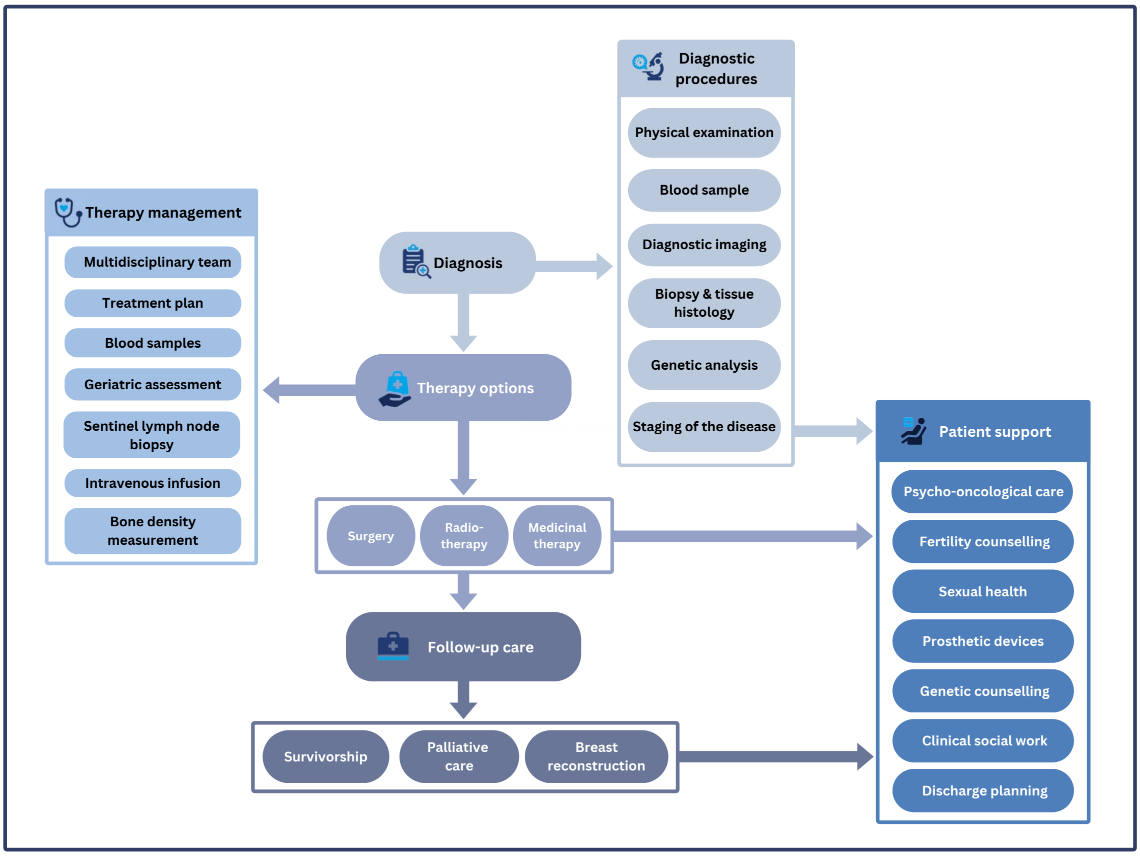


Figure 3-1: Breast cancer patient journey

3.1 Molecular Pathogenesis and Natural Course of Breast Cancer

Breast cancer is recognised as a diverse form of malignancy, characterised by its inter- as well as intratumour heterogeneity [30-32]. In former years, the heterogeneity was based on different expressions of the oestrogen receptor (ER), progesterone receptor (PR), and human epidermal growth factor receptor 2 (HER2). However, in recent years, the utilisation of microarray 50 (PAM50) prediction analysis has enhanced the understanding of breast cancer and thereby affected therapy paradigms and prognosis. PAM50 categorises tumours into five intrinsic subtypes – luminal A, luminal B, HER2-enriched,

inter- & intratumorale Heterogenität

Hormonrezeptor-Status

& molekulare Subtypen

basal, and normal-like – by assessing the messenger RNA (mRNA) expression of a selected panel of 50 genes. In addition, BRCA and PIK3CA gene mutations, as well as PD-L1 expression, should be tested prior to treatment [30].

The predominant form of breast cancer is ductal carcinoma, which originates in the cells lining the ducts. Conversely, lobular carcinoma begins in the lobes or lobules and tends to manifest in both breasts more frequently than other types. Inflammatory breast cancer, though less common, presents distinctively with warmth, redness, and swelling of the breast. Breast cancer can be anatomically staged by using the American Joint Committee on Cancer (AJCC) tumour node metastasis (TNM) staging system. This classification system defines the stage based on the extent of the tumour (T), involvement of lymph nodes (N), and presence of metastasis (M). Additionally, the grade of the tumour is assessed by evaluating its morphological characteristics, including tubule formation, nuclear pleomorphism, and mitotic count [33].

Formen von Brustkrebs: Duktales & lobuläres Karzinom, Entzündlicher Brustkrebs

Stadieneinteilung: AJCC TNM

3.2 Diagnosis

Most breast cancers are diagnosed following an abnormal mammogram. Generally, a mammogram of both breasts is performed to determine the size of the tumour and to check if the contralateral breast is affected. Breast magnetic resonance imaging (MRI) or ultrasound may be used to estimate tumour size and differentiate between a fluid-filled or solid mass. During a biopsy, a sample of breast cells or tissue from the lump is examined to identify the presence of cancer cells and to perform a genetic analysis. Additional diagnostic tests, including bone scans, blood tests, X-rays, computed tomography (CT) scans, and positron emission tomography (PET) scans, may be performed to determine whether breast cancer has metastasised to the bones, liver, lungs, or brain [32, 34].

Diagnose nach Mammographie → MRT/Ultraschall zur Tumorbewertung, Biopsie zur Krebszellanalyse, zusätzliche Tests (Knochenscan, Bluttests, CT, PET) zur Metastasenbestimmung

3.3 Treatment

3.3.1 Therapy Management

It is recommended that breast cancer treatment should be carried out in specialised breast units or centres by a specialised **multidisciplinary team (MDT)**, with referrals to other specialities as needed. An MDT should discuss the **treatment plan**, and all treatment decisions should be made through a shared decision-making process with the patient. In addition, treatment decisions should be tailored to each patient through an individualised risk-benefit analysis that considers the patient's disease characteristics and comorbidities. This also involves a **geriatric assessment** if it is indicated, which mainly includes assessing the overall health status, potential comorbidities, and how comorbidities might impact treatment decisions [35].

Behandlung sollte in spezialisierten Brustzentren erfolgen

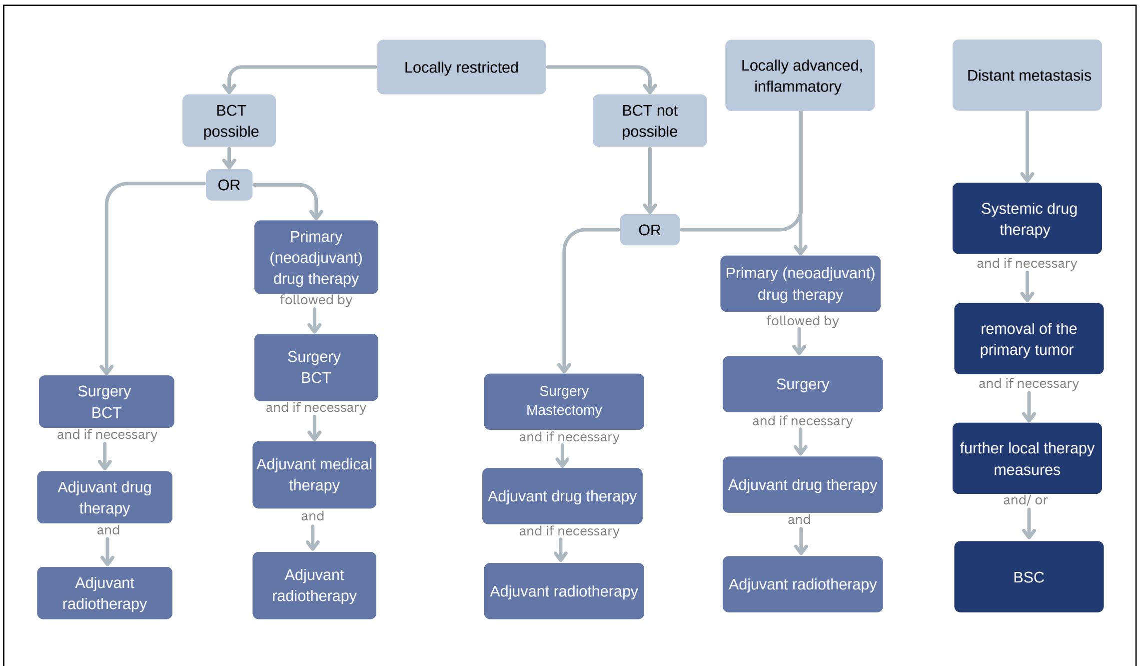
Additional **blood sampling** and **intravenous** access through a peripherally inserted central catheter (PICC) or port catheters may be necessary. Moreover, **bone density measurement** is a critical consideration for breast cancer patients, especially those undergoing treatment with aromatase inhibitors (AIs). AIs can lead to accelerated bone loss and an increased risk of fractures due to their impact on oestrogen levels, which are vital for bone health. Regular bone density assessments using Dual-Energy X-ray Absorptiometry (DEXA) scans are recommended to monitor and manage potential bone loss, helping to determine the need for bone-directed therapies, such as bisphosphonates or denosumab, to mitigate the risk of osteoporosis and fractures [36].

Therapiemanagement umfasst: MDT, Therapieplan, geriatrisches Assessment, Blutabnahmen, intravenöse Infusionen, Knochendichtemessungen

3.3.2 Therapy Options

The general treatment options for breast cancer patients include surgery, radiation, and drug-based tumour therapy [32, 37, 38]. Figure 3-2 illustrates a treatment algorithm for primary breast cancer therapy.

Therapieoptionen: OP, Bestrahlung & medikamentöse Tumortherapie



Abbreviations: BCT = Breast-conserving therapy, BSC = Best Supportive Care.

Figure 3-2: Algorithm for primary therapy of breast cancer patients (adapted from Helfgott R. et al. [2023])

Locally Restricted/Early Breast Cancer (stages I & IIA)

Locally restricted carcinomas also known as early breast cancers are classified as stages ≤IIA and have a therapeutic goal of achieving a cure. The risk of recurrence is primarily influenced by tumour size and biological characteristics, with five-year cancer-specific survival rates ranging from 90% to 100% [32]. Generally, surgical intervention is the cornerstone of curative therapy, whereas breast-conserving therapy (BCT) is the preferred surgical approach.

lokal begrenztes Karzinom: therapeutisches Ziel → Heilung

However, if BCT is not feasible or not desired by the patient, a modified radical mastectomy can be performed [32, 37]. Immediate or delayed breast reconstruction should be offered to the majority of women undergoing mastectomy [35]. Following breast-conserving surgery (BCS), adjuvant radiation therapy is indicated to mitigate the risk of recurrence, which involves irradiation of the entire remaining breast and adjacent chest wall [32, 37].

The **sentinel lymph node biopsy** (SLNB) is the standard procedure for evaluating axillary lymph nodes. If the sentinel lymph node is negative, neither axillary dissection nor radiation is indicated. In cases where micro metastases are present in the sentinel nodes, axillary dissection is still not recommended. For patients with macro metastases in one to three sentinel nodes and no other lymph node involvement, the management options include:

Sentinel-Lymphknoten-Biopsie (SLNB) → Standardverfahren zur Beurteilung der axillären Lymphknoten

- No axillary dissection if the following criteria are met: no more than two macro metastases, tumour stage T1 or T2, planned postoperative irradiation by tangential fields, and adequate adjuvant drug therapy.
- Axillary dissection.
- Radiation to the axillary region.

Adjuvant treatment options for hormone receptor (HR)-positive cancer at all stages include endocrine therapy. Regular bone density evaluation is recommended for patients receiving aromatase inhibitors [35]. In the case of HER2-positive cancer, trastuzumab is recommended; however, data is insufficient for tumours smaller than five millimetres. When adjuvant chemotherapy is indicated based on initial staging, it can also be administered neoadjuvantly [32, 39].

adjuvante Behandlungsoptionen für Hormonrezeptor (HR)-positiven Brustkrebs → endokrine Therapie

Locally Advanced (stages IIB, IIIA, IIIB, and inflammatory disease)

Locally advanced carcinomas, encompassing stages IIB and III, pose a curative therapeutic challenge with a notably heightened risk of recurrence. This risk depends primarily on local extension, involvement of regional lymph nodes, and the disease's biological characteristics. Cancer-specific five-year survival rates vary between 70 and 90% [32].

lokal fortgeschrittenes Karzinom erhöhtes Rezidivrisiko

Therapeutic approaches are multifaceted. Patients with HER2-positive or triple-negative breast cancer, as well as those with HR-positive breast cancer and additional risk factors, typically require chemotherapy. This may be administered either neoadjuvantly or adjuvantly, with a preference for neoadjuvant use in cases of the more prognostically adverse forms, such as triple-negative and HER2-positive breast cancers. For HR-positive and HER2-positive carcinomas, chemotherapy is combined with targeted anti-HER2 therapy, followed by endocrine therapy [32, 39].

vielfältige therapeutische Ansätze → adjuvante/neoadjuvante Chemotherapie, zielgerichtete Anti-HER2-Therapie, endokrine Therapie

The surgical objective is BCT, in addition to adjuvant radiation therapy. Should BCT be unfeasible or undesired by the patient, a modified radical mastectomy is recommended. The SLNB, involving targeted removal and examination of preoperatively marked lymph nodes, is the standard for axillary lymph node evaluation in cN0 cases. In instances of macroscopic lymph node involvement or SLNB failure, axillary clearance can be performed. Adjuvant therapy (chemo-, immuno-, endocrine-targeted drugs- and radiotherapy) is guided by the patient's clinical status and tumour characteristics. It includes up to ten years of endocrine treatment for HR-positive cancers and one year for HER2-positive cancers [32, 39].

OP-Ziel → brusterhaltende Therapie kombiniert mit einer adjuvanten Strahlentherapie

Locoregional Recurrence

therapeutisches Ziel bei lokoregionalen Rezidiven → Heilung durch OP und/oder Bestrahlung

The incidence of locoregional recurrences ranges from 5-10% within ten years following BCT and radiation, slightly lower after mastectomy. Approximately 90% of recurrences occur within the breast, with fewer occurrences on the thoracic wall or the axilla. The therapeutic aim for locoregional recurrence is curative via surgery and/or radiation if no distant metastases can be detected. Adjuvant treatment options include tamoxifen in patients with HR-positive carcinoma and chemotherapy. Possible approaches for systemic therapy include [32, 40]:

- Endocrine therapy.
- Chemotherapy.
- Anti-HER2 therapy.
- CDK4/6 inhibitors.

Distant Metastases

kurative & palliative Behandlungsansätze

Metastatic breast cancer treatment encompasses both curative and palliative approaches. For isolated metastases, particularly solitary lung or limited liver involvement, curative surgical approaches may be considered, showing survival rates up to 35% at 5 years for lung metastases. Such interventions are only pursued when there's no inoperable local recurrence or disseminated disease, and when metastasis occurs at least one year after primary treatment. Stereotactic radiotherapy offers an alternative for oligometastatic disease. Prognosis is generally better with positive hormone receptor status, well-differentiated tumours, and longer disease-free intervals [38].

individualisierte Behandlungsentscheidungen basierend auf Krankheitsmerkmalen, frühere Behandlungen und Patient*innenfaktoren

Primary tumour surgery is typically reserved for managing complications like ulceration or bleeding. For hormone receptor-positive disease, endocrine therapy combined with CDK 4/6 inhibitors forms the backbone of treatment, while HER2-positive cases benefit from combining endocrine therapy with targeted agents. Chemotherapy becomes primary when facing extensive visceral involvement, inflammatory carcinoma, or brain metastases, with single-agent treatment preferred unless rapid disease progression necessitates combination therapy. The management of specific metastatic sites, particularly bone and brain metastases, requires specialized protocols including bisphosphonates, surgery, and radiation therapy. Treatment decisions are continuously individualised based on disease characteristics, previous treatments, and patient factors, aiming to optimise survival while maintaining quality of life [38].

3.4 Patient Support

Pat.-Support: psychoonkolog. Betreuung, genetische Beratung

Generally, several aspects of patient support should be integrated into the breast cancer patient journey. For instance, **psycho-oncological care** is an essential part of the ongoing support and follow-up of breast cancer patients. Additionally, **genetic counselling** plays a crucial role for individuals at high risk of hereditary breast and ovarian cancers, typically associated with pathogenic variants in the BRCA1/2 genes and Li-Fraumeni syndrome (LFS), linked to TP53 gene variants. These syndromes share common features such as early-onset breast cancer and increased risk of other cancers inherited in an autosomal dominant pattern. Offspring of affected individuals have a 50% chance of inheriting the variant. Manifestations of these syndromes can vary widely within families, impacting the age of onset, tumour types, and severity [41].

Fruchtbarkeitserhaltung & sexuelle Gesundheit

Furthermore, it is crucial to integrate **fertility preservation and sexual health** into the comprehensive care of breast cancer patients who may experience fertility issues and sexual dysfunction due to treatment. Health care providers should assess these risks early, discuss fertility preservation options throughout treatment, and collaborate with an MDT. Immediate referral to fertility preservation clinics is essential for interested patients. Post-treatment follow-up with a fertility specialist and referral to a mental health professional, particularly for younger patients and those in sexual and gender minority communities, are recommended to address emotional and decision-making needs [41, 42].

3.5 Follow-up Care

Nachsorge/Follow-up: hoher Rehabilitationsbedarf → körperliche, psychologische & soziale Aspekte, Unterstützung bei der beruflichen Wiedereingliederung

The **rehabilitation** needs of breast cancer patients are extensive, addressing physical, psychological, and social dimensions, including support for vocational reintegration. These needs are primarily influenced by the physical and psychological impairments and resulting disabilities rather than by the cancer stage or treatment type. Patients should be thoroughly informed about available outpatient and inpatient rehabilitation options and other entitlements under social legislation, ideally before completing radiation or chemotherapy. Patient preferences and needs should be considered ensuring personalised care [32].

unterschiedliche Definitionen von "Survivorship"

There are various definitions and phases of cancer **survivorship care**. One definition is cancer survivor as any person with cancer, starting from the moment of diagnosis until the end of life [43, 44]. Currently, clear evidence on best practices for caring for patients with a history of cancer is lacking, leading to significant variation in care. However, the main objectives of follow-up care are [35]:

- To identify potentially curable local and regional recurrences or contralateral breast cancers.
- To assess and manage therapy-related side effects and complications.
- To encourage adherence to adjuvant systemic treatments.
- To offer support for returning to normal life after breast cancer.
- To detect second primary cancers.

psychologische Effekte, reproduktive & sexuelle Gesundheit sollten berücksichtigt werden

Besides, **reproductive and sexual health** considerations must be taken into account. Thus, with more cancer survivors, it's crucial to address long-term treatment consequences, particularly premature menopause and infertility in premenopausal women, which impact the quality of life (QoL). Additionally, long-term care must address the **psychological** and practical effects of breast cancer. Patients should adopt healthy lifestyles and receive support for anxiety, depression, sleep issues, sexuality, chronic fatigue, and neurocognitive dysfunction. Effective follow-up requires a well-organised, multidisciplinary approach to improve overall QoL [35, 45].

4 Results: Country Overview

This chapter provides an in-depth examination of breast cancer care across six selected European countries:

- Austria
- Germany
- Denmark
- Sweden
- The Netherlands
- Belgium

**6 EU Länder:
AT, DE, DK, SE, NL, BE**

The analysis focuses on exploring the organisation of cancer care systems within these countries. A total of 86 experts were contacted, with 17 participating in the consultation process through virtual meetings or written responses. The following chapters will offer a detailed overview of health care infrastructures and professions, patient journeys, and cross-sectoral care coordination, including health care data systems, providing a comparative perspective on breast cancer care models in each country.

**86 Expert*innen
kontaktiert →
17 teilgenommen**

4.1 Organisation of Breast Cancer Care in Austria

4.1.1 Cancer Epidemiology and Cancer Care Expenditures

Austria's healthcare system is characterised by a life expectancy at birth of 81.1 years and 19.2% of its population aged 65 years and over. Austria allocates 11.5% of its Gross Domestic Product (GDP) to health expenditures [5]. The total cost of cancer care was € 488 per capita in 2018, with direct cancer care costs of € 289 (defined as expenditures on cancer within the healthcare system) [46]. Furthermore, there was a cancer incidence of 488 per 100,000 population and a mortality rate of 230 per 100,000 in 2019 [2]. There were 21,040 new cancer cases in women, of which 28% were breast cancer. Inpatient health expenditures reached € 1,387 per capita in 2021, with acute bed numbers at 6.9 per 1,000 population [5] and inpatient cancer case rates above EU averages [2]. Despite these high rates, Austria shows an 85% five-year net survival rate for cancer [2].

**11,5 % des
Bruttoinlandsprodukts (BIP)
→ Gesundheitsausgaben**

**Gesamtkosten
Krebsbehandlung
€ 488 pro Kopf (2018)**

**KH-Gesundheitsausgaben
€ 1.387 pro Kopf (2021)**

4.1.2 National Health Strategies and Programmes & Health Care Infrastructure

A detailed description of the Austrian health care context and infrastructure can be found in the background section 1.2 Organisation of Health Care in Austria.

**→ 1.2 Organisation
des Gesundheitswesens
in Österreich**

4.1.3 Breast Cancer Patient Journey

Identification of Patients

In Austria, potential breast cancer patients are typically identified through an **organised screening program**, referrals from **general practitioners (GPs)**, or **incidental findings** during diagnostic workups for other conditions. Hence, the first **physical examination** of patients takes place depending on the location of identification, whether at a screening centre, GP's practice, gynaecologist's clinic, or in a hospital outpatient clinic.

Identifizierung: Screening, Allgemeinmediziner*innen (GPs), Zufallsbefunde

Since January 2014, a nationwide **breast cancer screening** program has been in place, automatically inviting women aged 45 to 69 every two years. This organised screening program has gradually replaced opportunistic screening, but it is still quite common [10]. In 2021, a national screening committee consisting of medical, legal, and public health experts and a patient representative was established to guide the expansion of national screening programs beyond breast cancer [8]. Since January 2023, the age range for the breast cancer screening program has been extended to include women aged 45 to 74. Despite the availability of mammography for early detection, only approximately 41% of women undergo an organised screening procedure [11].

seit Januar 2014 → landesweites Brustkrebs-Screening-Programm, Frauen im Alter von 45 bis 69 Jahren alle zwei Jahre automatisch eingeladen

Diagnosis

After a patient's diagnosis, various diagnostic tests must be performed. Laboratory tests, such as **blood tests** and **genetic analyses** of the tumour, are typically conducted in hospital outpatient clinics or external laboratories. Diagnostic imaging procedures and tumour staging are also performed in hospital outpatient clinics or external radiologic centres, such as screening or radiologic clinics. Moreover, radiologists perform **biopsies** in hospital outpatient clinics [47-49]. Depending on the tiers of cancer care (ONKZ, ONKS, ONKA), different diagnostic procedures can be offered directly in the associated hospital (ONKZ) or in cooperation with other hospitals or in the outpatient setting (ONKS, ONKA) [15].

Blutabnahmen, genetische Analysen, Biopsien → Spitalsambulanz

Patients often arrive in hospital outpatient clinics with varying degrees of diagnostic work-up, which may include initial imaging, partial imaging, blood test results, or just an anamnesis leading to a presumptive diagnosis. Cancer is a systemic disease, and it must be determined whether it is confined to the organ or has metastasised to other areas. Therefore, additional imaging procedures are typically initiated at the hospital outpatient clinic to ensure a comprehensive evaluation. Consequently, diagnostic imaging may be performed multiple times during a patient's journey, depending on the tests already conducted [48].

meist sind zusätzliche bildgebende Verfahren in der Spitalsambulanz notwendig

Treatment

Treatment Management

The implementation of interdisciplinary decision-making processes by "tumour boards" or **MDTs** is the primary quality assurance measure in cancer care that has been effectively established in Austria to date. Since 2015, a national policy informed by the Oncology Advisory Board recommendations has regulated the establishment and operation of these tumour boards. This policy specifies the boards' composition, decision-making procedures, and documentation requirements. Each tumour board must include at least five

seit 2015 regelt eine nationale Richtlinie → Einrichtung & Arbeitsweise des Tumorboards

specialists covering the relevant oncological sub-speciality, internal medicine and haematology, radiation therapy, radiology, and pathology [2].

After a patient is discussed with the MDT in hospital outpatient clinics, therapy options are presented to the patient, and decisions for a **treatment plan** are made jointly [48, 49]. Based on a breast cancer guideline from Upper Austria, a **geriatric assessment** is recommended for individuals aged 70 or older if a screening conducted by a breast care nurse shows that the patient is frail [38]. In the case of antihormonal treatment, **bone density measurements** are mainly performed at the hospital outpatient clinic. However, in some Austrian regions it may also be available in external radiologic centres. Additional **blood samples** can be taken in external laboratories or hospital outpatient clinics. **Intravenous infusions**, such as those administered via port catheters or PICC lines, take place in the hospital (inpatient setting) or hospital outpatient clinic [47-49].

nach dem MDT
→ Therapieentscheidung
mit Pat.

Genetic tests are either conducted in external laboratories or hospital outpatient clinics; consequently, **genetic counselling** is provided by the medical staff of the external laboratory or by trained clinicians within the hospital outpatient clinic [47-49]. However, in hospital outpatient clinics, genetic counselling is only available in ONKZ. On the contrary, ONKS and ONKA provide genetic counselling in cooperation with other hospital outpatient clinics or external laboratories [15].

genetische Analysen
→ Spitalsambulanz/
externes Labor

Therapy Options

Medicinal tumour therapies are administered in hospital outpatient clinics and provided by a range of health care professionals, including nurses, oncologists, surgeons, and gynaecologists. Data on access to medicines are scarce, but new cancer therapies are deemed to be highly accessible in Austria. Local constraints may be in place on individual hospitals' inpatient medicines, leading to access variations between hospitals [2].

medikamentöse
Tumortherapien
→ Spitalsambulanz

Surgeries, including **SLNB,** are typically performed during an overnight hospital stay in the inpatient setting. Conversely, **breast reconstruction** can be conducted with an overnight stay in a hospital or in a hospital outpatient clinic without the need for hospitalisation. After surgery, patients receive a prescription for any **prostheses or wigs** needed from the treating surgeon, gynaecologist, or nurse. Thus, the **discharge planning** of patients also takes place in hospitals as well as hospital outpatient clinics [47-49]. **Radiotherapy** is generally offered in hospital outpatient clinics, primarily in ONKZ [4]. However, although the number of radiotherapy centres and advanced imaging machines per 100,000 population is above the EU average, the density of radiation therapy equipment is below the EU average [2].

OPs → KH
Brustrekonstruktion,
Entlassungsplanung
→ KH/Spitalsambulanz

Strahlentherapie
→ Spitalsambulanz,
vor allem im ONKZ

Patient Support and Follow-up Care

In Austria, the majority of patient support services such as **psycho-oncology care, fertility counselling, sexual health,** and **clinical social work** occur in hospital outpatient clinics and outpatient settings [47-49]. The Austrian Cancer Aid Organisation plays a crucial role in providing after-cancer care in the outpatient setting. It operates 63 professionally staffed counselling centres that support patients and their families with advice on psycho-oncology, nutrition, social and legal matters, sexual health, and communication for parents of children with cancer [2].

psychoonkolog.
Betreuung,
Fruchtbarkeitsberatung,
sexuelle Gesundheit
& Sozialarbeit
→ Spitalsambulanz
& extramuraler Bereich

A request for **rehabilitation** stays can be submitted directly at the treating hospital and submitted to the respective social insurance provider. Most centres have waiting times, so it is usually not possible to start rehabilitation immediately after the hospital stay. During rehabilitation, patients generally remain on medical leave [50]. Rehabilitation services can take place at home, in hospital outpatient clinics, or in rehabilitation clinics within the outpatient setting [47-49].

Reha-Antrag direkt im KH, Wartezeiten bei Reha-Zentren

Palliative care is provided by specialised hospital departments known as palliative care units, which focus on caring for seriously ill patients. Admissions are typically short-term and aim to manage severe symptoms. Patients receive intensive treatment for physical issues and psychosocial support. Depending on their condition, patients may return home after their stay or transition to hospice care for continued support. Additionally, home treatment is available through mobile palliative teams [51].

Palliativversorgung: spezialisierte KH-Abteilungen, kurze stationäre Aufenthalte, mobile Teams

The described patient journey from diagnosis to follow-up, including the place of care provision, is depicted in Figure 4-1. Additionally, more detailed information can be found in the Appendix document.

"Patient Journey" Details in Abbildung (Abb.) & Tabelle (Tab.) im Appendix-Dokument

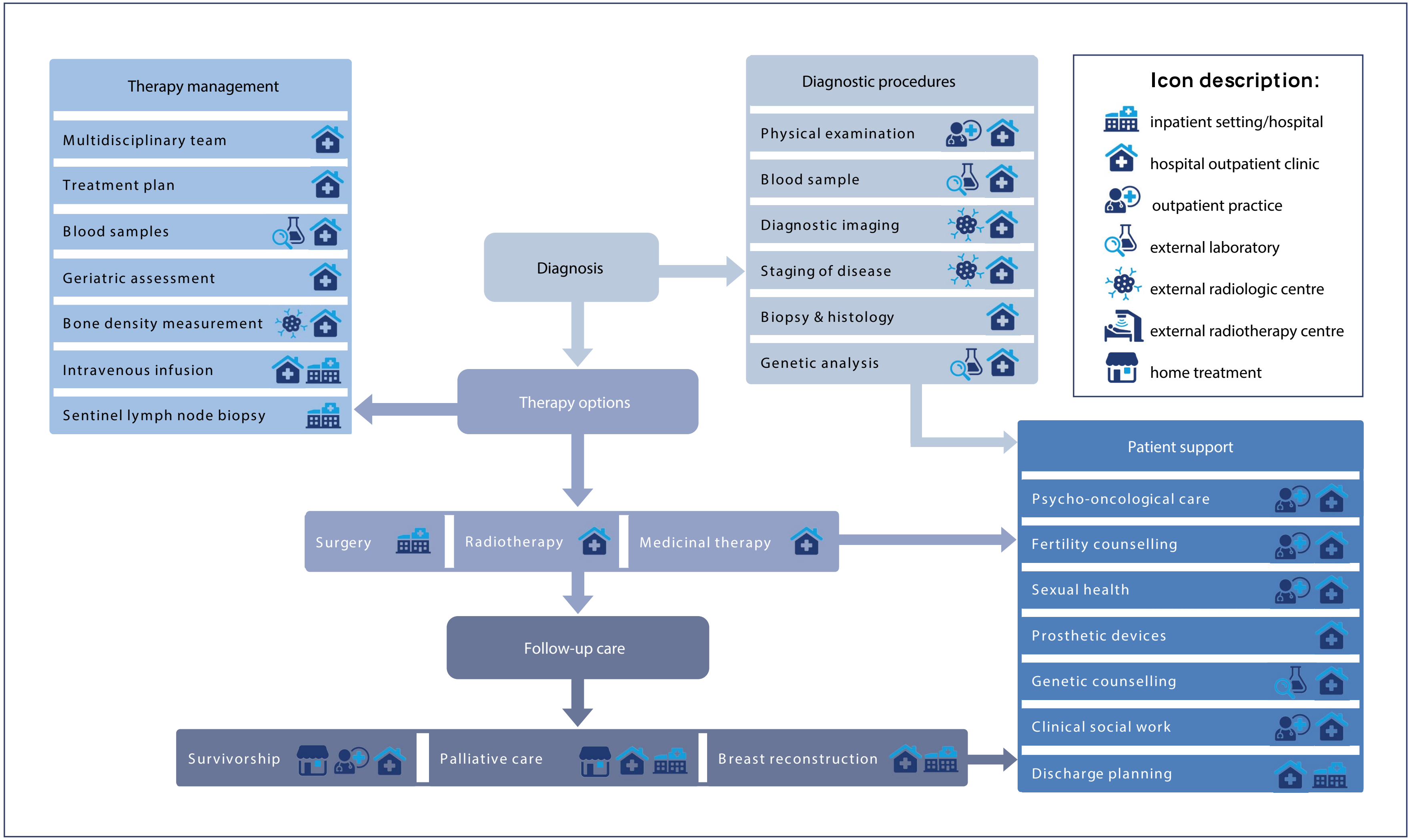


Figure 4-1: Patient journey and place of care provision in Austria

4.1.4 Cross-Sectoral Care Coordination

Care Coordination

keine zentrale sektorübergreifende Koordination, aber regionale Initiativen & DKG-zertifizierte Zentren

In Austria, there is no central cross-sectoral coordination network for oncological or, specifically, breast cancer care. However, regional initiatives exist, such as the breast cancer centres in Linz and Salzburg, which manage collaboration between peripheral and central hospitals, forming the core of an oncology network that facilitates comprehensive coverage with specialised services. Another oncology network operates in Vorarlberg, coordinated by a certified cancer centre in Feldkirch, connecting hospitals and outpatient physicians. Moreover, 27 cancer centres in Austria are certified by the DKG. An essential criterion for this certification is having coordination agreements with partner institutions in the same speciality. As a result, these centres also fulfil a coordinative role within Austria [4]. For more detailed information on the specific DKG certification requirements, including those for breast cancer centres, refer to the country profile of Germany, specifically the section on “DKG certification criteria and requirements for breast cancer centres”.

Health Care Data

Electronic Health Records System

elektronische Systeme auf Bundesländerebene, kein Zugriff auf Privatsektor-Daten

In Austria, electronic systems for public hospitals operate at the federal-state level, allowing health records to be accessed across both outpatient and inpatient areas within the respective federal state. However, data of patients treated exclusively in the private sector cannot be accessed through this system [49].

„Elektronische Gesundheitsakte“ (ELGA) als zentrales digitales Gesundheitsaktensystem

In addition to the electronic system at the federal level, there is a centralised digital health record system called ELGA (“Elektronische Gesundheitsakte”), or the Austrian Electronic Health Record (EHR) system. ELGA was designed to facilitate the efficient and secure sharing of health data among health care providers and patients. The primary goal of ELGA is to improve health care delivery and patient outcomes by making relevant health information more accessible and interoperable across the healthcare system [52, 53].

ELGA: Zugriff auf med. Dokumente & technische Struktur

ELGA provides patients and health care professionals access to critical medical documents, including laboratory results, imaging reports, and discharge summaries. It uses Clinical Document Architecture (CDA) to ensure records are readable by humans and machines, facilitating semantic interoperability [54, 55]. ELGA is structured around “ELGA Areas” or Affinity Domains, networks where health data sharing occurs, supported by the Centralised Master Patient Index (C-MPI) for patient identification and the Centralised Healthcare Provider Index (C-HPD) for provider identification [55].

ELGA: Datenschutz, Opt-out & aktuelle Limitationen

The system complies with legal requirements such as the Austrian Data Protection Act and the EU Data Protection Directive [54, 55]. Patients have control over who can access their data and monitor access logs to see who has viewed their records. They can also opt out of ELGA through a portal and service centres [55]. The implementation of ELGA is phased, focusing on gradually increasing the participation of health care providers and patients [55]. Currently, medical information on patients is dispersed across multiple individual documents, making the system cumbersome and limiting both accessibility and user-friendliness [48].

Furthermore, some federal states have initiatives that provide centralised oncology databases, such as in Upper Austria, to track all cancer cases and their developments. These databases are crucial for producing reliable data, outcomes, quality metrics, and necessary adjustments. In Upper Austria, the system is comprehensively implemented through the Tumorzentrum OÖ, where patients are consistently documented by study assistants and reviewed by data managers [49].

zentrale Onkologiedatenbank in Oberösterreich

Cancer Registry

Several cancer registries operate at the federal level in Austria, including those in Vorarlberg, Tirol, and Salzburg. However, each cancer treating centre must provide the data to the Austrian National Cancer Registry, which is operated by Statistics Austria [56-58]. This comprehensive, population-based system is dedicated to compiling cancer statistics and presenting them in a manner that is accessible to the general public. It offers critical insights into cancer epidemiology across Austria, thereby supporting informed decision-making in health care management [2, 59].

dezentrale & zentrale Krebsregister in AT

The National Statistics Agency publishes annual analyses that detail risk factors, incidence, prevalence, and survival rates. Since 2019, the registry has incorporated an encrypted, unique patient identifier (ID), allowing the agency to link registry data with other datasets while adhering to strict data protection guidelines. This enhancement has the potential to enable more detailed analyses of cancer data, including the exploration of inequalities beyond traditional demographics like sex and age. Although such linked dataset analyses have yet to be published, an examination of tumour staging data is currently underway [2].

seit 2019: verschlüsselte Pat.-ID ermöglicht Datenverknüpfung

Developments and Trends

The Austrian Oncology Advisory Board continues to advocate for integrating outpatient psycho-oncology care into the standard healthcare system. Since 2010, structured psycho-oncological support has been established in hospitals and rehabilitation centres, but outpatient services remain underfunded and largely depend on donations. The Oncology Advisory Board strongly recommends that the health insurance system covers these services to ensure continuous and high-quality care for cancer patients, including outreach and telemedicine options for those with mobility issues. Additionally, they propose extending psychosocial support to other severely ill patients who are at high risk of psychological comorbidity, with the goal of achieving equitable and comprehensive care across Austria [60].

Onkologiebeirat: Forderung nach Integration der ambulanten Psychoonkologie ins Regelversorgungssystem

In 2024, the BMSGPK published an e-health strategy. One focus of this strategy is the expansion of the EHR system, ELGA. This centralised infrastructure for health data is set to be significantly expanded in the coming years. The aim is for GPs, other health care professionals, and patients to have access to all essential health data, including information on recently taken medications, previous illnesses, and laboratory results. In the future, employees of rescue organisations will also have access to ELGA and the electronic vaccination record (e-vaccination record). This access will also be extended to the staff of the health hotline 1450, enabling better counselling for callers [52].

e-health Strategie 2024: ELGA-Ausbau & erweiterte Zugriffsrechte

To ensure a comprehensive overview, contracted GPs will be required to code diagnoses starting in 2025. From 2026, this requirement will also apply to private practitioners. Additionally, all imaging and laboratory findings will be stored in ELGA. Patients will retain the option to deregister from ELGA. Another action point of the Austrian e-health strategy is the adoption of DHTs (Digitale Gesundheitsanwendungen, DiGAs). Some pilot projects will commence from 2025 onwards. However, none of these projects currently focus on cancer care [52].

ab 2025: verpflichtende Diagnosecodierung im extramuralen Sektor & DiGA-(Digitale Gesundheitsanwendungen)-Pilotprojekte

4.2 Organisation of Breast Cancer Care in Germany

4.2.1 Cancer Epidemiology and Cancer Care Expenditures

In Germany, life expectancy at birth is 80.7 years, aligning with the EU average. Additionally, 22.1% of the population is aged 65 or older. The country dedicates 12.8% of its GDP to health expenditures [61]. In 2018, the total cost of cancer care was € 562 per capita, of which € 308 were direct costs [46]. Germany's cancer incidence rate was 571 per 100,000 population, with a mortality rate of 244 per 100,000 population in 2019. Among women, 249,323 new cancer cases were reported, of which 26% were breast cancer [62]. In 2021, inpatient health expenditures reached € 1,358 per capita, with 7.8 acute care beds per 1,000 population [61]. Furthermore, inpatient cancer case rates exceed the EU average. The five-year net survival rate was reported as 86% [62].

12,8 % des BIP → Gesundheitsausgaben

Gesamtkosten Krebsbehandlung € 562 pro Kopf (2018)

KH-Gesundheitsausgaben € 1.358 pro Kopf (2021)

4.2.2 National Health Strategies and Programmes

Germany was the pioneer in establishing a social health insurance system, introduced in 1883. Since then, the system has continuously evolved through numerous reforms, yet the core principles of the original legislation, particularly the strong emphasis on solidarity, have remained intact. A distinctive feature of the German health system is the coexistence of SHI and substitutive private health insurance (PHI), which together ensure de facto universal health coverage [63].

DE: Pionier für ein soziales Krankenversicherungssystem

Generally, the German healthcare system is hospital-centred [62]. Despite the comprehensive nature of the healthcare system, cancer care is currently organised in a heterogeneous manner, with a significant proportion of care, including breast cancer care, provided on an outpatient basis [64]. Cancer treatment in Germany is characterised by cross-sectoral and multidisciplinary approaches, frequently necessitating patient transitions between inpatient and outpatient care settings. The Hospital Care Improvement Act (Krankenhausversorgungsverbesserungsgesetz, KHVVG), which came into effect at the beginning of 2024, is expected to bring significant changes and standardisation to care structures, although the specific changes remain unclear. In particular, established cancer care processes will be integrated, with the cancer care standards defined by the German Cancer Society (Deutsche Krebsgesellschaft, DKG) becoming the legally prescribed "gold standard" (see section 4.2.3) [65, 66].

DE: heterogene Organisation der Krebsversorgung → Spital (inkl. Ambulanz) & extramuraler Sektor

Nationaler Krebsplan (NCP): 13 Ziele in 4 Handlungsfeldern

Further efforts to improve cancer care in Germany have been ongoing. In 2008, the Federal Ministry of Health, the DKG, the German Cancer Aid (Deutsche Krebshilfe, DKH) and the Association of German Tumour Centres (Arbeitsgemeinschaft Deutscher Tumorzentren e.V., ADT) launched the National Cancer Plan (NCP). Between 2008 and 2011, 13 objectives, approximately 40 sub-objectives, and around 100 implementation recommendations were developed across four fields of action [67]. The NCP aimed to …

- Further development and improvement of early detection of cancer.
- Further development of oncological care structures and quality assurance.
- Ensure efficient oncological treatment (focus on pharmaceuticals).
- Strengthen a patient-oriented cancer care approach.

2011 → NCP als Grundlage für Screening- & Registergesetz

Since its introduction in 2011, implementation of the NCP has been carried out independently by the relevant stakeholders. At the federal policy level, the NCP served as the foundation for the Cancer Screening and Registry Act, which established the framework for enhancing cancer screening programs and implementing clinical cancer registries nationwide. In the case of breast cancer, the quality-assured mammography screening program for women, introduced between 2005 and 2009, led to a typical trend in incidence rates, with a significant initial increase followed by a gradual decline. It will take several more years before the impact of screening on further reducing incidence rates can be accurately assessed [67-69]. Another central topic of the NCP was the improvement of psycho-oncological care for all cancer types [67].

Table 4-1 gives an overview of the focus and fields of action outlined in the German National Cancer Plan.

Table 4-1: Overview of the National Cancer Plan in Germany (adapted from Bundesministerium für Gesundheit [2017])

Action fields	Focus and selected aims regarding (breast) cancer (outpatient) care*
Development of early detection	Focus and aims: ■ Improvement of information services and participation rates in the screening programmes. ■ Cancer screening examinations consider the European recommendations for systematic population-based screening programmes. ■ Continuous evaluation of the screening programmes. Recommendations: ■ Specific recommendations for breast cancer: The expert group warns against a hasty and uncritical expansion and recommends an intensification of research activities in the field of risk-adapted early detection of cancer, including a discussion on socio-political and ethical aspects.
Development of oncological care structures and quality assurance	Focus and aims: ■ Cancer patients receive high-quality care regardless of age, gender, origin, place of residence and insurance status. ■ Uniform concepts and designations for quality assurance and quality promotion and certification of oncological treatment facilities. ■ Development and implementation of evidence-based treatment guidelines of the highest methodological development level (so-called S3 guidelines) for all common tumour types. ■ Cross-sector, integrated oncological care is guaranteed (e.g. MDT conferences/tumour board). ■ Valid oncological quality reporting for service providers, decision-makers and patients using clinical cancer registries. ■ Cancer patients receive appropriate inpatient and outpatient psycho-oncological care if required. Recommendations: ■ Specific recommendations for breast cancer: Data-saving uniform tumour documentation.

Action fields	Focus and selected aims regarding (breast) cancer (outpatient) care*
Ensuring efficient oncological treatment (focus on pharmaceuticals)	Focus and aims: ■ Patients receive fair and fast access to proven, effective, innovative cancer therapies. ■ Patient journey and care processes that lie before and after examination and treatment in the hospital, including early detection, rehabilitation and palliation (e.g., national Programme for rehabilitation and palliative care); revision of cancer care pathways for all cancer forms. Recommendations: ■ Specific recommendations for breast cancer: NR.
Strengthening a patient-oriented cancer care approach	Focus and aims: ■ Low-threshold, target-group-specific and quality-assured information services and quality-assured counselling and support services are available for all cancer patients and their relatives. ■ Providers working in oncological care have the necessary communication skills to deal appropriately with cancer patients and their relatives. ■ Strengthening patient competence. ■ Active involvement in the decision on medical measures. Recommendations: ■ Specific recommendations for breast cancer: NR.

* *The sources in German were searched for the terms "Brust" (breast) and "ambulant" and "niedergelassen" (outpatient) to identify relevant information on outpatient breast cancer care.*

Abbreviations: MDT … multidisciplinary team, NR … not reported

Disease Management Programme (DMP) Brustkrebs seit 2002, Revisionen 2005, 2011, 2017, 2023

In addition to the breast cancer-specific considerations within the National Cancer Plan (NCP), Germany has implemented a Disease Management Programme (DMP) specifically for breast cancer patients [67]. DMPs are structured treatment protocols designed for individuals with certain chronic conditions. Within the field of oncology, a DMP currently exists only for breast cancer. This programme was established in 2002 and has undergone revisions in 2005, 2011, 2017, and 2023 to incorporate the latest evidence-based practices. This form of care regulation is codified in the Fifth Book of the German Social Code (Sozialgesetzbuch V, SGB V). The Federal Joint Committee (G-BA) is responsible for defining the standardised requirements for DMPs through its guidelines [71, 72]. The nationwide requirements for DMPs are implemented in regional contracts between the various health insurance funds that also offer the DMPs and the Associations of Statutory Health Insurance Physicians (Kassenärztliche Vereinigungen, KV) [73]. Patients have the option to choose whether to participate in the DMP or remain within routine care.

S3-LL der Arbeitsgemeinschaft der Wissenschaftlichen Medizinischen Fachgesellschaften (AWMF) als wissenschaftliche Basis

The Oncology Guideline Programme (Leitlinienprogramm Onkologie) provides scientific evidence for breast cancer DMP through an S3 guideline. This guideline covers key aspects such as early detection, diagnosis, treatment, and aftercare of breast cancer, among other related topics [74]. The Oncology Guideline Programme is managed by the Association of the Scientific Medical Societies in Germany (Arbeitsgemeinschaft der Wissenschaftlichen Medizinischen Fachgesellschaften, AWMF), the DKG, and DKH. The DKH also provides funding for this guideline programme. These guidelines are continuously developed and updated to reflect the latest scientific evidence. Developing and implementing evidence-based treatment guidelines in oncological care are also key objectives of Germany's National Cancer Plan [70].

4.2.3 Health Care Infrastructure and Patient Journey

strukturiertes System von Zertifizierungen & Richtlinien für die Behandlung von Krebspat.

Germany's approach to cancer care involves a structured system of certifications and guidelines aimed at maintaining high standards across various treatment facilities. These certifications, developed by organisations such as the DKG, DKH, and the German Society for Haematology and Medical Oncology (DGHO), outline specific requirements for organ-specific, oncology, and comprehensive cancer centres. This chapter provides an overview of the certification criteria, the role of interdisciplinary care networks, and the organisational aspects of cancer care in Germany. Additionally, the chapter discusses the involvement of outpatient haematologists and oncologists ("Niedergelassene Hämatologen und Onkologen"), highlighting their role within the broader framework of cancer care.

Standard Requirements for Cancer Care

Zertifizierung: DKG & Deutsche Gesellschaft für Hämatologie und Medizinische Onkologie (DGHO)

Germany currently has various certifications for oncological treatment facilities that are being developed independently. The two primary certification providers on a national level are the DKG, in cooperation with the DKH and the DGHO. Other programmes for the certification of oncological care facilities exist in individual federal states. In some cases, the requirements of these state-specific programmes are congruent with those of the national programmes [67].

NCP-Ziel: Zertifizierung onkologischer Zentren, multi-/interdisziplinäre Netzwerke, Qualitätssicherung aller Versorgungssektoren

The certification of oncological care centres is also one of the 13 objectives embedded in the NCP to ensure top-quality cancer care [70]. With this objective in mind, the initiators of the NCP wanted to establish multi- and interdisciplinary care networks that would also serve the purpose of certified cancer centres. Hospitals, individual practices, rehabilitation centres, medical laboratories, and hospice facilities can join to form such a network. The aim is to ensure the quality of all areas of oncological care across all care sectors, from inpatient and outpatient to rehabilitative and palliative care [67].

Zertifizierung: dreistufiges Zentrenmodell

The National Cancer Plan proposes a three-staged centre model for the certification of such networks [67]:

Organzentrum

- An organ cancer centre (Centre, C) specialises in tumour diseases that occur in a specific organ or organ system or one specialist area. Organ cancer centres are intended to offer patients with common tumour diseases the most comprehensive, close-to-home and quality-assured care possible. The first organ cancer centres in Germany were breast cancer centres, which have been certified by the German Cancer Society since mid-2003.

Onkologie-Zentrum

- An oncology centre, also referred to as a Cancer Centre (CC), integrates multiple organ-specific or speciality areas under one roof. The tasks of oncology centres also include the treatment of rare tumour diseases that are not treated in organ cancer centres.

CCC

- Comprehensive Cancer Centre (CCC) is an oncology centre with a focus on research and development. Comprehensive Cancer Centre meets the same clinical care requirements as standard Cancer Centres, provide treatment for rare tumour diseases not managed in organ cancer centres, and actively engage in research.

DKG Certification Criteria and Requirements for Breast Cancer Centres

The definition of cancer care networks in the National Cancer Plan aligns with the DKG's definition, which consists of cooperating with oncological and/or organ-specific cancer centres. Therefore, the three-staged model outlined in the National Cancer Plan is also one main pillar of the DKG certificate [75]. According to the DKG, certified networks consist of cooperating, certified centres that encompass both inpatient and outpatient facilities, where all disciplines involved in the treatment of cancer patients work closely together. These disciplines include specialists in surgery, radiation oncology, pathology, palliative medicine, drug-based tumour therapy, and other relevant fields, as well as oncological nurses, psycho-oncologists, and social workers [70, 75]. The DKG's certification system focuses on high-quality patient care and aims to improve the cross-sectoral care of oncological patients.

DKG-Zertifizierung zielt auf eine Verbesserung der sektorenübergreifenden Versorgung onkolog. Pat. ab

The DKG stipulates specific structural and procedural requirements (criteria) for certification as a cancer care network, oncological centre, or organ-specific cancer centre. Typically, the leading clinical cooperation partners ("Hauptkooperationspartner"), who oversee a cancer care network, oncological centre, or organ-specific cancer centre (such as a breast cancer centre), are required to establish written agreements (cooperation agreements) with each of the external cooperation partners ("Kooperationspartner") based on these requirements [75].

strukturelle & verfahrenstechnische Anforderungen

All criteria are outlined in so-called data collection forms ("Erhebungsbogen") and must be satisfied by each specific cooperation partner in an organ cancer centre or oncology centre. Usually, many institutes of classic cross-sectional disciplines such as radiotherapy, pathology or internal oncology cooperate with several organ cancer centres or are part of an oncology centre. Specific certification criteria exist for organ cancer centres treating breast, bowel, skin, lung and prostate cancer as well as gynaecological tumours [76]. Certification as an oncology or comprehensive cancer centre and associated requirements are built upon the existing certifications for organ-specific cancer centres [70].

Kriterien sind in Erhebungsbögen festgehalten → müssen von allen Partnern erfüllt werden

In summary, the following data collection forms outlining the requirements for the respective certified centres are publicly available [76]:

- Oncology centres [77].
- Organ cancer centres and cooperation partners of an organ cancer centre or oncology centre (e.g. pathology, radiation oncology) [76].
- Leading clinical cooperation partners such as pathology [78] or radiation oncology [79].
- Uro-oncological centres [76].
- Visceral oncology centres [76].
- Cooperating outpatient practices ("Kooperierende Praxen"): For individual organ cancer centres, there is the possibility of certification of cooperating partners such as dermatological practices, gastroenterological practices (colorectal cancer centres), urological practices (prostate cancer centres), gynaecological practices (breast/gynaecological cancer centres) and gynaecological dysplasia consultations/units [76].

Auswahl an zugänglichen Erhebungsbögen

The criteria and requirements listed in the data collection form for breast cancer centres are summarised in the Appendix document [80].

Details zu Kriterien im Appendix-Dokument

After initial certification, the centres must regularly provide proof of continued compliance with the certification requirements. This is checked during the annual surveillance audit or every three years during recertification. The DKG publishes annual benchmarking reports of the certified organ cancer centres, in which quality indicators of the corresponding guidelines are presented [67].

regelmäßiger Nachweis, dass Kriterien weiterhin erfüllt werden

As mentioned, the DGHO offers a further certification programme. The definition of oncology centres in the DGHO programme differs from the definition by the DKG. In the DGHO programme, an oncology centre is not an association of several organ-specific cancer centres. Rather, the centres must meet fundamental structural requirements for inpatient, outpatient, psycho-oncological and palliative care. Structural requirements pertain to medical-technical equipment, the qualifications of staff, and the provision of guideline-based care. A key element of the DGHO certificate is the assessment of cross-sectoral cooperation between all involved professions in treating the most common tumour diseases. The requirements of the DGHO certification are nearly identical to the requirements of the DKG programme for breast cancer centres [67].

DGHO-Programm weist eine andere Definition von Onkologie-Zentren auf

So far, the DKG and DGHO certification is only obligatory in the federal state of North Rhine-Westphalia [67]. However, with the implementation of the KHVVG, the DKG certificate will likely become mandatory. Preparing, maintaining and regularly renewing certification is time-consuming and costly for hospitals and oncological service providers [66, 81].

verpflichtende Zertifizierung nur in Nordrhein-Westfalen

Outpatient Haematologists and Oncologists (”Niedergelassene Hämatologen und Onkologen”)

Compared to other countries, a distinctive feature of the healthcare system in Germany is the existence of outpatient haematologists and oncologists. They play a crucial role in Germany’s cancer care networks and are a key factor in the extensive provision of cancer care services in the outpatient setting. Established in 1984, the oncology agreement is the legal basis for this form of care [82]. Outpatient haematologists and oncologists aim to prevent supply bottlenecks and enhance oncological care through SHI-accredited physicians [64].

niedergelassene Ärzt*innen für Hämatologie & Medizinische Onkologie (HMO)

Gynaecology, urology, or gastroenterology specialists are authorised to provide medical tumour therapy in the respective specialist area if they have the appropriate additional qualifications. Furthermore, oncological specialisation in internal medicine leads to the qualification of “haematology and oncology specialists”, which entitles them to treat any cancer with medication. Most specialist disciplines are involved in pre- and aftercare and acute therapy [64, 66].

Ärzt*innen für HMO → medikamentösen Behandlung aller Krebserkrankungen berechtigt

Outpatient haematologists and oncologists who manage and coordinate the care of cancer patients can conclude a so-called “oncology agreement” with the responsible KV [82]. In addition, outpatient haematologists and oncologists can be certified as a cooperation partner – so-called partner practice – of a DKG-certified oncology or specific organ cancer centre. This certification is currently possible for colorectal cancer centres, gastroenterology practices, breast cancer centres/gynaecological cancer centres, gynaecological practices, skin cancer centres, dermatology practices, prostate cancer centres, and urology centres [83].

Ärzt*innen für HMO können Onkologie-Vereinbarung mit der Kassenärztlichen Vereinigung (KV) treffen

Both agreements aim to ensure nationwide qualified outpatient treatment for cancer patients. Participating outpatient haematologists and oncologists must meet certain structural, procedural, and organisational requirements. These requirements include, for example, minimum volume standards regarding the number of oncology patients, specialist qualifications and further training, the development of an overall therapy plan and interdisciplinary cooperation in the cancer care network, oncology centre, or specific organ cancer centre [67]. Specialists in internal medicine, haematology and oncology must provide evidence of 15 patients (previously 30) with intravascular, intracavitary or intralesional treatment per quarter in order to obtain or maintain approval to participate in the oncology agreement. For urologists, gynaecologists, dermatologists and all other specialist groups, this number will only be ten patients (previously 20) from January 2024 onwards [84]. If all the requirements are fulfilled, outpatient haematologists and oncologists are eligible to provide health care services similar to the service providers in the hospital outpatient clinic [66, 67].

Voraussetzungen für niedergelassene Ärzt*innen für HMO ab Januar 2024

The Professional Association of Outpatient Haematologists and Oncologists (Berufsverband der niedergelassenen Onkologen und Hämatologen, BNHO e.V.) serves as the representative body for outpatient haematologists and oncologists. The BNHO is committed to high-quality outpatient oncological care throughout Germany. Currently, 590 practising specialists in internal medicine, focusing on haematology and oncology or with comparable full-time oncological activities, treat 300,000 patients across 360 speciality practices and are members of this association [85]. The BNHO also has a scientific institute (Wissenschaftliches Institut der Niedergelassenen Hämatologen und Onkologen GmbH, WINHO) that deals with quality assurance, health services research, and health economics in outpatient care, and it regularly publishes quality reports [86, 87].

Berufsverband der niedergelassenen Hämatologen & Onkologen (BNHO e.V.) → Vertretung der niedergelassenen Ärzt*innen für HMO

Outpatient Specialist Care („Ambulante spezialfachärztliche Versorgung")

Besides the DKG-certification system that should ensure cross-sectoral cancer care on a high standard, the GBA launched the Outpatient Specialised Care ("ambulante spezialfachärztliche Versorgung", ASV) in 2014 [88]. While a professional society initiated the DKG certificate, the ASV was set up in cooperation with the National Association of Statutory Health Insurance Fund (Spitzenverband der Gesetzlichen Krankenversicherung, GKV-Spitzenverband), the German Hospital Federation (Deutsche Krankenhausgesellschaft), and the Federal Association of Statutory Health Insurance Physicians (Kassenärztliche Bundesvereinigung, KBV) and has been continuously expanded [88, 89].

seit 2014 → ambulante spezialfachärztliche Versorgung (ASV)

ASV promotes treatment on an outpatient basis and cooperation between outpatient specialists, such as outpatient oncologists, hospital clinicians in outpatient clinics, medical care centres, professional practice groups, and authorised physicians. Treatment takes place in the practices of the respective ASV physician or on the premises of the participating hospitals, including outpatient clinics [82, 88].

ASV fördert die extramurale Behandlung & sektorenübergreifende Kooperation

ASV is a separate care area and has its own fee scale. ASV is not included in the SHI's regular physicians' fee scale ("einheitlicher Bewertungsmaßstab", EBM). In addition to the "traditional" care sectors, the programme aims to improve medical care for patients with rare and certain serious diseases. The G-BA specifies the scope of treatment and the requirements for participants, as well as equipment and quality assurance for each individual clinical pic-

ASV → eigener Versorgungsbereich & Bewertungsmaßstab

ture. So far, 13 diseases with a particular disease pattern and nine orphan diseases are part of the ASV. Among them are also gynaecological tumours, including breast cancer [82, 88].

ASV-Ärzt*innen: umfassende Leistungen für gynäkologische Tumore und Brustkrebs

Physicians with an ASV authorisation can essentially provide all services that are necessary for diagnosis, treatment and consultation of gynaecological tumours as well as breast cancer. This also includes services that are not part of SHI-contracted health care services. To provide oncological services within ASV, ASV teams must fulfil certain quality criteria on top of the requirements that apply to all ASV indications. A specific guideline for gynaecological tumours regulates billing, remuneration, structural procedural requirements, and requirements for quality assurance [90].

LL: Abrechnung, Vergütung, Qualitätsanforderungen

These include requirements regarding:

- *Organisation and cooperation:*
    - Personnel requirements and cooperation: The ASV team consists of a team leader, a core team, and specialists to be consulted (see Care Coordination within Outpatient Specialist Care (ASV)).
    - Personnel, structural and organisational requirements (Table 4-2).
- *Documentation:* The findings (including diagnosis according to ICD-10-GM, including the diagnostic certainty scale, TNM status, ER status, and HER2 status), the treatment measures and the services ordered, including the day of treatment, must be documented.
- *Minimum volume standards:*
    - Breast carcinoma (ICD-10 code C50): The core team must treat at least 250 patients with breast carcinoma (with a confirmed diagnosis) per year.
    - Gynaecological tumours (ICD-10 codes C51 to C58): The core team must treat at least 60 patients per year with a gynaecological tumour (with a confirmed diagnosis).
    - In addition, the core team must also fulfil one of the following criteria as an additional admission requirement in order to perform the tumour-specific services (ICD-10 code C50 and ICD-10 codes C51 to C58): (i) Specialist in internal medicine and haematology and oncology must provide evidence of the care of an average of 120 patients with solid or haematological neoplasms per quarter (of which 70 patients with drug tumour therapy, 30 of which with intravenous or intracavitary or intralesional treatment), or intralesional treatment) or (ii) a specialist from another group of physicians in the core team must demonstrate the care of an average of 80 patients with solid neoplasms per quarter (of which 60 patients with antineoplastic therapy, 20 of which with intravenous or intracavitary antineoplastic or intralesional treatment).

Table 4-2: Personnel, structural, and organisational requirements in the ASV (adapted from Gemeinsamer Bundesausschuss (G-BA) [2024])

Personnel requirements	**Collaboration with the following specialists and other facilities (interdisciplinary care)**
	■ Outpatient home nursing care (preferably with special knowledge in the care of oncological patients or additional qualification in oncological care) ■ Outpatient and inpatient palliative care facilities ■ Physiotherapy ■ Social services such as social services or comparable facilities with social counselling services ■ Stoma therapy and incontinence therapy by nursing staff with relevant experience
	24-hour emergency care is available at least in the form of an on-call service by one of the following physicians:
	■ Internal medicine, haematology and oncology. ■ Gynaecology and obstetrics with a focus on gynaecological oncology.
	Nursing staff
	■ Most nursing staff must have a state-recognised additional qualification in oncological care.
	MDT conference
	■ Presentation of every patient with an oncological disease to an MDT conference by a core team member.
Structural requirements	**Adequate structural requirements and capacity (on weekends)**
	■ A sufficient number of treatment facilities for medical and transfusion treatments are available, including treatment at weekends and on public holidays if necessary. ■ Suitable treatment options and facilities for immunodeficient patients are available. ■ Quality-assured preparation of the active substances required for intravenous tumour therapy is ensured. ■ Daily preparation and disposal of tumour-specific intravenous therapeutics, including the necessary safety mechanisms to prevent cytostatic solutions or blood product mix-ups. ■ A microbiology and haematology laboratory with the possibility of cytological blood and bone marrow examinations with special cytochemical staining is available. ■ Emergency plans, the equipment and medication required for resuscitation and other emergencies are available for typical emergencies in the treatment of oncological patients. ■ The possibility of intensive medical treatment exists. ■ Inpatient emergency surgeries are possible. ■ The 24-hour emergency care also includes an emergency laboratory and diagnostic imaging required in emergencies.
Organisational requirements	**Information requirements**
	■ The patient must be informed of the outcome of the MDT conference, including all significant risks, side effects, and expected consequences. ■ Patients are provided industry-independent, free information about their illness and treatment alternatives.
	Timeliness
	■ Diagnosis and treatment must be initiated promptly.
	Data recording and documentation
	■ Patients are registered in cancer registries in accordance with the regulations of the respective federal state. ■ Documentation of findings and treatment in compliance with data protection regulations is in place, which allows timely access to all specialists of the core team. ■ Specialists of the core team involved in the treatment in compliance with data protection regulations.
	Gene expression analysis requirements
	■ The recommendation on the indication for the use of gene expression analysis must be justified separately at the MDT conference. ■ The patient must be informed about the evidence-based state of knowledge on gene expression analyses in the treatment decision, in particular about the type, scope, implementation, expected consequences and risks of the measure as well as its necessity, urgency, suitability and prospects of success as well as the alternatives. ■ A sequential or combined use of different test procedures for gene expression analysis on the patient's primary tumour tissue is excluded.

Abbreviations: MDT … multidisciplinary team

Breast Cancer Patient Journey

Identification of Patients

In Germany, potential breast cancer patients are generally identified in three ways:

Brustkrebspat. auf 3 Wege identifiziert

- **Early detection programme:** Women from the age of 30 with German statutory health insurance are entitled to an annual breast cancer examination (palpation of the breasts and an examination of the regional lymph nodes) by a gynaecologist [91].
- Identification during the **National Breast Cancer Screening Programme**: Since 2005, women between the ages of 50 and 69 are invited to an X-ray examination every two years. The women receive an information sheet on the background, objectives, content and procedure, and possible advantages and disadvantages of the screening program. The program complies with relevant quality process indicators of the European Guidelines on Breast Cancer Screening (EUREF) [69]. The focus is no longer solely on participation rates but rather on ensuring that eligible women make evidence-based, informed decisions [92]. Only recently, the inclusion of younger (<50 years) and older (≥70 years) women was decided [93].
- **Outside the screening programmes**: Mammograms are also performed outside the screening program for medically indicated reasons, such as abnormal palpation findings. In addition, opportunistic screenings occur when a physician recommends a mammogram due to the presence of another disease or a family history of increased breast cancer risk. However, no systematic invitations or quality assurance measures are in place for these cases [91].

Früherkennungsprogramm

nationales Screening

Zufallsbefunde

Diagnosis

In cases of suspected breast cancer, the initial assessment involves several different health care professions and is conducted in several settings. In general, professionals with relevant expertise conduct **physical examinations**, **blood sample** collection, **diagnostic imaging**, **disease staging**, and **biopsies** in either the hospital outpatient clinic or outpatient setting. As mentioned above, outpatient haematologists and oncologists have a unique role in cancer care in Germany. Hospital outpatient clinics provide all diagnostic procedures necessary throughout a breast cancer patient's journey. All medical services, except for genetic analyses, are also offered in the outpatient setting by outpatient oncologists [66].

**Diagnose:
physische Untersuchung, Blutabnahmen, genetische Analysen, Biopsien
→ Spitalsambulanz & niedergelassenes Setting**

Moreover, external laboratories and external radiology institutes are part of the care structure regarding diagnostic services. For example, external radiology clinics conduct diagnostic imaging such as X-ray or MRI, and external laboratories also take blood samples outside the hospital clinic setting. **Genetic analysis** of the tumour is usually conducted in hospital outpatient clinics but also by external laboratories [66, 81]. A pathologist typically performs genetic analysis. If the analysis is insufficient or involves genetic samples from metastatic patients, the sample is reanalysed by a molecular tumour board. If the molecular tumour board cannot adequately analyse the sample, whole-genome sequencing is then conducted [66].

spitalsexterne Radiologie-Institute & Labore sind Teil der Versorgungsstruktur hinsichtlich Diagnostik

**genetische Analysen
→ Spitalsambulanzen & externe Labore**

Treatment

Therapy Management

Therapiemanagement: Besprechung neuer Fälle in MDT-Konferenzen (spitalsambulant oder niedergelassen)

In Germany, newly diagnosed cancer cases are reviewed in **MDT conferences** within hospital outpatient clinics or practices of outpatient oncologists. The review involves evaluating whether immediate surgery or upfront systemic therapy, such as chemotherapy or hormone therapy, is the most appropriate course of action. These decisions are based on detailed tumour and lymph node findings. MDT conferences were not mandated by law until the implementation of the KHVVG, but they are mandatory for all DKG-certified cancer centres [94].

MDT für Behandlungsplan verantwortlich

Teilnahme von Pat. möglich, aber selten (5-10 % der Pat.)

The MDT is responsible for the **treatment plan** and must convene at least once per week. The MDT involves a broad range of specialists. In DKG-certified centres, the participation of a breast surgeon, radiologist, pathologist, radiotherapist, internal oncologist, or gynaecological oncologist (if the gynaecology department carries out chemotherapy) is mandatory. Experts from associated specialist groups such as psycho-oncology, plastic surgery, or nurses who coordinate cancer care can be consulted if necessary. Patient participation is permitted if patients wish to attend, although this is very rare (~5-10% of cancer patients in Germany) [66, 80, 94].

Web-MDT-Konferenzen möglich

MDT-Protokoll muss elektronisch verfügbar sein

If web conferences are used for the MDT conferences, audio and presented documents must be transmitted, allowing each leading clinical cooperation partner to present documents and images independently. Telephone conferences without visual material are not permitted. The results of the MDT include a written, interdisciplinary treatment plan (MDT protocol), which must be available electronically in the hospital information system (HIS). Patients with neoadjuvant and surgical therapy must be presented again postoperatively in the MDT [80].

geriatrisches Assessment → spitalsambulant & niedergelassen

SNLB nur im KH

Geriatric assessments are conducted by geriatric staff in both hospital outpatient clinics and outpatient settings. **Blood samples** and **bone density measurements** (if hormone therapy is administered) are organised within hospital outpatient clinics [66, 81]. **Intravenous infusions**, such as those administered via port catheters, are performed in both inpatient settings and hospital outpatient clinics by an interdisciplinary team that includes anaesthetists, nurses, surgeons, oncologists, and gynaecologists. However, **sentinel lymph node biopsies** are conducted exclusively in the inpatient hospital setting [66, 81].

Therapy Options

Therapieoptionen: OPs hauptsächlich in KHs

„semi-ambulante" OP-Zentren mit 1-2 Tagen Aufenthalt für ausgewählte OPs

Surgeries, such as lumpectomy, mastectomy, or breast-conserving measures, are only conducted in the hospital inpatient setting. In most cases, the patient is admitted to the hospital for a few days. Still, there are also small centres in the outpatient setting that perform semi-outpatient operations with hospital stays of one to two days [81]. Currently, approximately 700 out of 1,800 hospitals in Germany perform breast cancer surgeries [66]. In DKG-certified cancer centres, at least two specialists (who can also be breast surgeons) are required in accordance with the staffing plan [80].

Radiotherapie in mehreren Settings möglich

Radiotherapy is conducted by radio-oncologists in hospital outpatient clinics, outpatient settings by outpatient oncologists, and external radiotherapy clinics [66, 81]. The number of CT and MRI scanners per 100,000 people is among the highest in the EU. The density of particle therapy centres is also higher than the EU average [62].

Generally, **medicinal tumour therapies** are administered in hospital outpatient clinics involving oncologists, nurses, and gynaecologists. Outpatient oncologists and gynaecologists also prescribe and monitor antihormonal treatment. Usually, anti-hormonal therapy is applied for five years with a check every three months by an (outpatient) gynaecologist [81]. Germany is among the EU countries with the easiest access to new medicines in the outpatient sector, including oncology medicines. There is immediate coverage of new medicines by the SHI based on regulatory approval and without price regulation for the first year from approval. Therefore, the pharmaceutical industry often launches products first in Germany [62].

medikamentöse Tumortherapien vorwiegend in Spitalsambulanzen

Hormontherapie auch im niedergelassenen Bereich

Patient Support and Follow-up Care

After completing initial oncological treatment, patients are entitled to follow-up **rehabilitation/survivorship care** if they are fit for rehabilitation. Survivorship care/rehabilitation is entirely managed by specialised non-hospital rehabilitation units in the outpatient setting [95]. Rehabilitation measures can be provided on a day-care or outpatient basis or with overnight stays, depending on the patient's needs. Rehabilitation can be claimed up to one year after the initial inpatient treatment if immediate follow-up care is not feasible for medical or therapeutic reasons, such as ongoing chemotherapy. These multiprofessional rehabilitation services include medical and nursing care, psycho-oncological support, physiotherapy and physical therapy, nutritional counselling, social counselling, and general aftercare [67]. Therapeutic rehabilitation approaches are increasingly being utilised as preventive measures, known as prehabilitation, to improve prognosis. These approaches also include exercise programmes designed to accompany ongoing therapy [64].

Pat. Begleitung und Nachsorge: Anspruch auf Rehabilitation nach Behandlung → Rehab in spezialisierten ambulanten Einrichtungen

Palliative care in Germany also follows a multidisciplinary approach and is carried out in different settings. Similar to rehabilitation, palliative care became part of routine care with the Hospice and Palliative Care Act in 2015 [96]. Furthermore, there has been a paradigm shift in recent years [97]. Palliative care is no longer seen as the last option, i.e., after all, oncological treatment options have been exhausted, but should now be discussed at an early stage when a survival prognosis of twelve to 24 months is probable, in conjunction with oncological treatment options [64].

multidisziplinäre Palliativversorgung in unterschiedlichen Settings

Paradigmenwechsel: Abklärung der Palliativversorgung findet bereits früher statt

Tumour pain therapy is individually adapted to the patient's needs, allowing cancer patients to remain in their familiar environment for a long time and take their medication independently. However, when this becomes increasingly difficult in the final stages of the disease, modern palliative care structures enable patients to live their last weeks and days with dignity [67].

individuelle Schmerztherapie im bekannten Umfeld

According to the DKG, Germany now has 1,500 outpatient facilities, over 200 inpatient hospices for adults and children and over 200 palliative care units at hospitals. Only around 10-15% of all patients require special care that necessitates inpatient accommodation in a hospice or palliative care unit [98]. The German Society for Palliative Medicine (Deutsche Gesellschaft für Palliativmedizin, DGP) provides an online guidepost for hospice and palliative facilities [99].

nur kleiner Anteil der Pat. (10-15 %) benötigt stationäre Palliativversorgung

Breast reconstruction and plastic surgeries are only performed on an inpatient basis, like surgical procedures. Furthermore, **psycho-oncological** and **sexual health counselling** takes place in hospital outpatient clinics but can also be provided by psychologists in the outpatient setting [66]. In addition to the S3 guideline „Early detection, diagnosis, treatment and aftercare of breast cancer" [37], the S3 guideline "Psycho-oncological diagnostics, counselling and treatment of adult cancer patients" provides guidance on evidence-based psycho-oncological care [100].

Brustrekonstruktionen & plast.Chirurgie nur im KH

psychoonkolog. & sexuelle Gesundheit spitalsambulant & niedergelassen

In DKG-certified centres, every patient must be offered the opportunity of a psycho-oncological consultation post-diagnosis, during the inpatient stay, and post-inpatient stay in a timely and appropriate manner. At least one psycho-oncologist with specific qualifications and training must be available at the breast cancer centre. In order to determine the need for treatment, a screening for psychological stress must be carried out and documented. An organisational plan presenting the available care capacities must be available if psycho-oncological care is provided by external cooperation partners [80].

DKG-Brustkrebszentren müssen mindestens 1 psychoonkolog. Fachpersonal haben

Specialists in both hospital outpatient clinics and outpatient settings routinely provide **fertility counselling**. Similarly, clinical geneticists conduct **genetic counselling** in these settings [66, 81]. **Prosthetic devices**, such as whigs and prostheses, are administered by oncologists and nurses in the hospital outpatient clinic or by outpatient oncologists and nurses. **Social workers** also contribute to patient support in hospital outpatient clinics and outpatient settings [66, 81].

Fertilitäts- & genetische Beratung, Prothesenleistungen im spitalsambulanten und niedergelassenen Setting

According to the DKG requirements, every patient must be offered social counselling by the social service (social worker/social education worker) in a timely manner during all phases of the illness. At least one full-time equivalent (FTE) for 400 patients must be available for counselling patients at the centre. Contents of social counselling include the identification of social, economic and psychological emergencies and the initiation of medical rehabilitation measures. Counselling on social law and economic issues, disability law, wage replacement benefits, pensions, benefit requirements, personal contributions, etc.), advice on outpatient and inpatient care options, referral to support services and specialist services, discharge management, and emergency intervention [80].

DKG-zertifizierte Zentren müssen Sozialberatung anbieten (1 Vollzeitäquivalent pro 400 Pat.); Beratung deckt mehrere Themen ab: sozialgesetzliche, ökonomische, psychologische Inhalte

Physicians in the inpatient setting typically manage **discharge planning** for breast cancer patients [66]. According to the DKG guidelines, a discharge interview covering disease status, treatment planning, aftercare, and supportive measures are mandatory [80]. Relevant documents, including the MDT conference protocol, treatment plan, discharge letter, and aftercare plan, should be provided to the patient. Additionally, an accredited breast cancer centre must have a complaints management system in place [80].

Entlassungsgespräch als Teil einer systematischen Entlassungsplanung

The described patient journey from diagnosis to follow-up, including the place of care provision, is depicted in Figure 4-2. Additionally, the Appendix document provides more detailed information on the place of health care provision and the involved professions.

"Patient Journey" Details in Abb. & Tab. im Appendix-Dokument

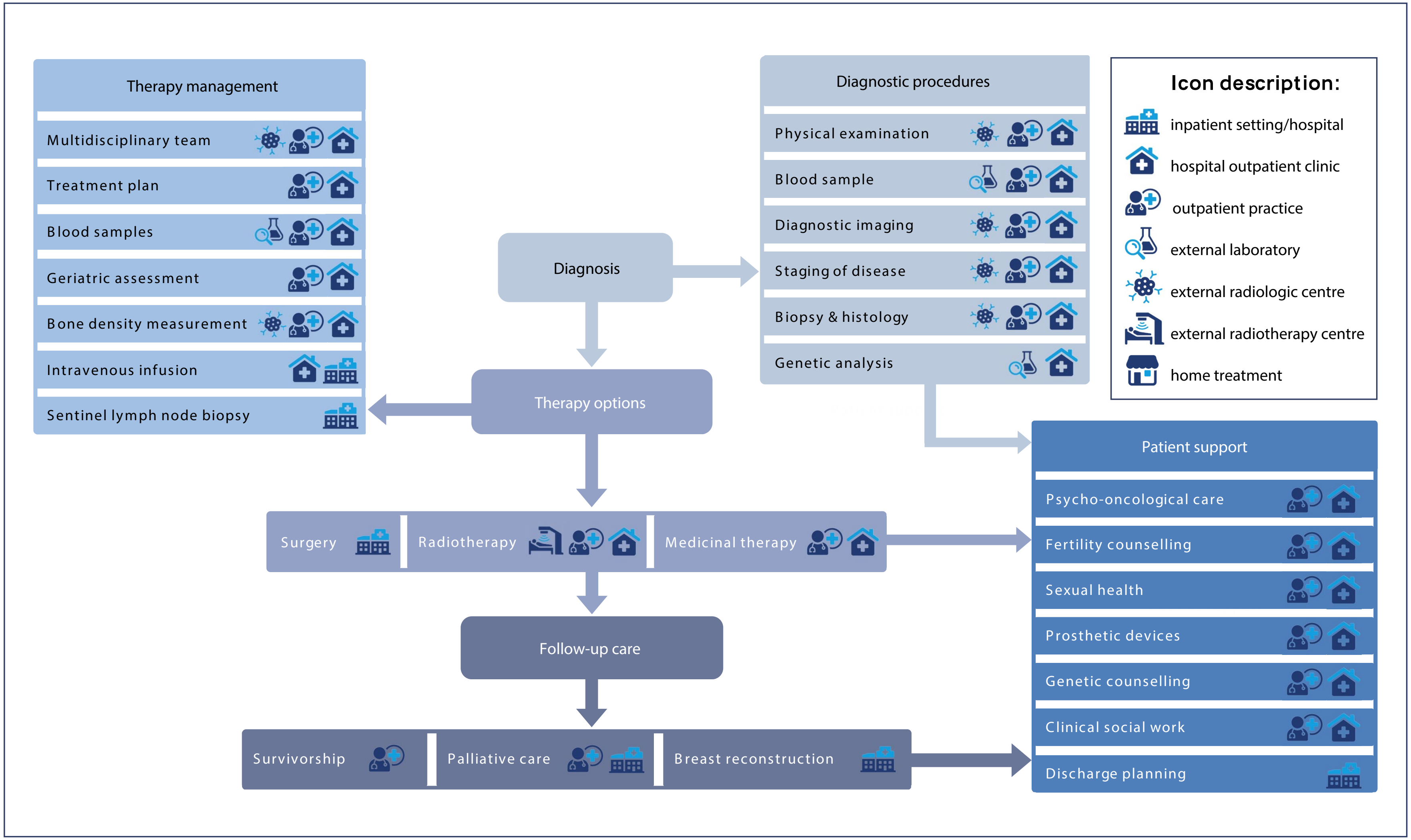


Figure 4-2: Patient journey and place of care provision in Germany

4.2.4 Cross-Sectoral Care Coordination

Care Coordination

keine umfassende & sektorübergreifende Abbildung der Versorgung jedoch MDT zentrales Element bei Behandlungsplanung

The health care of people with cancer requires multi-professional, often long-term and coordinated cooperation. In Germany, hospital inpatient treatment is usually followed by outpatient care by specialists, e.g. outpatient haematologists and oncologists. This may be followed by rehabilitation and regular follow-up appointments. A comprehensive, nationwide mapping of care in the various sectors of the German healthcare system does not yet exist [67]. However, there is consensus in Germany that the (breast) cancer patient must be guided through her illness by an MDT [66, 81].

Care Coordination within DKG-certified Networks

DKG-Netzwerke: Steuerungskomitee koordiniert teilnehmende Zentren & Kooperationspartner

Table 4-3 illustrates the organisational structure within a DKG-certified cancer network and centre, detailing the responsibilities of each partner in coordinating care. Within the DKG-certified cancer care networks and single-organ cancer centres such as breast cancer centres, the steering committee of the centre or network oversees general management tasks and coordinates the centres. The steering committee takes on interdisciplinary tasks such as tumour documentation, further training events, and public relations work [75, 80].

Hauptkooperationspartner verantwortlich für die Versorgung & Teil des MDTs

The leading clinical cooperation partners take on essential parts of the care and take part in the MDT conference. The MDT is the central steering element for the entire treatment chain. The MDT is responsible for treatment planning, counselling and decision-making and aims to ensure comprehensive and coordinated care at a high level [101].

niedergelassene Ärzt*innen für HMO nehmen an MDT-Konferenzen in DKG-zertifizierten Einrichtungen teil

Although most MDT conferences take place in hospitals, most outpatient haematologists and oncologists regularly participate in MDT conferences in hospitals as external participants or conduct internal tumour boards in their practices [102]. According to Hermes-Moll et al. [2016], three-quarters of outpatient haematologists and oncologists participate in internal tumour boards, and 94% participate in external tumour boards. The common goal of providing the best possible care for cancer patients and regular collaboration in MDT conferences can improve cooperation between outpatient and hospital-based specialists [102].

Table 4-3: Level of organisation, partners within and around the cancer centre/network and their responsibilities according to OnkoZert GmbH [2024]

Level of organisation	Responsibilities and tasks
Steering committee	▪ Manage, control and coordinate the centre. ▪ Frequently take on cross-departmental tasks such as tumour documentation, training events, and public relations work.
Leading clinical cooperation partners	▪ Take over essential parts of the care ▪ Take part in the MDT conferences regularly. ▪ Integration and cooperation within the centre are regulated in writing in an agreement. ▪ They are audited as part of the certification process to ensure that they fulfil the certification requirements.
Cooperation partners	▪ Integration and cooperation within the centre are regulated in writing in an agreement. ▪ Are audited as part of the certification process to ensure that they fulfil the certification requirements.

Level of organisation	Responsibilities and tasks
Admitting/referral bodies	■ The referrers themselves do not have to fulfil any direct certification requirements. ■ A written agreement is concluded with the referring physicians in which the cooperation is generally regulated (participation in events of the centre and cooperation with regard to follow-up data is regulated).
Treatment partners	■ No special integration into the network ■ Cooperation is only considered concerning patient-related care in the audit. ■ Treatment partners have no special obligations within the centre's certification framework.

The DKG-certification allows for flexibility and various options when structuring and coordinating a centre or network. Nevertheless, the criteria in Table 4-4 and the cooperation partners' qualifications should still be carefully considered.

Kriterien → Gestaltung eines DKG-zertifizierten Netzwerks/Zentrums

Table 4-4: Basic criteria to consider when designing the structure of a centre or network

Criterion	Aim	Description
Spatial proximity of the cooperation partners to the main treatment site	Short distance (max. distance 45 km)	A direct location of the cooperation partners at the main treatment site is often considered ideal. As this cannot be guaranteed 100%, the integration of (external) cooperation partners is possible (e.g. for genetic counselling, radiology, etc.)
Number of cooperating partners	Manageable number of cooperation partners	Every network requires support. The necessary amount of support and the complexity of the network increase with the number of co-operation partners.
Several cooperation partners of one specialisation	One cooperation partner per specialisation at max (if possible)	In many cases, one cooperation partner per speciality is recommended. This partner should treat a high percentage of the centre's patients. However, the individual case must be considered here; for example, it may make sense to work with several cooperation partners in the case of drug-based tumour therapy.

Care Coordination within Outpatient Specialist Care (ASV)

Non-DKG-certified hospitals and networks of outpatient specialist groups generally have some form of MDT or haematology boards to coordinate patient care. Still, detailed information on their structure, procedural requirements, or number is lacking [101]. An exception is the ASV care framework, which provides organised care coordination outside the DKG system. In addition to the structural and organisational criteria outlined in Table 4-4, ASV teams must meet specific personnel requirements to ensure adequate care coordination and collaboration [88, 104]. An interdisciplinary ASV team treating patients with gynaecological tumours as well as breast cancer consists of a team leader, a core team, and consulting specialists, as outlined in Table 4-5 [89].

Koordination der ASV-Versorgung durch ein interdisziplinäres Team

The team leader coordinates the ASV and is the first point of contact for the patient. The role of the team leader is usually assumed by the specialist who focuses on patient care based on their expertise. For example, a specialist in gynaecology and obstetrics with a focus on gynaecological oncology is the team leader in the case of breast cancer. The core team members are specialists who contribute their knowledge and experience. They work closely with the team leader. The core team members should offer consultation hours in the team leader's office at least one day a week, if necessary.

Teamleiter koordiniert das ASV-Team & ist Hauptansprechperson für die Pat.

Specialists and psychotherapists to be consulted are those whose knowledge and experience are typically required as a supplement for some of the patients. Their place of work must also be within a reasonable distance of the team leader's practice.

weitere Spezialist*innen können hinzugezogen werden

Table 4-5: Composition of the ASV team for gynaecological tumours, including breast cancer (adapted from Kassenärztliche Bundesvereinigung (KBV) [2024])

Core team		**Level 3: Consulting specialists**
Level 1: Team leader	**Level 2: Members of the core team**	
A physician from the core team heads the ASV team.	▪ Specialist in gynaecology and obstetrics with a focus on gynaecological oncology ▪ Specialist in internal medicine, haematology and oncology ▪ Specialist in radiotherapy	Anaesthetist, angiologist, human geneticist, cardiologist, laboratory physician, neurologist, neurologist, nuclear medicine specialist, pathologist, psychiatrist or psychotherapist (medical or psychological) or psychosomatic doctor, radiologist, Only for gynaecological tumours (not for breast cancer): Endocrinologist and diabetologist, gastroenterologist, nephrologist, urologist, visceral surgeon One specialist in the interdisciplinary team must have additional training in palliative medicine.

Abbreviations: ASV … Outpatient specialised care/ambulante spezialfachärztliche Versorgung

The ASV guideline requires cooperation agreements across sectors, ensuring that at least one physician from another sector, such as the outpatient sector, is included in the team. ASV team members can practice at different locations, and a referral is needed if a non-ASV physician wishes to have a patient treated by an ASV team. However, no referral is required for patients from ASV-authorised hospitals if a confirmed diagnosis is available at the time of referral to a service provider in accordance with § 116b (2) SGB V [89].

ASV-LL: sektorübergreifende Kooperationsvereinbarungen essenziell

The relationship between ASV and DKG certification remains unclear, and ASV currently accounts for only a small proportion of care. Despite its structured coordination approach, ASV implementation has not met political expectations, mainly due to the high level of bureaucracy involved [105].

Beziehung ASV & DKG-Zertifizierung unklar, aber ASV nicht weit verbreitet in DE

Health Care Data

As part of the NCP initiated in 2008 by the Federal Ministry of Health together with the DKG, DKH, and ADT, the further development of informative oncological quality reporting using registry data was prioritised to improve cancer care [70].

Gesundheitsdaten & Digitalisierung wichtiger Teil des NCP (2008)

The following specific sub-goals were defined:

- Comprehensive expansion of clinical cancer registries to record the quality of care for all cancer patients.
- Strengthening the networking of regional clinical cancer registries.
- Stronger networking of clinical and epidemiological cancer registries.
- Integration into cross-sectoral quality assurance in accordance with § 137 SGB V.

Ziele:

Etablierung Krebsregister

Zusammenarbeit verschiedener Registertypen & Nutzung zur sektorübergreifenden QS

Epidemiological and Clinical Cancer Registries

Epidemiological cancer registries on a federal-state level have been implemented nationwide since 2009 with the enactment of the Federal Cancer Registry Data Act (Bundeskrebsregisterdatengesetz, BKRG) [106, 107]. The epidemiological data is mainly used to assess the impact and quality of organised cancer screening programmes such as mammography screening for breast cancer [108].

epidemiolog. Krebsregister seit 2009

On 9 April 2013, the Cancer Screening and Registry Act (Krebsfrüherkennungs- und -registergesetz, KFRG) came into force. The KFRG has taken up critical recommendations of the NCP and set the course for the expansion and development of clinical cancer registries. The KFRG created the legal and financial framework for establishing and operating nationwide clinical cancer registries. In addition to epidemiological cancer registries, the Federal Cancer Registry Data Act required all federal states to establish clinical cancer registries for quality assurance purposes. These registries collect detailed data on diagnoses, individual treatment steps, aftercare, relapses, complications, and deaths [109]. The establishment of clinical cancer registries was completed in 2020 [107].

Krebsfrüherkennungs- und -registergesetz (2013): alle Bundesländer müssen Krebsregister zur QS etablieren

In the meantime, both epidemiological and clinical registries have been combined into integrated cancer registries in most federal states [107]. The Act on the Consolidation of Cancer Registry Data of 18 August 2021, which reformed the Federal Cancer Registry Data Act (Bundeskrebsregisterdatengesetz BKRG), further regulates the data consolidation of epidemiological and clinical registries from the federal states' cancer registries at the federal level in two stages [110].

mittlerweile (2021) wurden epidemiolog. Register & Krebsregister in einem zweistufigen Prozess zusammengeführt

In the first stage, the data set to be transmitted to the Centre for Cancer Registry Data (Zentrum für Krebsregisterdaten, ZfKD) by the cancer registries of the federal states will be expanded to include clinical data, such as information on the treatment and progression of cancer. Reporting is based on a uniformly defined data set from the ADT so that information is comparable [111]. Only cancers in adults are reported to the general cancer registries, while childhood cancers are reported separately to the paediatric cancer registry [112].

1. Schritt: Übermittlung aller Daten an das Zentrum für Krebsregisterdaten (ZfKD) des Robert-Koch-Instituts

The Robert Koch Institute operates the ZfKD. The main aim of the ZfKD is to provide scientific research with reliable data on cancer, to check whether the guidelines of the medical and scientific societies are being followed during treatment, or whether the treatment results differ systematically between the various treatment centres. The ZfKD checks the completeness and reliability of the data sets from the federal states and analyses them across the federal states. The results are regularly published in various formats [113]. The first stage has already been implemented at the ZfKD.

ZfKD verantwortlich für Datenmanagement & QS der Versorgung auf Basis der erhobenen Daten

In the second stage, a concept is to be developed by the end of 2024 to create a platform for a nationwide consolidation of all cancer registry data from the federal states. Therefore, this integration will also include data that is unavailable in the first stage. In line with the legal requirements, it should also enable linking cancer registry data with other health-care-related data [108].

2. Schritt: Erarbeitung Konzept für eine bundesweite Registerplattform bis Ende 2024

Currently, a reporting obligation on the part of those treating patients is in place and is also considered a fundamental prerequisite for the full functioning of the registries. The details on reporting are regulated in the respective state cancer registry laws and in the agreement on reporting fees for the transmission of clinical data to clinical cancer registries following § 65c (6) 4 SGB

Meldepflicht der behandelnden Einrichtungen gesetzlich geregelt

V [114, 115]. Generally, the physicians and hospitals that transmit their patients' data to a clinical cancer registry receive a reporting fee from the clinical cancer registries to compensate for the additional work involved [114].

Honorar für die datenmeldenden Zentren

Furthermore, the collected information is regularly analysed, and the results are reported to the treatment facilities. This assures qualified feedback on the current treatment quality for the respective facility. The costs incurred by the cancer registry are, in turn, reimbursed by the statutory health insurance fund with which the patient is insured [115]. The contractual partners are obliged to review the appropriateness of the individual reporting fees at regular intervals and adjust them if necessary [110].

datenmeldende Zentren bekommen Feedback über Behandlungsqualität

Electronic Health Records System

As previously mentioned, treating physicians and hospitals must report specific data to the federal cancer registries by default. However, the registry data does not constitute data in the sense of electronic patient records. Since January 2021, all individuals with statutory health insurance can receive an electronic patient file (elektronische Patientenakte, ePA) from their health insurance provider. This file allows comprehensive storage of medical findings and information from previous examinations and treatments, accessible across both outpatient and inpatient settings. Although the ePA system is in place, cross-sectoral data exchange via a universal platform has not been implemented, and universal access is not yet possible. According to expert information, each hospital has its own data system for EHRs. Outpatient haematologists and oncologists do not have direct access to the data reported by hospitals. Information is passed on verbally by e-mail, fax, or other means [66, 81].

Krebsregisterdaten ≠ elektronische Gesundheitsakte (eGA)

eGA-Daten seit 2021 für Pat. verfügbar, aber nicht sektorübergreifend nutzbar

jedes KH hat zudem eigenes eGA-System

With the implementation of the Digital Act, the ePA will be made available for all people with statutory health insurance from 2025 onwards [116, 117]. The ePA intends to digitally consolidate patient data previously stored at different locations, such as outpatient practices and hospitals. The aim is to foster the exchange and utilisation of health data and provide targeted treatment and support. A health data infrastructure featuring decentralised data storage and a central data access and coordination centre will be established to facilitate the use and management of health data [118, 119].

Implementierung einer sektorübergreifenden & bevölkerungsweiten „elektronischen Patientenakte" (ePA) ab 2025

In future, physicians and psychotherapists will be legally obliged to enter a range of data collected during the treatment in the ePA. The prerequisite is that the patient has not objected to access or the general use [116, 118].

Datenmeldung eines Minimaldatensatz (MDS) wird Pflicht

The documentation of the following data will be mandatory:

- Clinical findings from invasive or surgical, as well as non-invasive or conservative diagnostic and therapeutic measures
- Findings data from diagnostic imaging
- Laboratory findings
- Electronic physician's letters

MDS umfasst:
→ allg. klinische Befunde
→ diagn. Bildgebung
→ Laborbefunde
→ elektron. Pat.-Briefe
→ weitere Daten wie bspw. Medikationsdaten folgen

Further documents and data will follow gradually, including the electronic medication plan and data for checking the safety of drug therapies (allergies, patient body weight) [118].

Developments and Trends

Trend: "Ambulantisierung" & Zentralisierung

While a trend towards outpatient oncological care has emerged in Germany over the last three decades with the establishment of the ASV model, the recently passed KHVVG (15/05/2024) additionally indicates a shift towards the centralisation of cancer care [87].

KHVVG → 3 Ziele

Verbesserung der Versorgungsqualität, Daseinsvorsorge & Effizienz

The hospital reform pursues three central objectives [120]:

- Ensuring and increasing the quality of treatment nationwide.
- Guaranteeing comprehensive health care for patients ("Daseinsvorsorge").
- Increasing efficiency in hospital care and reducing bureaucracy.

zentrale Maßnahmen

The following three core measures are intended to support the achievement of these three central objectives:

sektorübergreifende Versorgungseinrichtungen

- Implementation of (hospital) care levels:
    - *Level 1:* Primary care ("Grundversorgung"): Primary care provider with emergency care (Level In) and Primary care provider for integrated outpatient/inpatient care (Level Ii).
    - *Level 2:* Standard and specialised care ("Regel- und Schwerpunktversorgung").
    - *Level 3:* Maximum care, whereby the university hospitals are to be differentiated from the other maximum care providers.
- Development of a system of 65 service groups assigned to the hospital care levels: Service groups pool medically homogeneous services. They include the allocation of procedures or operations and diagnoses. Uniform nationwide quality standards (structural and personnel criteria) are assigned to each service group and can only be provided in the hospital if the quality standards are met.
- A needs-based and quality-oriented funding system.

KH-Planung nach bundeseinheitlichen Leistungsgruppen und Standards

bedarfsgerechte Finanzierung

DKG-Zertifizierung möglicherweise als verpflichtende Voraussetzung

Oncological care is located in care levels 2 and 3 and should be provided in certified centres [120]. The KHVVG generally stipulates that each service group should have an associated certification (e.g., oncology certifications for stroke units, trauma centres, and centres for rare diseases). Although the KHVVG does not explicitly mandate the DKG certification, it may serve as a blueprint for developing quality criteria and requirements. [66, 121]. The DKG certification is widely established in Germany, and the evidence indicates that patients treated in a certified centre have a greater survival benefit and suffer less frequently from complications compared to non-certified facilities [121-123]. However, due to competition law considerations, holding a specific certificate from a particular provider is not mandatory for meeting the quality criteria [120].

Kliniken mit Fallzahlen < Mindestmengen für spezifische Krebsindikation erhalten keine Vergütung mehr

The KHVVG stipulates that a greater specialisation in oncological services may lead to better quality treatment of existing cases, including a reduction in readmission and complication rates and the corresponding costs for the payers [120]. The specialisation and concentration of oncological surgical services, for example, is therefore promoted. Clinics with the lowest number of cases for a particular cancer indication will no longer receive remuneration, up to the point where their cumulative case numbers amount to 15 percent of the total cases. This measure is intended to promote an appropriate concentration of care structures in the area of oncological surgical services, which ensures demand-oriented, comprehensive inpatient care at a high level of quality and creates an incentive to avoid “occasional care”. However, the quality criteria for a service group can also be met through collaboration with other hospitals and care facilities [120, 124].

A medium-term goal of the concentration efforts is to ensure that 95% of patients are treated within certified structures. Currently, approximately 700 out of 1,893 hospitals in Germany perform breast cancer surgeries. This number is expected to decrease to around 300 hospitals within the next two years [66].

mittelfristiges Ziel: 95 % der Pat. sollen in zertifizierten Strukturen behandelt werden

Furthermore, under certain conditions, cross-sectoral care facilities should be enabled to admit patients requiring inpatient treatment reserved for hospitals of higher care levels. This should be possible if the cross-sectoral care facility has agreed on longer-term cooperation with a hospital of a higher care level that has the corresponding medical expertise and is supported by this hospital to the necessary extent by telemedicine. The German Hospital Federation and the GKV-Spitzenverband, in consultation with the Association of Private Health Insurers (PKV-Verband), still have to agree on which services are suitable for such a division of services across sectors in the future [120].

Kliniken auf niedrigeren Versorgungsebenen sollen auch komplexere Leistungen durchführen → verpflichtende, sektorübergreifende Kooperation

According to expert information, the key consideration in cancer care is not whether services are provided on an outpatient or inpatient basis but rather whether patients have access to the appropriate structures and whether the system efficiently guides them through these structures in an evidence-based, treatment-oriented manner [66, 81]. This perspective is reinforced by a joint position paper from the oncological scientific societies of the AWMF Ad hoc Commission on Health Care Structures, which emphasises the importance of long-term collaboration between medical disciplines and professional groups throughout the tumour-specific patient journey [121]. The paper stresses that treatment should be coordinated, whether in hospitals, outpatient clinics, or other care settings. The critical factors for achieving good treatment outcomes and efficiency are the qualifications and expertise of health care providers and the integration of services within a network. Consequently, it is recommended that oncology services in Germany be offered in hospitals from level 2 upwards, with the DKG certification criteria serving as the minimum standard for oncological care [121]. This approach ensures that cancer care is delivered within a structured network, focused on both quality and efficiency, providing patients with comprehensive, multidisciplinary support across all phases of their treatment.

zentraler Aspekt bei Krebsversorgung: nicht ambulant versus stationär, sondern ob Pat. adäquaten & kontinuierlichen Zugang zu Versorgungsstrukturen haben

koordinierte Versorgung zwischen & innerhalb Sektoren essenziell

4.3 Organisation of Breast Cancer Care in Denmark

4.3.1 Cancer Epidemiology and Cancer Care Expenditures

10,5 % des BIP → Gesundheitsausgaben

Gesamtkosten Krebsbehandlung 680 € pro Kopf (2018)

KH-Gesundheitsausgaben € 1.069 pro Kopf (2021)

Denmark's healthcare system is characterised by a life expectancy at birth of 81.3 years and 20.3% of its population aged 65 and older. The country allocates 10.5% of its GDP to health expenditures [63]. In 2018, the per capita cost of cancer care was € 680, with direct costs of € 259 [46]. The cancer incidence rate was 688 per 100,000 population, with a mortality rate of 283 per 100,000 in 2019. Among women, there were 19,267 new cancer cases, with 26% being breast cancer [61]. In 2021, inpatient health expenditures were € 1,069 per capita, with 2.5 acute care beds per 1,000 population [63]. Although inpatient cancer case rates were not reported, Denmark had an 86% five-year net survival rate for cancer [61].

4.3.2 National Health Strategies and Programmes

dezentrales Gesundheitssystem auf 3 Ebenen: bundesstaatliche, regionale & kommunale Ebene

Denmark's universal, tax-funded health system provides comprehensive coverage, although gaps remain in areas such as outpatient prescription medications and adult dental care. The healthcare system is largely decentralised, with planning and regulation occurring at three levels [125, 126]. The state handles regulatory, supervisory, and fiscal responsibilities, while the five regions manage hospitals and oversee the planning and funding of primary care services. The Danish Regions Association coordinates policy development across these regions, and the 98 municipalities are responsible for rehabilitation, home and institutional long-term care, and public health [125, 127].

5 "Versorgungsregionen"

On a system level, the 14 Danish counties were transformed into five Danish health care regions (Danske Regioner). This change in policy meant that the counties lost their authority to levy taxes, becoming entirely dependent on the central government for the funding of their operations. The five Danish health care regions are the North Denmark Region (Region Nordjylland), Central Denmark Region (Region Midtjylland), Region of Southern Denmark (Region Syddanmark), Region Zealand (Region Sjælland), and the Capital Region of Denmark (Region Hovedstaden) [128].

DK in 90ern hohe Krebsraten → Implementierung von verschiedenen Reformen & NCPs

In the 1990s, a series of epidemiological studies by the Danish Institute for Clinical Epidemiology showed that Denmark had higher cancer rates than its Scandinavian neighbours [128]. Especially breast and lung cancer rates were substantially elevated. Furthermore, survival rates for all common forms of cancer were significantly lower than in comparable countries. Since then, several healthcare policy reforms and NCPs on different levels have been implemented that have affected the organisation and provision of health care services, including (breast) cancer care [128, 129]. Table 4-6 overviews the evolution of the NCPs in Denmark.

Dänische Krebsgesellschaft spielt eine wichtige Rolle in der Implementierung der Reformen & NCPs

Cancer care gradually changed from 2000 onwards with the first Cancer Plan (Kræftplan 1) [130]. One of the main contributors and drivers of these policy processes in cancer care was and still is the Danish Cancer Society (Kræftens Bekæmpelse) [131]. The Danish Cancer Society provides policy- and decision-makers with scientific evidence at individual and population levels [128]. It has more than 400,000 members, almost 700 employees and a turnover of DKK 750 million (€ 100 million). For example, around 60% of its budget is spent on cancer research in its own research centre.

So-called Cancer Patient Pathways or Cancer Care Pathways (Pakkeforløb, CCPs) were introduced with the Cancer Plan 2 in 2005 for all cancer types, including a CCP for breast cancer. A CCP is a treatment algorithm that goes beyond traditional clinical guidelines and defines what should be done for a specific diagnosis. It also specifies how much time each measure should take to diagnose and treat a cancer patient [132].

Cancer Care Pathways (CCPs) wurden 2005 durch Krebsplan 2 eingeführt

All the Danish CCPs underwent major revisions in 2010 during the preparation of the Cancer Plan 3 and are continuously adapted depending on the most recent evidence [133-136]. Until now, four Cancer Plans have been developed and presented. Each Cancer Plan undergoes periodic evaluation. For example, the achievement of the defined aims of the Cancer Plan 4 was assessed four times since its publication. The most recent, fifth Cancer Plan is currently in development and will be presented in Autumn 2024 [137]. Table 4-6 gives a chronological overview of all Danish Cancer Plans and lists the main developments outlined in each plan.

CCPs wurden 2010 wesentlich reformiert und seitdem kontinuierlich evaluiert & angepasst

Table 4-6: Overview of National Cancer Plans in Denmark

Cancer Plan (Year)	Focus and selected recommendations regarding breast cancer (outpatient) care	Sources*
Cancer Plan 1 (2000)	Focus: ■ Epidemiology in Denmark compared to Nordic countries ■ General cancer treatment and implementation questions (Areas of action: Prevention, education of health personnel, inquiry, referral and visitation, organisation of diagnostics and investigation, expansion of diagnostics and treatment capacity, collection of surgical treatment expertise, screening, research and development, rehabilitation, palliation) Recommendations regarding breast cancer: ■ Surgical treatment of patients with breast cancer is recommended to be based in specialist units in each county ■ Recommendation for a gradual, nationwide implementation of screening for breast cancer and support and further development of a clinical quality registry for breast cancer	[130] (Danish), [138] (English)
Cancer Plan 2 (2005)	Focus: ■ Prevention (focus on tobacco prevention); optimisation of patient processes; improve quality of cancer surgery and standard medical treatments/implementation of Cancer Care Pathways (CCPs) and Multidisciplinary Cancer Groups (DMCGs) for all cancer groups; monitoring and dissemination of data documenting the care quality Recommendations regarding breast cancer: ■ Recommendations for establishing a nationwide screening for breast cancer ■ Waiting time requirements: Maximum response times for fine needle biopsies of one day, histological examination of 4-5 days, and surgery of 14 days ■ A prerequisite for the so-called "same-day diagnostics" (one-stop clinic) is that the mammography teams work within the same hospital. ■ Centralisation of breast cancer surgery (Minimum volume standards: 150 annual surgeries per department and 50 surgeries per surgeon/Maximum surgeries per department: >500-600 surgeries per year not appropriate) ■ Breast surgery should only be done in pure breast or breast endocrine surgery departments. In centres that do not have a separate breast or breast endocrine surgery department, breast surgery patients should be grouped in separate units with associated nursing staff and associated physiotherapists. ■ Primary reconstruction and oncoplastic surgery capacities should be increased ■ Patient hotel to ensure patient safety: Streamline and restructure the hospitals or breast surgery centre's operations by targeting staff efforts, especially nursing efforts, in relation to patient needs ■ Follow-up/Aftercare: Examination every 3-6 months for five years and then annually for 10 years; mammography every two years for the 50-70 age group and every 1.5 years for younger patients	[139-141] (Danish), [142] (English)

Cancer Plan (Year)	Focus and selected recommendations regarding breast cancer (outpatient) care	Sources*
Cancer Plan 3 (2010)	Focus: ■ Patient journey and care processes that lie before and after examination and treatment in the hospital, including early detection, rehabilitation and palliation (e.g., national Programme for rehabilitation and palliative care); revision of CCPs for all cancer forms Recommendations regarding breast cancer: ■ Hospital-based and hospice-based specialised palliative care services should be expanded (e.g., access to interdisciplinary palliative care specialists and implementation of special palliative care wards in hospitals, hospices, home care, outpatient services and daycare) ■ Communication with the patient and coordination across sectors in the patient pathway: Professionals should inform the cancer patient verbally and in writing about the next steps, offer the patient a copy of the medical record and provide guidance on how the patient can improve their situation. In an outpatient programme, patients should receive regular information and status updates on their progress.	[133, 134] (Danish), [135] (English)
Cancer Plan 4 (2016/2017)	Focus: ■ Patient-centred care (patient focus); prevention targeted at children, young people and special groups; increased quality and improved survival; duty of care/due diligence Recommendations regarding breast cancer: ■ Surgical treatment of patients with breast cancer is recommended to be based in specialist units in each county ■ Rehabilitation and palliative care should focus on quality of life and functioning both in the primary and secondary care sectors (e.g., women who have undergone surgery for breast cancer and need rehabilitation focusing on upper limb function.)	[136] (Danish)
Cancer Plan 5 (2024)	Currently, no complete information is available: the presentation of the Cancer Plan 5 will take place in Autumn 2024	[143] (Danish)

* *The Danish sources were searched for the terms "bryst" (breast) and "ambulant" (outpatient) to identify relevant information on outpatient breast cancer care.*

Despite the implementation of new cancer care policies and the substantial decline in cancer incidence and mortality, the estimated cancer incidence and mortality rates in Denmark are still higher than the EU averages (688 vs 569 per 100,000 population and 283 vs 247 per 100,000 population) [5, 144]. The more recent Cancer Plan 4 and the available information on Cancer Plan 5 indicate that Danish cancer policy focuses more on early detection and prevention measures, emphasising social inequalities and socio-economic disadvantage [61, 136].

rezentester NCP fokussiert auf Krebsfrüherkennung, Prävention & soziale Ungleichheiten

4.3.3 Health Care Infrastructure and Patient Journey

Standard Requirements for Cancer Care

In Denmark, breast cancer care is almost exclusively provided through the universal healthcare system by respective breast cancer units located in hospitals [145-147]. Some small private departments in Denmark provide limited oncological services [145, 146].

Brustkrebsversorgung in DK hauptsächlich durch Brustkrebszentren

Cancer care-relevant certifications are not exclusive to breast cancer centres but are part of larger oncology departments that treat multiple cancer entities. These departments have designated areas for breast cancer patients but no standalone certified breast cancer centre [145]. One cancer centre (Vejle Cancer Centre – Lillebaelt Hospital) is OECI-certified (see Chapter 1.3.2), and one is in the accreditation process (Aarhus University Hospital) [27].

Zertifizierungen sind nicht brustkrebszentrums-spezifisch, sondern universell (z. B.: OECI)

Breast cancer Patient Journey

Identification of Patients

Potential breast cancer patients are generally identified in three ways in Denmark [146]:

Brustkrebspat. auf 3 Wege identifiziert:

- Identification by **GPs**: 85-90% of all cancers are diagnosed based on symptomatic presentation [148]. Regarding breast cancer, this number is approximately 66% [149]. GPs in Denmark act as gatekeepers to the secondary health care sector and are often the first contact point for patients with potential cancer symptoms. The Ministry of Health in Denmark introduced CCPs, including a three-legged diagnostic strategy linking GPs, hospitals and specialist diagnostic centres to improve the diagnostic process quality-wise but also regarding coherent cross-sectoral coordination [148, 150]. When GPs suspect non-specific severe symptoms and signs of cancer (NSSC), they can either refer patients to hospital departments through one of the CCPs based on the severity of symptoms or initiate the first mandatory diagnostic step of the CCP for non-specific Symptoms and Signs of cancer (NSSC-CCP) themselves [150-152].

GPs fungieren als "Gate Keeper" & sind die erste Anlaufstelle

- Identification during the **National Breast Cancer Screening Programme (by specialists)**: Denmark also offers an organised breast cancer screening program for early detection [148]. Approximately 33% of breast cancer cases are detected by mammography screening [149]. All women aged 50-69 years are eligible for screening for breast cancer every other year. The screening is organised at the national level and operationalised at the regional level [5, 153]. Women are invited by digital invitation letters with a fixed appointment and link to an information leaflet. Examinations, including diagnostics, will be offered within 14 days if there is suspicion of cancer [153].

nationales Screening

- A minority of breast cancer cases are **identified incidentally**, for example, through a PET scan.

Zufallsbefunde

In all three cases, the Danish healthcare system provides a clear patient path based on guidelines elaborated by the Danish Breast Cancer Group (DBCG) [146, 147, 154, 155]. The path (Figure 4-3) is outlined in an official document by the Danish Health Authority ("Sundhedsstyrelsen") describing the CCP in breast cancer care [156].

in allen 3 Fällen folgt ein klarer CCP

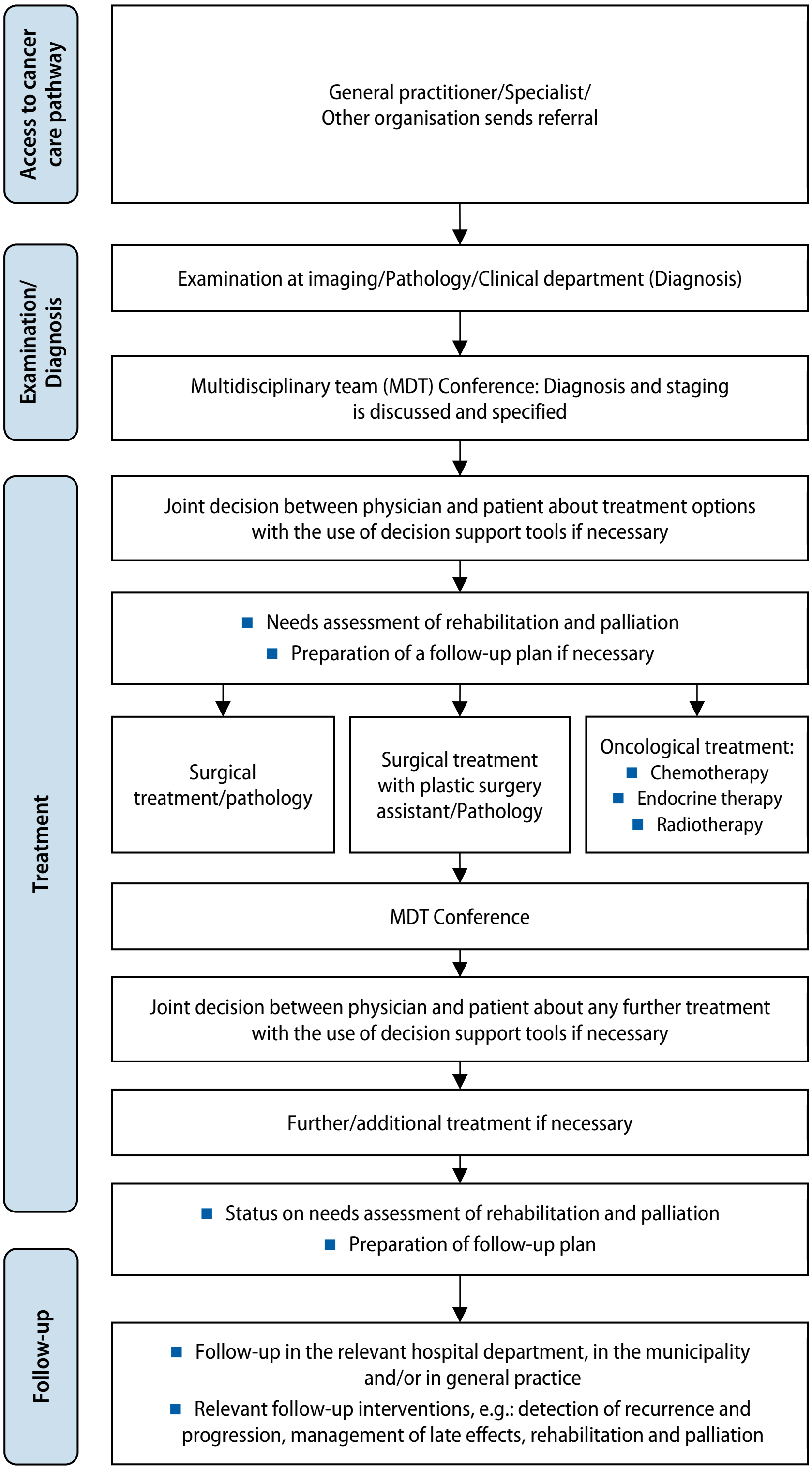


Figure 4-3: Overview of breast cancer care pathway (adapted from Danish Health Authority (Sundhedsstyrelsen) [2024], own depiction)

Diagnosis

As described, GPs in Denmark have extensive competencies in the breast CCP. GPs are eligible to initiate the first mandatory step of the NSSC-CCP. The first step in the NSSC-CCP includes anamnesis, physical examination and a pre-specified blood panel. According to Danish guidelines, GPs can even order diagnostic images (X-ray, ultrasound, CT scan) [152]. After the initial work-up, including the first **physical examination**, GPs typically refer patients directly to hospital (outpatient) clinics, which are responsible for all the NSSC-CCP steps based on expert input [146]. The official document for the breast CCP states that the imaging department is the primary contact unit responsible for managing the pathway prior to the first imaging examination [156].

GPs haben umfangreiche Kompetenzen in der Krebsversorgung → physische Untersuchung & umfangreiches Blutbild

Generally, Denmark has consolidated breast cancer care in specialised clinics in eight oncology departments, each handling a substantial number of cases annually, driven by advancements like **sentinel node technology** that necessitated centralisation. Diagnostic services such as a second **physical examination, blood samples, diagnostic imaging, pathology (biopsy),** and **genetic analysis** of the tumour tissue are centralised in hospital outpatient clinics. Propagation diagnostics, including **staging**, are conducted in the hospital outpatient clinic setting and private certified radiology clinics. A diagnostic work-up follows any suspicious clinical observations within six days [146].

Großteil der Diagnostik in Onkologie-Departments in Spezialkliniken auf spitalsambulanter Basis

As described, breast cancer care, including diagnostics, is almost exclusively provided through public health care providers, primarily done in hospital outpatient clinics by specialised personnel. Only some specific private **radiology** clinics collaborating closely with hospitals and outpatient clinics to expedite care offer mammography, ultrasonography, and **biopsy** services. For example, private clinics conduct the initial imaging and biopsies before sending samples to hospitals for testing [146].

KH kooperierende private Radiologie-Zentren → Biopsien, Mammographien & Sonographien

Treatment

Therapy Management

All treatment recommendations are made at the **MDT** conference in hospital outpatient clinics, ensuring comprehensive treatment plans tailored to each patient's needs and following national guidelines rigorously [145, 146]. MDT conferences are held every morning in larger departments, while in smaller departments, they typically occur three times a week [146]. During MDT conferences, specialists from various disciplines discuss each patient's case, including biopsy results, to determine the most appropriate course of action. If there is a consensus at the MDT conference, the treating physician presents those therapy options to the patient. The MDT in the hospital outpatient clinic usually consists of surgeons, gynaecologists, nurses, medical oncologists, radiotherapists, pathologists, and radiologists.

spitalsambulante MDT-Konferenzen sind für Behandlungsplan verantwortlich

Final treatment decisions are made jointly by the treating physician and patient with the use of the MDT conference recommendation and further decision support tools if necessary ("shared-decision making") [156]. While the MDT strives for consensus during initial MDT conferences, ultimately, the patient retains the right to decide the treatment path. However, the patient's decisions must align with Danish guidelines [145]. One of the decision support tools that is used in the breast cancer care context is "Together on the choice of treatment for breast cancer" ("Sammen om valg af behandling for brystkræft"). This tool is intended to be implemented in all breast surgery centres in Denmark to strengthen the patient's and carer's right to decide on their treatment [157].

finale Behandlungsentscheidung zwischen behandelndem Arzt/Ärztin und Pat. → MDT-Konferenz & nationalen LL

If necessary, a first needs assessment of rehabilitation, palliation, and preparation of a follow-up plan is also part of this stage [156]. **Geriatric assessment** conducted in the inpatient setting or hospital outpatient clinic can be part of such an initial needs assessment. However, geriatric assessment is not systematically implemented. **Bone density measurements** and additional blood samples are typically performed in hospital outpatient clinics.

initiale "Bedarfsanalyse" von Rehamassnahmen, Palliation & Knochendichtemessung

Therapy Options

While some private clinics assist in diagnostics, all **adjuvant** and **neoadjuvant treatments** and **radiotherapy** are performed exclusively within hospital outpatient clinics, reflecting Denmark's rather hospital-centred cancer care approach [146]. **Surgical procedures,** such as lumpectomy, mastectomy and breast conservations, are conducted in the inpatient setting with an overnight stay, if necessary, or in hospital outpatient clinics [145, 146]. **SLNB** is an integrated part of the surgical procedure and therefore conducted during inpatient surgery procedures. Surgery is centralised in a few departments, while oncological therapies are carried out in several departments, such as oncology or surgical departments. Surgeons specialising in **breast surgery** collaborate closely with plastic surgeons for primary reconstructions.

Radiotherapien, adjuvante & neoadjuvante Therapien Spitalsambulanz

OPs grundsätzlich ohne Übernachtung (nur im Bedarfsfall)

Oncology departments primarily provide **endocrine treatment**, but for selected patients, it can be provided by a surgical department [156]. This setup ensures comprehensive and coordinated care [145]. Oncologists are primarily responsible for radiation and chemotherapy [61]. In 2019, the number of radiation therapy equipment units in hospitals and the ambulatory sector per 1,000,000 inhabitants was one of the highest among EU countries. Denmark has eight radiotherapy centres: two each in the Hovedstaden, Syddanmark and Midtjylland regions and one each in the Sjælland and Nordjylland regions. Proton ion therapy is only available in Aarhus at the Danish Centre for Particle Therapy, in region Midtjylland [61].

endokrine Therapie in Onkologie-Abteilungen oder auch in onkolog.-chirurgischen Abteilungen

After the initial treatment, the MDT conference takes place a second time in order to make a recommendation for further treatment. The recommendations are subsequently reviewed with the patient, and the physician and patient collaboratively decide on the next steps in treatment, utilising decision support tools as needed [156]. If necessary, additional treatment is initiated.

nach Erstbehandlung ein zweites Mal → MDT-Konferenz

Women undergoing **endocrine treatment** visit hospitals every six months for monitoring, medication, and nurse consultation. Long-term use of endocrine therapy can also be administered as home treatment or in an outpatient setting. **Chemotherapy** is currently not administered at home, although future trends might lean towards such practices, which are still under hospital oversight [145, 146]. Denmark has easier access to new cancer treatments than most EU countries [61].

langfristige endokrine Behandlung auch auf Home-Treatment-Basis

Chemotherapie aktuell im spitalsambulanten Setting

Patient Support and Follow-up Care

For patients already diagnosed with cancer, **counselling** is overseen by oncologists from hospital outpatient clinics. Additionally, **social workers** are available for support upon request in the outpatient setting [146]. The Danish Cancer Society in Copenhagen offers comprehensive supportive care services, including **psycho-oncological support**. Hospital outpatient clinics also offer **psycho-oncological care**. However, such comprehensive services are less available in smaller regions and are only systematically implemented in the paediatric setting [145, 146, 158]. The small number of private oncology departments in Denmark also provide support services such as psycho-oncolo-

Sozialarbeiter*innen auf Anfrage im ambulanten Setting

psychoonkolog. Beratung hauptsächlich im spitalsambulanten Bereich

gical support. **Geriatric assessment** is not as systematically conducted for all patients. Instead, decisions regarding additional consultations with specialists like cardiologists or pulmonologists are made on a case-by-case basis, depending on the patient's needs and health profile [146].

geriatrisches Assessment nicht systematisch für alle Pat.

In Denmark, **fertility counselling** is prioritised for young breast cancer patients under 40 years, discussing preservation options prior to treatment initiation. **Genetic counselling** is recommended for patients who are disease-free but aware of carrying genetic mutations like BRCA. For patients undergoing mastectomy, the process includes an automatic provision of prostheses such as bras. The process is managed by cancer nurses from the surgical department after wound healing. **Fertility counselling**, **sexual health counselling**, and **genetic counselling** are conducted in the respective hospital outpatient clinics [146].

Beratung → Fertilität, Genetik, sexuelle Gesundheit erfolgt in der jeweiligen KH-Ambulanz

Further needs regarding **rehabilitation** and **palliation** are assessed after determining the necessity for additional therapies. Furthermore, a follow-up plan is prepared. The follow-up plan can be initiated early in treatment and must be prepared by the treating department at the end of the treatment at the latest [156]. Hospitals are responsible for treatment and rehabilitation during the patient's hospitalisation and for treatment and specialised outpatient rehabilitation after discharge. All patients who have completed treatment for breast cancer have the option to contact either the treating follow-up department directly if they suspect recurrence or new breast cancer without first visiting their GP [156].

konkrete Reha- und Palliativmaßnahmen nach Feststellung weitere Therapiemaßnahmen geplant

In case of tissue damage or impaired shoulder-arm function, referral for treatment by a physiotherapist with expertise in the physiotherapeutic treatment of breast cancer patients is indicated. Physiotherapeutic rehabilitation can be done within the rehabilitation plan (follow-up plan) of the treating clinical department or with a referral to an appropriate health care professional in the municipality. Women with chronic pain affecting their daily lives where the GP is unable to solve the problem should be referred to a pain clinic. If lymphoedema is suspected, relevant imaging procedures are conducted to rule out recurrence or other causes of lymphoedema. The patient is then referred to a lymphoedema-trained physiotherapist for treatment. For some patients, it may be helpful to refer them to counselling on physical activity and exercise in everyday life after breast cancer in the municipality [156]. Annual imaging is provided, and prophylactic surgery options are discussed if desired [146].

physiotherapeutische Reha im Rahmen des Rehabilitationsplans oder mit einer Überweisung an Gesundheitsdienstleister (GDL) in der Gemeinde

Follow-up or **survivorship care** can occur in specific hospital outpatient clinics, municipalities, and/or general practices. Relevant follow-up interventions include detecting recurrence and progression, managing late effects, breast reconstruction, rehabilitation, and palliation. Breast reconstruction and plastic surgery are exclusively conducted in an inpatient setting. **Palliative care** begins in the inpatient setting, continues to be provided by outpatient clinics, and is available at home [156].

Survivorship-Care findet im spitalsambulanten & niedergelassen Setting statt

The described patient journey from diagnosis to follow-up, including the place of care provision, is depicted in Figure 4-4. Additionally, the Appendix document provides more detailed information on the place of health care provision and the involved professions.

"Patient Journey" Details in Abb. & Tab. im Appendix-Dokument

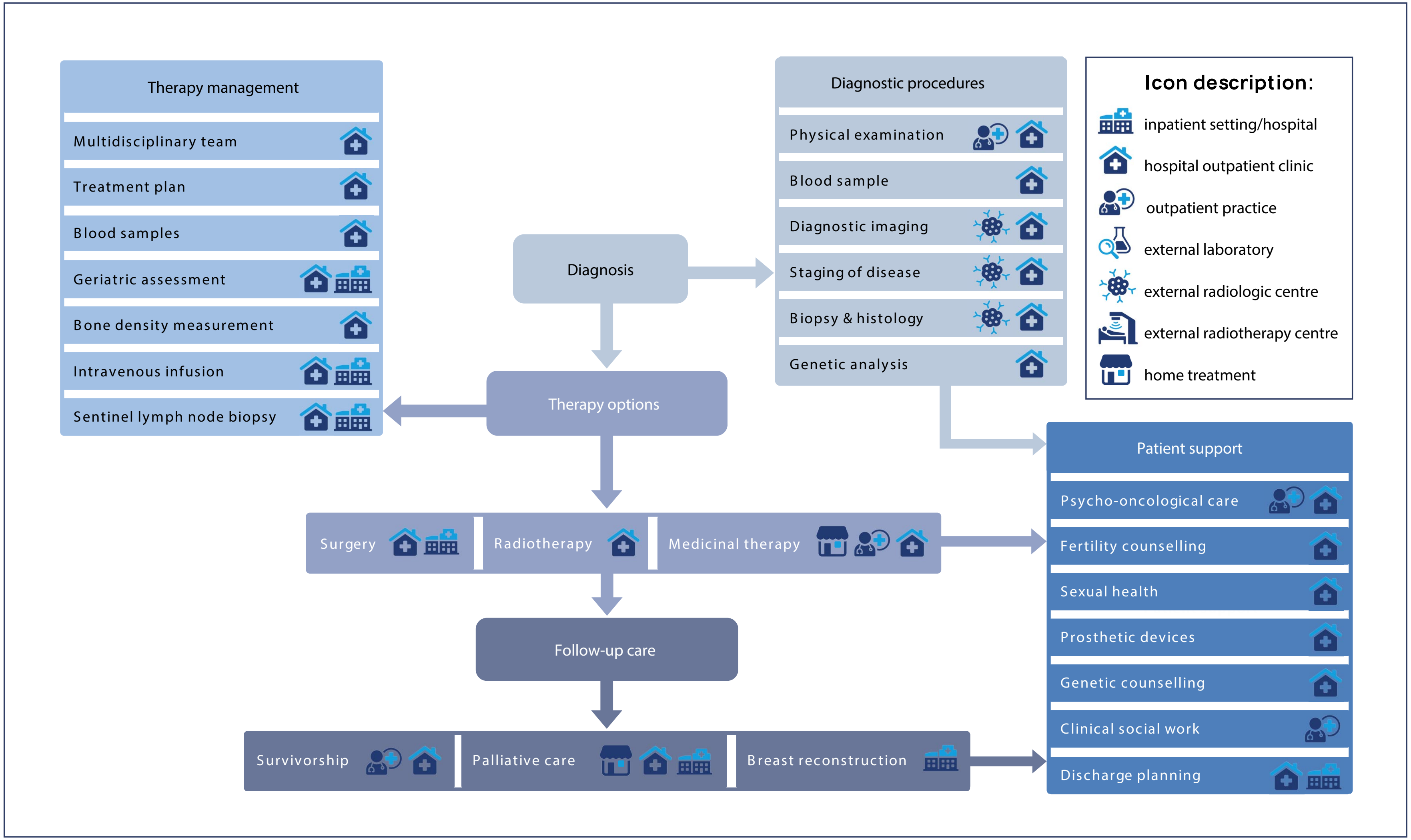


Figure 4-4: Patient journey and place of care provision in Denmark

4.3.4 Cross-Sectoral Care Coordination

Care coordination

In Denmark, individuals with cancer, as well as their caregivers, often feel burdened with the responsibility of coordinating their treatment. Many patients experience a "disease-centric approach" rather than a "patient-centric approach" to care and find that no single physician assumes responsibility for their treatment at the clinic [159, 160].

Pat. wünschen sich "Pat.-zentrierte" Versorgung

Based on these observations, the Danish Health Authority (Sundhedsstyrelsen) [2016] emphasised the importance of a coherent and well-coordinated health care process for the patient in the fourth Cancer Plan evaluation report. The three previous Cancer Plans have already concentrated on strengthening cancer patients' rehabilitation and coordinating rehabilitation. Since then, rehabilitation coordinators have been implemented to ensure coherence across sectors. In addition, research and development units for rehabilitation have been established in all regions. For example, municipal cancer rehabilitation projects were already initiated and evaluated from 2007 to 2009 [160].

Dänische Gesundheitsbehörde: kohärente und gut koordinierte Krebsversorgung für Pat. essenziell

Though oncologists play a major role in cancer care as they are accountable and responsible for patient treatment, they only step in mainly for complex cases or when treatment plans need to be reviewed. In the North Denmark Region, for example, the term "responsible physician" is used to describe a physician responsible for the treatment within a given speciality, including responsibility for preparing a treatment plan and logistics and progress in the process [160].

"zuständiger Arzt/zuständige Ärztin" verantwortlich für Pat.-Behandlung

Experienced nurses play a crucial coordination role in breast cancer care, particularly in palliative care. Nurses handle most patient interactions and treatments and ensure that responsibility for the care process is transferred when patients change between sectors or clinics [146, 147, 160]. This division of tasks and responsibilities is deemed resource-efficient, though it has become more demanding due to new treatments' complexity and side effects [147].

erfahrene Pflegefachkraft verantwortlich für Koordination & Pat.-Interaktion

An open telephone hotline is in place to coordinate care between treating practitioners and patients. According to expert information, this consultation form has proven effective in remotely managing patient care. A digital health initiative involving the Danish Cancer Society is currently developing and piloting a digital health app (DHA) for patients to report side effects of treatments (such as pain or sleep disturbances), recurrences, and other patient-reported outcomes (PROMs). The aim is to reduce the need for frequent hospital visits and to simplify care coordination [146, 161]. The DHA is currently piloted in four hospitals. However, the DHA is planned to be rolled out on a national level in the future [146].

Telefonhotline effektiv für die Koordinierung zwischen Pat. & behandelnder Einrichtung

aktuell Entwicklung einer digitalen Gesundheitsanwendung (DiGA)

Health Care Data

Electronic Health Records System

Denmark has a unified electronic Health Information Exchange (HIE) portal. This eHealth Portal (sundhed.dk) provides both access to and information about all the Danish health care services. The eHealth portal includes health information, access to medical records, and medication. The portal is mainly focused on general health care services; therefore, the platform is used by GPs and citizens to have insight into their updated health care information[162].

einheitliches eHealth-Portal in DK mit Fokus auf allg. Gesundheitsleistungen

The portal has the following functionalities:

Funktionen des Portals

- View treatments and diagnoses from own hospital patient record.
- Book appointments with GP.
- Renew prescripted drugs.
- Monitor own drug compliance.
- Survey shortest waiting lists for operations and quality ratings of hospitals.
- Register as an organ donor.
- Get access to local DMPs in outpatient clinics.

Überblick Leistungen, Terminvereinbarung, Rezepte erneuern, Compliance-Monitoring, Wartelisten für OPs,

Zustimmung Organspende & Zugang zu lokalen DMPs

Health providers can also log on, but due to data protection and privacy reasons, they have access only to personal data regarding patients they are actively treating [162]. Therefore, according to expert consultation, Denmark has no comprehensive EHRs system for the whole population that allows for extensive cross-sectoral or inter-hospital data access and transfer [146, 147]. Hospitals, including outpatient clinics, operate with separate systems. However, data is transferred between hospitals to ensure the continuity and accessibility of patient information, albeit not on the basis of a comprehensive software system [146].

GDL können auch Einsicht haben, aber nur wenn Pat. Einverständnis gibt

KH haben eigene ePA-Systeme

Cancer Registry and Quality Registry

Denmark has a patient registry, but it is mainly used for planning purposes at a healthcare system level, including analysis of hospital statistics. The registry collects patient data from patients treated in hospitals and data from ambulatory and emergency departments [163, 164]. Furthermore, authorities in Denmark operate several databases and clinical quality registries (QRs) for which cancer-related data is collected. For example, the Danish Quality Database for Breast Cancer is a QR specifically for breast cancer care, which was initially established by the Danish Breast Cancer Cooperative Group (DBCG). The fully digitalised registry is now operated and managed by the Danish Regions Clinical Quality Program (RKKP) [165]. The DBCG provides evidence-based expertise to the QR and creates annually published reports [166].

Qualitätsregister (QR) für verschiedene Krebsentitäten (auch Brustkrebs)

jährliche Berichte über die Qualität der Brustkrebsversorgung

The primary purpose of the database is to monitor and improve the quality of diagnostics and treatment on a health system level while also serving as a foundation for breast cancer research. The DBCG is predominantly based on selected clinical breast cancer data entered by the departments that have registered patients since 1978. The data is directly entered either by the treating physicians (surgeons, pathologists, oncologists, radiotherapists) or their secretaries. The database coverage is about 95%. During the data collection, 195 variables were collected, including patient characteristics, information on the diagnosis, and treatment data [167]. In addition, the DBCG monitors ten quality indicators with three indicators collecting sub-indicators. All ten quality indicators have target values that must be met to fulfil a certain standard of care [168].

Brustkrebs-QR mit einer Abdeckung von 95 %

195 Variablen werden gesammelt & 10 Indikatoren „überwacht“

The data collection in the DBCG does not include comprehensive socio-demographic, socio-economic, or other patient-related characteristics such as smoking status or body mass index (BMI) information. Furthermore, this database may not fully capture some older patients who undergo only biopsy and antihormonal treatment [146]. The Danish QR data is supplemented with extracts from the National Patient Register, the Pathology Register, and the Danish Central Person Register (CPR). Furthermore, it is planned that the

sozioökonomische & -demographische Charakteristika werden im Brustkrebs-QR nicht gesammelt

patient-reported data, such as late side effects and symptoms, from the currently developed DHA is fed into the DBCG.

seit 1943 Dänisches Krebsregister

Datensammlung verpflichtend → Daten fast vollständig

Another database where data collection is mandatory is the Danish Cancer Registry (DCR), managed by the Danish Health Data Authority. The DCR is a population-based registry collecting information about all incident cancers and pre-stages, including breast cancer, since 1943 [169]. The primary purpose of the registry is to monitor the incidence and survival of all patients with cancer. According to expert information, the DCR is almost complete data-wise and is a comprehensive backup to the DBCG [146].

Developments and Trends

Projektion 2029-2033: Aufwärtstrend hinsichtlich Behandlungen im (spitals)ambulanten Sektor aufgrund der wachsenden Zahl von Krebserkrankungen

According to the Danish Health Authority, for the period 2007-2014, there was a general increasing trend in the number of patients with all types of cancer treated with surgery, radiotherapy, or chemotherapy. The increase in numbers can be attributed to both the growing incidence of cancer patients and a rising trend in treatment availability [160]. Outpatient chemotherapy has been increasing due to the growing cancer incidence and rising costs of hospitalisation. The projection for the period 2029-2033 indicates that the upward trend in the outpatient sector will persist because of the growing number of cancer cases [160]. Breast cancer-specific numbers were not available. However, breast cancer is by far the most common cancer in women in Denmark [153]. For this reason, it can be assumed that the increasing trend towards outpatient chemotherapy also applies to breast cancer.

Verlagerung hin zu OPs in Spitalsambulanzen ohne Übernachtung

According to expert information, there has been a shift towards surgeries without overnight stays in hospital outpatient clinics for breast cancer patients over the past two decades [145, 146]. Patients undergo breast cancer procedures under general anaesthesia and return home the same day [145].

Home-Treatment-Konzepte in Planung

zudem auch Bemühung zur Steigerung der Pat.-Compliance

Specific treatments, like endocrine therapy and fertility preservation injections, are also administered at home. GPs also provide some treatments, such as bone protection medications [145]. However, immunotherapy and chemotherapy are currently not administered at home [146]. According to expert information, home treatment concepts are being developed for some drugs, such as cyclophosphamide or bortezomib [170]. However, ensuring patient compliance with medication is a significant concern in Denmark [145]. Studies have shown that non-compliance negatively impacts survival rates [171-173]. Innovations like hospital pharmacy services help distribute medication, and other factors relating to patient condition, therapy, healthcare system, and socioeconomic condition help to sustain adherence, but monitoring compliance remains challenging [145, 173]. Efforts are ongoing to improve compliance through various strategies and further research [145, 173].

Entwicklung von „Patient-Reported Outcomes“ (PROM)-Tools für den ambulanten Bereich

Besides the intended implementation of PROMs for patient reporting, the Danish Health Authority stated that PROM tools will be developed for use in the outpatient setting [160, 174]. Tasks may be shifted across sectors, e.g., home treatment with chemotherapy or follow-up may be conducted in general practice rather than in a hospital setting. Integrating PROM tools in post-surgery follow-up for prostate cancer exemplifies how patient self-assessment can mitigate the necessity for hospital outpatient check-ups, thereby optimizing resource allocation. However, the extent of implementation of these recommendations remains uncertain. An expert has confirmed the implementation of PROMs for chemotherapy, suggesting varying degrees of adoption across different treatment modalities [147].

The Danish Health Authority (Sundhedsstyrelsen) [2016] concluded in their 2016 report that the potential pressure on the healthcare system as a result of more cancer patients would depend on several factors, such as general public health trends and organisation of care, including the shift to outpatient treatment, productivity development, and new technological opportunities. Furthermore, the increasing specialisation and centralisation of the hospital system, combined with more outpatient contacts and shorter hospitalisations, can challenge the ability to ensure a coherent care pathway due to potential cross-sectoral referrals [160].

Spezialisierung & Zentralisierung der Versorgung in Verbindung mit kürzeren Aufenthalten → kann kohärenten Versorgungspfad negativ beeinflussen

4.4 Organisation of Breast Cancer Care in Sweden

4.4.1 Cancer Epidemiology and Cancer Care Expenditures

In Sweden, life expectancy at birth is 83.1 years, and 20.3% of the population is 65 and older. The country allocates 11.2% of its GDP to health expenditures [175]. In 2018, the per capita cost of cancer care was € 413, of which € 187 is direct [46]. The cancer incidence rate was 557 per 100,000 population, with a mortality rate of 217 per 100,000 in 2019. Among women, there were 26,228 new cancer cases, 29% of which were breast cancer [176]. In 2021, inpatient health expenditures were € 957 per capita, with 2.1 acute care beds per 1,000 population [175]. While inpatient cancer case rates were not reported, Sweden had an 89% five-year net survival rate for cancer [176].

11,2 % des BIP → Gesundheitsausgaben

Gesamtkosten Krebsbehandlung 413 € pro Kopf (2018)

KH-Gesundheitsausgaben € 957 pro Kopf (2021)

4.4.2 National Health Strategies and Programmes

The Swedish healthcare system is predominantly decentralised with national oversight, providing universal health care to all residents, regardless of nationality, with only a small portion of costs covered through out-of-pocket copayments [176]. The system is divided into three governance levels. All three levels of government are involved in the governance of the healthcare system, each with distinct responsibilities [175, 177]:

- The **national government** is responsible for regulation and supervision.
- **21 Swedish regions** are responsible for regional cancer plans, financing, organising and providing health care services, whether it is directly provided by the region, purchased from a private health care provider, or from another region.
- **290 municipalities** are responsible for care for people with disabilities, rehabilitation services, home care, elderly and long-term care, and school health care.

dezentrales Gesundheitssystem auf 3 Ebenen: bundesstaatliche, regionale & kommunale Ebene

Since 2010, a mandatory system granting freedom of choice in primary care has been in place, and in 2015, a national system extending freedom of choice to outpatient care was implemented [177]. Both public and private health care providers are publicly funded in Sweden. Public hospitals at the regional level provide acute care, while university hospitals offer highly specialised care [175].

gesetzliche Wahlfreiheit in der Primär- & ambulanten Versorgung (seit 2010 bzw. 2015)

In 2009, Sweden adopted a National Cancer Strategy (NCS) that introduced national guidelines, improved quality assurance and standardised CCPs [176, 178].

nationale Krebsstrategie (NCS) 2009 implementiert

The general goals of the NCS were to

- Reduce the risk of developing cancer.
- Improve the quality of cancer patient management.
- Improve survival time and improve quality of life after a cancer diagnosis.
- Reduce regional differences in survival time.
- Reduce differences in morbidity and survival time between population groups.

Ziele der NCS:

Risikoreduktion,

Verbesserung Pat.-Management & Qualität der Nachversorgung,

regionale Outcome-Unterschiede verringern

Table 4-7 overviews the Swedish NCS and outlines its focus areas. The NCS is divided into three domains: cancer from a public perspective, cancer from a patient perspective, and the supply of knowledge and expertise.

NCS hat 3 Domänen: öffentliche, GDL & Pat.-Perspektive

Table 4-7: Overview of National Cancer Strategy in Sweden (Source: Commission of Inquiry on A National Cancer Strategy [2009])

National Cancer Strategy domains	Focus areas
Public perspective	■ Primary prevention with a focus on smoking cessation, obesity, lack of physical activity, high alcohol consumption, and excessive exposure to UV radiation ■ Cancer vaccines: Future preventive cancer vaccines should benefit everyone (national coordination) and introduction into care and follow-up as for medicines ■ Early detection: introduction of coordinated and structured screening programmes; continuous assessment of existing and future screening programmes; uptake of mammography should be at least 80% and emphasis on groups with a lower take-up rate ■ Public access to knowledge: providing information on health and how to prevent disease adapted to people's differing opportunities to benefit from information
Patient perspective	■ Cancer from a patient perspective: each patient should have a specific contact at the cancer care clinic; involvement of an MDT from the outset; availability of an individual care plan for each patient; collection of health-related QoL (HRQoL) and satisfaction data and communication of the data to providers and the management; appointment of care coordinators; involvement of patient representatives ■ Children and young people: Put greater effort into research and development of knowledge of side-effects of cancer medicines ■ Palliative care: Improve availability and quality; avoid under-resourcing of (increasing need) of palliative care ■ Access to and use of medical technology: Coordination of the introduction of new medicines by healthcare authorities; HTA of inpatient medicines; nationally coordinated follow-up
Supply of knowledge and expertise	■ Cancer centres and level structuring: Development of regional cancer centres (RCCs) alongside university hospitals and regional strategic plans for the sharing of responsibilities and level structuring in cancer care ■ Commitment to cancer research: Continued commitment to research and other development of knowledge ■ Improved follow-up of cancer care outcomes: Strengthening of existing health data and QR; QR should serve as a model for mandatory reporting ■ Measures to ensure future supply of expertise: Healthcare authorities should make a plan for long-term supply of care, training, and continuing professional development in knowledge of supporting functions, IT, technology, and logistics.

Abbreviations: HRQoL … Health-related quality of life, MDT … multidisciplinary team

While the Swedish healthcare system is mainly decentralised, specialised care tends to be more centralised [176, 179]. Therefore, Sweden is additionally organised into six larger health care regions that cooperate to provide specialised health care. In the context of cancer care, six Regional Cancer Centres (RCCs), along with the Confederation of RCCs, were established during the adoption of the NCS. Each health care region has at least one university hospital [176]. The RCCs' primary responsibilities include supporting the NCS implementation, facilitating the formation of national and regional specialist collaborative groups, and establishing national guidelines. Currently, there are approximately 50 care guidelines for various cancer diagnoses and general care guidelines, such as those for cancer rehabilitation and palliative care [180, 181]. Simultaneously, the first clinical QR to monitor guideline adherence were set up [176].

spezialisierte Versorgung bspw. Krebsversorgung zentralisiert → 6 große Gesundheitsregionen mit 6 kooperierenden regionalen Krebszentren (RCCs)

mind. eine Universitätsklinik in einer Gesundheitsregion

In the next step, standardised CCPs ("Standardiserade vårdförlopp") were introduced in 2015 based on the NCS. The CCPs serve as an additional pillar of cancer care in Sweden, complementing the role of the RCCs. The CCPs were introduced in response to the realisation that the maximum waiting times for certain clinical areas, as specified in the National Guaranteed Access to Health Care Policy and enacted into law in 2010, were not suited to cancer care [132]. Given that cancer care is generally more urgent than other clinical areas, the CCPs were primarily designed to reduce waiting times, a longstanding issue debated since the 1960s. Additional objectives of the CCP implementation included standardising diagnostic strategies, enhancing patient satisfaction, and reducing regional inequalities in terms of timely access to care. During 2015-2018, more than 30 standardised pathways, including a breast cancer CCP, were introduced [176, 182, 183].

CCPs zusätzliche Säule in der Krebsversorgung & ergänzen die Rolle der RCCs

CCPs implementiert, um Wartezeiten zu reduzieren

insgesamt 30 CCPs inkl. Brustkrebs-CCP

To achieve the goals outlined in the NCS and those pursued through the implementation of the CCP, ten focus areas were defined on which the RCCs were to concentrate their work [184, 185]:

Fokusbereiche der RCCs und CCPs

- *Preventive measures and early cancer detection:* Developing a better understanding of risk behaviours and targeted preventive support measures, optimising secondary prevention, and increasing knowledge about early cancer symptoms.

  Prävention und Früherkennung

- *Cancer Care Pathways:* Development of CCPs that are perceived as smooth, coherent, and efficient.

  kohärente & effiziente CCPs

- *Psychosocial support, rehabilitation, and palliative care:* Implementation of guidelines on rehabilitation and palliation, provision of support to relatives of cancer patients, and fostering the development of advanced home care.

  psychosoziale Unterstützung, Reha- & Palliativversorgung

- *Patient perspectives in cancer care:* Contribute to the establishment of individual treatment plans for all patients considering geographical and socioeconomic inequalities, offer all patients support from a contact nurse and collaboration with relatives, including education measures, develop cancer care through patient-reported outcome measures, and increase awareness about the right to second opinion.

  Einbindung der Pat.-Perspektive

- *Education and competence profiles:* Mapping of education needs of heath care professionals and developing knowledge improvement initiatives for contact nurses.

  kontinuierliche Fortbildung

- *Knowledge-based health care:* Provision of QR data and inclusion of patient-reported outcomes, follow-up data, and data on side-effects.

  wissensbasierte Versorgung

- *Clinical cancer research and innovation:* Contribution to cancer research by using clinical QR, improving structures for collaboration with academic research and the biotech industry, and developing innovations in cancer care.

Forschung und Innovation

- *Management structure:* Clear leadership structure, collaboration with other RCCs, and use of QR data in follow-up care.

Management-Struktur

- *Strategic development plan:* Establish and implement a regional cancer plan by the RCCs.

regionale Krebspläne

- *Level structuring:* Participation in national-level structuring initiatives, contribution to regional-level structuring, and promotion of regional MDT conferences.

nationale und regionale Versorgungsstrukturen

4.4.3 Health Care Infrastructure and Patient Journey

Standard Requirements for Cancer Care

Generally, cancer care in Sweden adheres to National Clinical Cancer Care Guidelines, which are yearly updated based on the best medical knowledge and the particular CCP. The national breast cancer care guideline and the CCP for breast cancer (Figure 4-5) provide recommendations on patients' diagnosis, treatment, nursing, rehabilitation and follow-up [183, 186]. The goal is that at least 70% of cancer patients should be included in a CCP, and 80% of patients included in a CCP should start treatment within the set time limits (35 days after clinical findings and symptoms). In 2021, about 75% of all cancer patients were included in a CCP [176]. The adherence to the care guideline is monitored with the help of the National Quality Registry for Breast Cancer (NKBC), overseen by a working group of breast cancer experts. Cancer rehabilitation and palliative care must adhere to national guidelines. The palliative care guideline is regardless of diagnosis [187, 188].

nationale klinische Brustkrebsleitlinie und Brust-CCP → Fundament der Brustkrebsversorgung

75 % der Brustkrebspat. partizipieren im Brust-CCP in 2021 (Ziel: 70 %)

Adhärenz LL mit Brustkrebs-QR überwacht

Sweden now has three OECI-accredited comprehensive cancer centres (Karolinska Comprehensive Cancer Centre, Sahlgrenska Comprehensive Cancer Centre and Skåne University Hospital Comprehensive Cancer Centre). Three other university hospitals (Linköping University Hospital, Uppsala University Hospital and University Hospital of Umeå) are currently in different stages of accreditation towards comprehensive cancer centres or cancer centres [176]. Therefore, selected centres adhere to the OECI-quality system that covers standards regarding cancer diagnosis, treatment, education, research, indicators, and peer review processes (see Chapter 1.3.2.). Furthermore, Sahlgrenska Hospital in Gothenburg achieved EUSOMA accreditation in 2021; another hospital unit is currently accredited [179, 189].

3 OECI-akkreditierte CCC und 3 weitere in Akkreditierung

1 KH EUSOMA-akkreditiert und 1 weiteres KH in Akkreditierung

According to the CCP for breast cancer, the patient must be assigned a named contact nurse no later than at the time of diagnosis. The contact nurse must adhere to the national job description, which includes responsibilities such as creating and updating the patient's care plan and ensuring active handovers. The contact nurse must also facilitate connections with appropriate support services or rehabilitation professionals based on the patient's needs, such as a psychologist, psychiatrist, physiotherapist, or lymphatic therapist. The nurse must also provide support through regular calls and pay special attention to the patient's relatives, particularly to children [183].

zugewiesene „Contact Nurse" ist Grundvoraussetzung (spätestens zum Zeitpunkt der Diagnose)

"Contact Nurse" = Bindeglied & Koordinierungsfunktion

Since 2010, there has been a statutory right to permanent care contact in the Patient Act ("Patientlag" 2014:821) [190]. The contact nurse can fill the statutory permanent care contact. The responsibilities of the statutory permanent care contact are on top of the primary responsibilities provided by the contact nurses. The permanent contact aims to improve accessibility to health care services and foster communication between the patient, the care unit, other parts of the health service and social services, and other relevant authorities such as the Swedish Social Insurance Agency [186, 191]. A permanent contact can be appointed upon the patient's request, regardless of whether it is necessary or not [191].

seit 2010 gesetzlicher Anspruch auf „ständigen Pflegekontakt" → „Contact Nurses"

Advanced Health Care in the Home ("Avancerad sjukvård i hemmet", ASIH) is a supplement or alternative form of care to hospital care when the basic home health care services are insufficient. The focus of ASIH teams is on end-of-life and palliative care. A prerequisite for care within ASIH is that the patient and the relatives in the patient's household accept this form of care [179, 192, 193]. Furthermore, the cancer care provider, i.e. the treating hospital clinic, must have an agreement with ASIH centres [194]. Nurses from ASIH centres in the Stockholm Region are also trained in giving chemotherapy at home (not just for breast cancer) in constant correspondence with the hospital contact nurses [179, 192, 194, 195]. However, the ASIH services are not fully implemented across all of Sweden; they are currently available primarily in the larger Stockholm Region [192-195].

"erweiterte Gesundheitsversorgung zu Hause": Ergänzung zur KH-Versorgung, wenn die Grundversorgung zu Hause unzureichend ist (Stockholm)

Breast Cancer Patient Journey

Identification of Patients

As mentioned, Sweden has over 30 CCPs to standardise cancer care across the healthcare system. The CCP for breast cancer, like all CCPs, begins with a well-founded suspicion of cancer [182]. The National Clinical Cancer Care Guideline for breast cancer specifies what constitutes a well-founded suspicion, how it should be investigated, and the maximum allowable time before treatment begins [182, 183]. Figure 4-5 depicts the CCP for breast cancer based on the National Clinical Cancer Care Guideline for breast cancer [183, 186].

nationale LL & Brust-CCP spezifizieren, Definition Krebsverdacht & max. zulässige Zeit bis Behandlungsbeginn

Potential breast cancer patients are typically identified through a nationwide **population-based cancer screening programme** with a recommended screening interval of 18-24 months. The Swedish breast cancer screening programme started in the mid-1980s and is free of charge for participants. All Swedish regions offer mammography screening for women aged 40-74 [176, 186]. Approximately 45% of women aged 40 to 74 have their cancers detected through screening programs [179]. However, a significant portion of cases are also clinically detected via referrals from **GPs** or identified through interval screenings or **incidental findings** via clinical mammography [179].

Brustkrebspat. auf 3 Wege identifiziert

organisiertes nationales Screening; im Zuge von Überweisungen von GPs/Intervall-Screenings & Zufallsbefunde

Hence, the first **physical examination** of patients, including the detection of first symptoms (early examination), takes place depending on the location of identification [179, 196]. If the criteria for well-founded suspicion of breast cancer are met, the patient must be referred for triple examination (Examination block A) according to the CCP (Figure 4-5) [186]. If no cancer is detected, examination block F is conducted, and the CCP concludes. If breast cancer is detected and neoadjuvant treatment may be appropriate, examination blocks B, C, E, and F are performed. Similarly, if breast cancer is detected but further treatment is deemed unnecessary, blocks B, C, E, and F

Setting der physischen Untersuchung abhängig wo erste Symptome identifiziert werden; Kriterien für einen begründeten Verdacht erfüllt → Überweisung zu Untersuchungsblock A („Dreifachdiagnose")

are still carried out. In cases with an increased risk of metastasis, as outlined by national guidelines, the examination process is supplemented by block D, which involves metastasis screening [183].

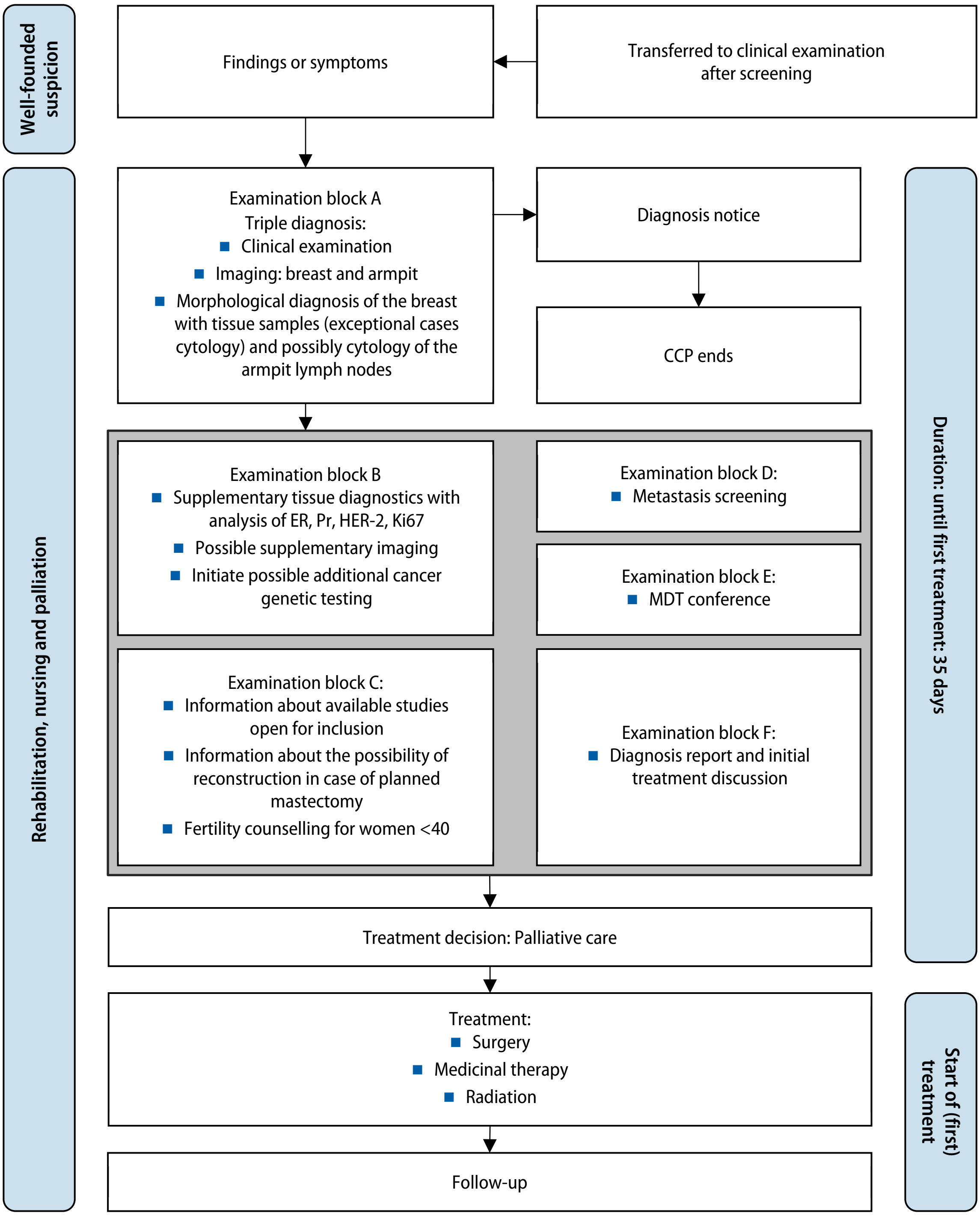


Figure 4-5: Flowchart of the Swedish CCP for breast cancer (adapted from Regional Cancer Centres (RCC) [2024], own depiction)

Diagnosis

Breast abnormalities are diagnosed based on the so-called "triple diagnosis" (examination block A), which includes a clinical examination, imaging, and cytology or tissue biopsy [183, 186]. This collaborative approach ensures a thorough and precise diagnosis, essential for initiating appropriate treatment plans tailored to each patient's condition and needs [179].

"Dreifach-Diagnose": klin. Untersuchung, Bildgebung & Zytologie/Gewebebiopsie

Depending on the situation, **blood samples** are taken directly in hospital outpatient clinics, external laboratories, or even at home. Generally, laboratory staff collect the samples, though nurses may also occasionally perform this task. For instance, advanced health care nurses may visit patients at home to draw blood. Additionally, patients can choose from different laboratories for their blood tests. A more comprehensive **physical examination** is performed by the treating clinician, oncologist, or surgeon at the hospital outpatient clinic [179, 196].

Blutproben → spitalsambulant, ext. Laboren oder zuhause entnommen („Advanced Health Care Nurses")

Mammography is the first choice when investigating clinical findings in the breast. Radiologists in hospital outpatient clinics handle **diagnostic imaging** and a first **staging process** [179]. For patients under 25 years of age, ultrasound examination may be a first choice. A reduced number of mammography projections can be considered if the individual is between 25 and 30 years old. When using preoperative MRI for specific tumour types and complex breast cancer patients, communication between radiologists and surgeons is of particular importance for more precise radiological mapping to result in more precise surgery [186]. The formal, systematic staging process is conducted at the MDT conferences, where all the clinical facts come together [179, 196].

diagnostische Bildgebung & Staging → spitalsambulant durch Radiolog*innen

systematischer Staging-Prozess in MDT-Konferenzen

Biopsies are conducted in hospital outpatient clinics, usually by radiologists, but sometimes by the treating clinician if it is impossible to refer the patient to mammography. Laboratory staff in hospital outpatient clinics is responsible for the **genetic analysis** of the tumour tissue [179].

Biopsien & genetische Analyse des Gewebes → Spitalsambulanz

If any of the three examinations suggest malignancy, the case must be discussed at an MDT conference for further action. Patients must be provided with factual information about their disease, its treatment options, and the expected outcomes to enable them to make an informed decision regarding the treatment offered. The contact nurse should be present when the diagnosis is communicated, and if the patient desires, close relatives may also be present. Patients should be allowed for follow-up discussions and phone calls, during which the information from the diagnostic report can be reiterated and supplemented [183, 186].

bei Malignität → Besprechung & weiteres Vorgehen in MDT-Konferenz

Pat. muss umfangreich informiert werden

Treatment

Therapy Management

According to national guidelines, all patients with primary breast cancer and the findings from their triple examination must be discussed at least once, both preoperatively and postoperatively, during an **MDT conference** [186]. In practice, and depending on the hospital, MDT conferences are held twice preoperatively and twice postoperatively per week, during which the treatment plan for every patient with a tumour change in the breast is discussed.

Besprechung Brustkrebsfall mindestens einmal vor und nach OPs in MDT-Konferenz

The following professions must participate in the MDT conference [179, 186]:

- A surgeon with special knowledge of and focus on breast cancer.
- A plastic surgeon or surgeon with knowledge of oncoplastic surgery.
- An oncologist with special knowledge of and focus on breast cancer.
- A diagnostic imaging specialist with special knowledge of and focus on breast cancer diagnostics.
- A cytologist and/or pathologist with special experience and knowledge of morphological biopsy diagnostics and diagnostics on the surgical patient's surgical tissue.
- A liaison nurse/contact nurse.
- A person responsible for coordination (contact nurse can fill the coordinator function).

MDT-Konferenz-Zusammensetzung:

Chirurg*in mit Fokus Brustkrebs & plastische Chirurgie, Onkolog*in, Spezialist*in diagnostische Bildgebung, Spezialist*in Zytologie/Pathologie, „Contact Nurse" & für die Koordinierung zuständige Person

In addition, the national guideline on palliative care specifies that participation of palliative medicine expertise at the MDT conferences is desirable [187]. Treatment of breast cancer during ongoing pregnancy requires an extended MDT with sufficient experience in treating cancer in pregnant women and an obstetrician from specialist maternal care. Therefore, investigation and treatment planning should take place in consultation with university hospitals and, if necessary, with regional cooperation. Women with a diagnosis or treatment for breast cancer during an ongoing pregnancy must be linked to specialist maternity care at the same hospital [186].

LL: Teilnahme von Palliativmediziner*innen wünschenswert & Brustkrebs während laufender Schwangerschaft erfordert ein erweitertes MDT

The **treatment plan**, including preoperative treatment measures, is discussed with the patient by the treating breast surgeon and/or oncologists from the hospital's outpatient department and reviewed during the MDT conference [179, 186]. For example, in the case of mastectomy, the patient must always be objectively informed about the surgical alternative of mastectomy without reconstruction and the possibilities for direct and delayed reconstruction. If reconstruction is desired but cannot be provided at the treating hospital clinic, a referral must be made to a unit where the procedure can be offered [186].

Behandlungsplan mit Chirurg*in & Onkolog*in besprochen & durch MDT-Konferenz überprüft → Pat. muss über Behandlungsalternativen aufgeklärt werden

A pathologist may be consulted to identify the tumour-bearing area, particularly in patients with a favourable treatment response, such as those achieving complete clinical remission. Furthermore, frequent remission evaluations should be performed during ongoing preoperative medical treatment, primarily with mammography, ultrasound and clinical examination [186].

Patholog*in kann hinzugezogen werden

Geriatric assessment is not formally in place, but if necessary, it is provided and discussed at the MDT conference at the hospital outpatient clinic [179, 186]. An expert group has published guidelines suggesting that follow-up decisions should be based on recurrence risk based on the characteristics of the tumour and the patient's life expectancy [197]. **Bone density measurement** is conducted by radiologists in nuclear medicine departments in hospital outpatient clinics. **Port catheters** for chemotherapy are typically inserted by general, vascular, or breast surgeons in the hospital outpatient clinic on the day of the first chemotherapy session [179].

kein systematisches geriatrisches Assessment (nur bei Bedarf)

Knochendichtemessung & Portkatheter → spitalsambulant

Therapy Options

A breast or oncoplastic surgeon from the hospital outpatient clinic is responsible for the **surgery** (breast conservation, lumpectomy or mastectomy). In most cases, surgeries are performed in the hospital outpatient clinic without an overnight stay. Overnight stays are only necessary in Sweden if complications occur during or after cancer surgery [179].

Brust-OPs prinzipiell ohne Übernachtung

The need for oncoplastic surgery should already be considered when planning surgical treatment. Breast-conserving surgery requires familiarity with both plastic surgery and purely tumour surgical techniques [186]. Furthermore, reconstructive surgery with implants should be performed in a plastic surgery unit or breast unit with specific expertise in reconstructive surgery in accordance with national guidelines. Reconstructive surgery using the patient's own tissue must be performed in a unit with expertise in plastic surgery [186]. **Sentinel lymph node biopsy** is carried out in conjunction with the surgical procedure in the hospital outpatient clinic by a breast surgeon [179, 196].

Notwendigkeit einer onkoplastischen OP bereits bei OP-Planung zu berücksichtigen

SLNB wird im Zuge der spitalsambulanten Brust-OP durchgeführt

Radiation therapy is conducted in the hospital as an outpatient procedure (hospital outpatient clinic) [179]. Sweden has the highest level of radiation therapy equipment per capita in the EU (13 centres per 1,000,000 people compared with the EU average of 9 centres). Based on data reported by the International Atomic Energy Agency (IAEA), Sweden has 79 radiotherapy units and 23 brachytherapy units. Furthermore, the Uppsala region has a proton therapy centre [176].

Radiotherapie → spitalsambulant

Medicinal tumour therapy is carried out by oncologists with the support of nurses in the hospital outpatient clinic. Generally, chemotherapy is given as day procedures in allocated chemotherapy suites in hospital outpatient clinics. Advanced health care nurses from ASIH centres in the Stockholm Region are also trained in giving chemotherapy [192, 194, 195] (see ASIH in section 4.4.3). Typically, the nurses are in constant correspondence with the hospital contact nurses [179]. However, as mentioned, the ASIH services are not fully implemented across all of Sweden [192-195].

medizinische Tumortherapie → spitalsambulanten „Chemotherapie-Suites"

Patient Support and Follow-up Care

As previously mentioned, overnight stays are generally only necessary in Sweden if complications arise during or after cancer surgery. Additionally, patient hotels are not commonly available [179]. Patients usually return to the hospital outpatient clinic for wound checks, or alternatively, support for their wound check at home is provided [196].

„Pat.-Hotels" nicht weit verbreitet

Fertility counselling, genetic counselling, and **clinical social work** are typically provided within hospital outpatient clinics. Oncological nurses are not involved in fertility counselling but are responsible for the referral. The university centres in the six larger health care regions have specific fertility centres that offer fertility counselling. Additionally, each of the six larger health regions has at least one hospital with a genetics department, where blood samples can be sent, and the results and their implications are discussed accordingly. Genetic counselling is typically provided by genetic counsellors and clinical geneticists, who often have foundational training as oncologists [179].

Fertilitätsberatung, genetische Beratung & klinische Sozialarbeit → spitalsambulanten Setting

Usually, **discharge planning** is organised by contact nurses in collaboration with the treating oncologists or breast surgeons. In the case of neoadjuvant therapies, specialised neoadjuvant contact nurses in the therapy suites assume responsibility for this task. **Psycho-oncological services** are available in all hospital centres. In-house psychologists and **social workers** provide psycho-oncological services in an inpatient setting or hospital outpatient clinic. Contact nurses in the surgical department of the outpatient clinic usually manage prosthetic device prescriptions. Once prescribed, patients are referred to local shops that provide these devices [179].

Entlassungsplanung wird von „Contact Nurses" organisiert

psychoonkologische Leistungen in allen KHs verfügbar

Sexual health counselling is also available in the hospital outpatient clinic provided by social workers in collaboration with the respective oncologists. Alternatively, sexual health counselling is conducted via telephone by contact nurses [179, 196].

sexuelle Gesundheit → spitalsambulantes Setting

In most cases, follow-up after all postoperative check-ups is handled by oncological nurses over the telephone. However, patients can also communicate with contact nurses and treating physicians via a hospital-based chat function (Alltid Öppet) [179]. The nurses guide the patient through the remainder of the CCP for up to five to ten years. For patients who do not have scheduled yearly appointments with their treating physician, the cancer nurses contact them once a year for an annual check-up. Additionally, patients can always reach out to the cancer nurses as needed [196].

post-OP-Checks durch "Onco Nurses" & „Contact Nurses" über Chatfunktion

Further **survivorship care** measures are provided in specialised **rehabilitation centres** outside the hospital, connected to physiotherapists, social workers, psychiatrists, and psychologists, or by rehabilitation centres, such as ASIH, on a home treatment basis (see ASIH in section 4.4.3) [179, 192]. Nurses and physicians have a guiding role in rehabilitation, but several other professions are involved, including psychologists, dietitians, physiotherapists, sexologists, and counsellors. Rehabilitation includes crisis support during the diagnostic phase, as well as psychological support and counselling before, during, and after cancer treatment [198].

"Survivorship Care" in spezialisierten Reha-Zentren

Reha beinhaltet Krisenhilfe in der Diagnosephase & kontinuierliche psychologische Unterstützung

Specialised **palliative care** is organised into palliative inpatient units and hospices and ASIH teams consisting of registered nurses, physicians, physiotherapists, occupational therapists, and psychosocial and social workers. Additionally, multidisciplinary palliative care consultant teams support hospitals, primary care, and municipal health care services [176, 179, 192]. Generally, oncology care providers should be competent in palliative medicine. Increased collaboration between oncology treatment facilities and professions is essential. Every palliative care facility that provides care for terminally ill patients should have well-established protocols for symptom management at the end of life [187].

spezialisierte Palliativversorgung in stationären Zentren & Hospizen

In the event of a relapse, every patient with breast cancer recurrence should be discussed at internal conferences in the outpatient oncology clinic managing their treatment. Additionally, discussing these cases in an MDT conference may be valuable when appropriate. This should be particularly considered when surgery is planned in conjunction with medical treatment and radiation therapy. In cases involving complex psychosocial issues, an expert with the relevant expertise must be consulted [186].

Rezidive sollten wieder in MDT-Konferenzen besprochen werden

After completing medical treatment and being deemed healthy, the patient may return to work. The individual's capacity is assessed in relation to the tasks and duties required by their job. A job contract cannot be terminated if the individual is capable of performing relevant tasks, even partially. Rehabilitation and matching of the individual to the workplace are conducted in collaboration with the employer, the Swedish Social Insurance Agency, and the individual [176].

koordinierte Reintegration in den Arbeitsalltag

The described patient journey from diagnosis to follow-up, including the place of care provision, is depicted in Figure 4-6. Additionally, the Appendix document provides more detailed information on the place of health care provision and the involved professions.

"Patient Journey" Details in Abb. & Tab. im Appendix-Dokument

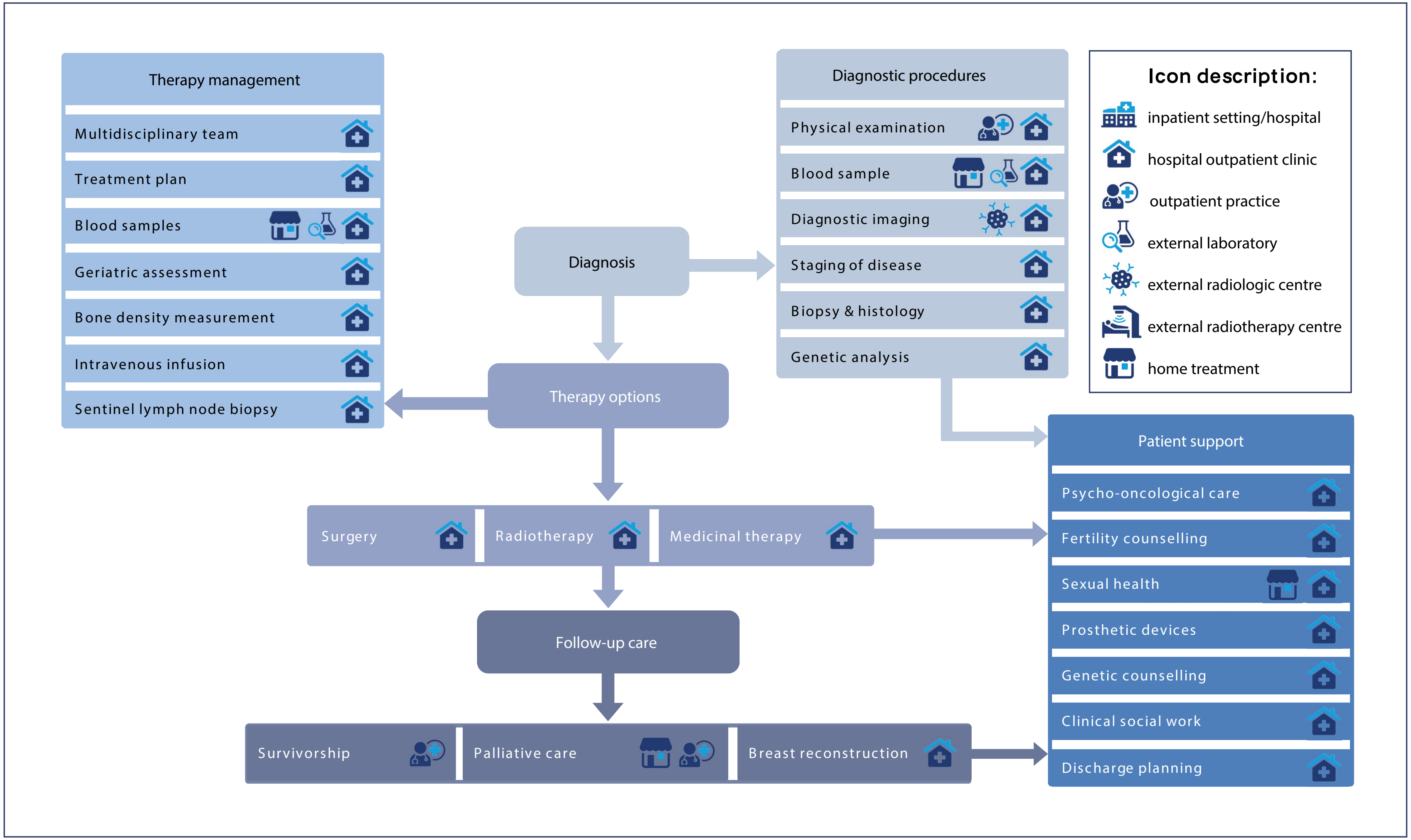


Figure 4-6: Patient journey and place of care provision in Sweden

4.4.4 Cross-Sectoral Care Coordination

Care Coordination

Cancer care coordination in Sweden is multifaceted and takes place on several levels. According to national guidelines, the management of care should entail the full range of services from the time of diagnosis over the provision of treatment in the designated breast care clinics to follow-up. In less populated areas, fewer hospitals offer advanced treatment options, such as reconstructive surgery, or patients may have to travel to another region that provides radiotherapy. The six RCCs have developed structures for local, regional, and national collaborations to fill potential gaps in cancer care, emphasising the importance of cooperation across health care regions and sectors [179]. The RCCs coordinate and develop cancer care according to the intentions of the NCS and the EU's cancer plan on a national level but do not directly influence cancer care [179, 184, 199].

Koordination der Krebsversorgung in SE findet auf mehreren Ebenen statt

6 RCCs haben Koordinierungsfunktion auf nationaler Ebene

Furthermore, the patient has the right to receive outpatient care in any region according to the Swedish Patient Act [190]. The introduction of the CCP for breast cancer was another vital pillar in ensuring coordinated breast cancer care within the care pathway itself and across sectors, coordinating care across regional boundaries and reducing unnecessary waiting times for patients. The coordinator function within the CCP is part of the MDT and can be filled by a contact nurse. This structure ensures that the entire MDT has up-to-date patient care status and journey information. However, how the care coordinator role is staffed and organised is determined and developed locally, adapted to specific local conditions. Additionally, the coordinator function does not need to be filled by the same person throughout the process [183].

Brust-CCP ist weitere wichtige Säule in Brustkrebsversorgung

Koordinierungsfunktion innerhalb der MDT-Konferenz des Brust-CCPs → „Contact Nurse“

As mentioned, the CCP for breast cancer stipulates that the patient must be assigned a named contact nurse at the time of diagnosis at the latest. The contact nurse is the personal guide through the patient's journey and is also responsible for appropriate support, including regular calls and referrals to rehabilitation services [183, 186]. One of the primary responsibilities is coordinating the patient's care plan (My Care Plan in Cancer Care) and ensuring active handovers. The My Care Plan in Cancer Care ("Min vårdplan", MVP) helps to ensure the availability of equivalent and quality-assured information throughout the cancer trajectory, regardless of age, gender and socio-economic status.

„Contact Nurse“ koordiniert „Patient Journey“ basierend auf elektronischen Behandlungsplan der Pat. (MVP)

The MVP contains [200]:

- In-depth, diagnosis-specific, and individualised multimedia information about the disease, care, treatment and possible side effects.
- Information on late and long-term effects and other consequences of the disease and its treatment.
- Self-care advice.
- A rehabilitation plan.
- Information about patients' rights.
- The care provider's contact information (in the digital version, there is also a two-way messaging function).
- It is possible for the patient to independently report symptoms or concerns by filling out PROMs or sending free-text messages to their care provider.
- At the end of primary treatment, there is a summary of the care and information about follow-up.

Inhalte & Funktionen des MVPs:
Infos zur Diagnose, Erkrankung & zu Behandlungsoptionen;

Selbstfürsorge-Tipps;

Rehaplan;

Infos zu Pat.-Rechten;

Kontaktinformationen;

Feedbackfunktion (PROMs); Zusammenfassung der Behandlung & Infos über Nachsorge

The MVP is accessible digitally on a platform or, for those who prefer, in paper form. It is not a medical record. [200].

MVP digital zugänglich

As mentioned, the possibility of applying for a statutory permanent care contact is another, more extensive care coordination option in addition to the contact nurse. The purposes are to improve information and communication between the patient and the care unit, to create accessibility, continuity and security and to strengthen the patient's opportunities to participate in their care [186, 191]. Therefore, the contact nurse in practice sometimes fills the statutory permanent care contact.

„ständiger Pflegekontakt" → weitere, umfangreichere Koordinierungsoption

Health Care Data

Electronic Health Records System

Sweden, like Denmark, has a national HIE platform. The HIE aims to facilitate communication between different health information systems (HISs) and combine related e-services that give citizens access to the following services [201, 202]:

Funktionen der eHealth-Plattform in SE:

- E-scheduling, e-pharmacy, e-referrals, telemedicine.
- Access to personal health information digital self-services around the clock.
- Internet-Psychiatry.
- EHR logs.
- E-services that visualise planned care procedures, including upcoming encounters.
- Pre-visit form submission.
- E-communication with their physician or nurse.
- Secure disclosure of their health data.

eTerminvereinbarung, eMedikation, eÜberweisung & Telemedizin;

Log der eGA;

Visualisierung des Behandlungsplan;

eKommunikationsmöglichkeiten (bspw. Chat mit "Contact Nurse") etc.

However, challenges regarding cross-sectoral and inter-hospital data access exist due to local implementation differences that lead to fragmentation and unequal access to information [179]. Initiatives are in place to reconcile some of the problems [203].

Herausforderungen beim sektor- & KH-übergreifenden Datenzugang trotz eHealth-Platform

Cancer Registry and Quality Registry

Sweden has more than 150 national QRs, of which 30 are cancer-care specific, including the NKBC. The QRs are used for quality improvement by monitoring and evaluating the CCP from diagnosis to treatment, follow-up and possible relapse and death in a standardised way [177, 186, 204]. Furthermore, the data is used for research purposes. Clinicians originally developed the QRs as a system to improve clinical care quality, but they became a tool for benchmarking and governance used to assess provider performance [177].

über 30 krebsspezifische QR inkl. Brustkrebs-QR

The six RCCs are responsible for the QRs, their operation, and the support and assembling of the data on a common national web-based platform. Each registry has a steering group that ensures the QR runs according to its aims while respecting patients' rights. In addition, the steering groups oversee the registry and partly take responsibility for administrative, legal/ethical, and scientific decisions that guide the direction of the registry. The steering group also initiates and coordinates research projects within the registry framework [205]. The Swedish Association of Local Authorities and Regions (SALAR) represents and advocates local governments in Sweden and is responsible for the confederation of the six RCCs, quality management, and the finances of the registry through yearly grants [179].

6 RCCs sind für die Krebs-QR verantwortlich

Data for the NKBC is provided by all hospitals, municipalities, and regions involved in breast cancer care in the manual form to the RCC web-based platform by the respective care provider [179, 186]. The NKBC contains information on lead times, diagnostics, tumour characteristics, preoperative oncological treatment, breast and axillary surgery, including oncoplastic/direct reconstruction, postoperative oncological treatment and outcomes in the form of recurrence and survival.

alle GDL melden an das Brustkrebs-QR

Since 2020, PROMs have been collected within the NKBC, but progress is slower than expected due to initial recruitment challenges at baseline [179]. Despite these challenges, 50 to 60 per cent of all Swedish patients respond to the automated follow-up requests at six, 12, and 36 months after the start of treatment, providing valuable insights. The collection of PROMs in Sweden adheres to the International Consortium for Health Outcomes Measurement (ICHOM, https://www.ichom.org/) questionnaires and validated instruments that ensure robust and standardised evaluation of treatment outcomes across the patient population [179].

Einbindung von PROMs in das Brustkrebs-QR seit 2020, aber Erhebung verläuft schleppend

Each hospital in Sweden has access to its own patient data via a secured login. Aggregated data is publicly accessible and updated twice yearly on a specific platform, including an English version (https://statistik.incanet.se/brostcancer/) [179]. The platform provides a comprehensive data overview view and particular figures, such as patient volumes at a specific hospital, their diagnoses over the years, and a customisable selection of metrics, including invasive and neoadjuvant cases, age demographics, and surgical procedures. Furthermore, the NKBC allows quality indicators to be monitored, including the achievement of target levels, to evaluate quality improvements [206]. If any outstanding discrepancy occurs, the steering group members are contacted. This transparency fosters a deeper understanding of regional health care practices and outcomes, supporting informed decision-making and quality improvement initiatives nationwide [179].

alle datenmeldenden GDL haben Zugang zu eigenen QR-Daten

Monitoring von Indikatoren & Erreichung von Zielwerten möglich

The patient information is not anonymised but protected by hardware and software measures within the QR data environment. Patients can opt out of a QR. Validation of registry data is done regularly. The NKBC has a 99 per cent coverage and shows high comparability, high validity, and low attrition [207]. The NKBC excludes patients who are deceased or not receiving active treatment [179].

Brustkrebs-QR → 99 %-ige Abdeckung

Another cancer-care-related QR is the Swedish Registry of Palliative Care (SRPC). The SRPC aims to improve palliative care, regardless of diagnosis, age, type of care unit and location in the country. The focus is currently on palliative care at the end of life. The governance and operationalisation work are similar to that of the NKBC or other Swedish QRs. A multi-professional steering group manages the registry. A reference group comprising representatives of palliative care professional associations, knowledge and competence centres, and national palliative care organisations assists the steering group. Furthermore, the registry operators also publish an annual report with compiled results of various quality indicators and current research based on registry data [208]. There are further QRs among the 150 Swedish QRs that are relevant to (breast) cancer care, such as the National Registry for Pain Rehabilitation (NRS) or the Breast Implant Registry. A complete list of the Swedish QR can be found on the webpage of the National system for knowledge-driven management within Swedish health care (https://kunskapsstyrningvard.se/kunskapsstyrningvard/kvalitetsregister/hittakvalitetsregister.77500.html).

Palliativversorgungs-QR auch relevant im Brustkrebs-Kontext

ähnliche Organisationsstruktur wie Brust-QR

weitere relevante QR: Schmerzrehabilitations-QR & Brustimplantat-QR

Besides the NKBC, Sweden also has a National Cancer Registry (NRC). The registry provides a basis for planning and evaluation of health care services as well as research [179, 209]. The NRC is part of a larger ecosystem of national health registries. These registries can be linked to each other and to other national registries, such as the cause of death and education registries [176].

nationales Krebsregister (NRC) zu Planungszwecken

All care providers, including hospitals, regions, and municipalities, are obliged by law to report to the NRC. In addition, data from the NKBC is also transferred to the NRC [179]. Data must be reported on all tumours and tumour-like conditions diagnosed by clinical diagnostics, including radiological and other imaging examinations, morphological diagnostics or other laboratory examinations, and clinical autopsy. Not only malignant tumour diseases but also certain conditions must be reported, such as benign, premalignant, or unclear malignancy potential [209]. The cancer notification must be sent to the RCC in the respective health care region as soon as the diagnosis has been made and the information for notification is available. The particular RCC codes and forwards the data to the National Board of Health and Welfare (Socialstyrelsen). The NCR is updated once a year with data from each RCC. National cancer statistics are published once a year in the report (https://www.socialstyrelsen.se/statistik-och-data/statistik/alla-statistikamnen/cancer/) [186].

alle GDL sind gesetzlich verpflichtet, dem NRC-Daten zu liefern

While the regions own the QR, the state owns the NCR and other national health registries [176].

unterschiedl. Zuständigkeiten

Developments and Trends

Ongoing development in Sweden is the centralisation of advanced cancer surgery and advanced oncological treatment, enabling procedures that require high resources and competence to be performed at a limited number of centres [176, 179]. Since the inception of the NCS, CCPs, and the NKBC in 2008, there has been a significant consolidation of breast cancer surgery units within hospitals. Breast cancer care units are defined as facilities that provide the full spectrum of health care services related to breast cancer. Initially, 64 hospitals across Sweden offered breast cancer surgery; however, this number has now stabilised at 33 units. The reduction was driven by the fact that many smaller hospitals lacked the capability to perform critical procedures, such as sentinel node biopsies, and had limited access to reconstructive surgery options. A unique case is the island of Gotland, which is administratively part of Stockholm. Patients from Gotland travel to the mainland by boat for scintigraphy injections, then return to the island for same-day surgery [179].

Trend in SE zu Zentralisation der spezialisierten Krebschirurgie & onkologischen Behandlung

Konsolidierung der Abteilungen für Brustkrebschirurgie in KHs → von 64 auf 33 Abteilungen

A simultaneous development, alongside the centralisation of specific health care services, is the shift of cancer care in the outpatient setting. According to Berglund et al. [2015], a significant part of inpatient admissions were shifted to outpatient visits during the last decades. This shift also led to different supportive care strategies, such as the implementation of advanced cancer nurses, follow-up by telephone by contact nurses, and nurse-led care and clinics that have been tested and integrated into breast cancer care to meet patients' needs [179, 210, 211]. In 2015, nurse-led clinics accounted for about 15% of outpatient care episodes (excluding radiotherapy and ambulatory chemotherapy) at the Karolinska University Hospital's Oncology department. The nurses at nurse-led clinics administer curative, adjuvant or palliative treatments. Furthermore, they are responsible for and carry out symptom controls, controls of side effects, and skin examinations and inform, support and educate patients and families before and during oncological treatment [210].

zusätzlich zur Zentralisierung auch Verschiebung von Leistungen in den (spitals)ambulanten Bereich

Currently, most follow-up and supportive care measures in cancer care are managed by contact nurses by telephone [183]. Advanced cancer nurses can also visit patients at home to draw blood for blood samples. Patients can go to different laboratories for their blood tests, meaning they do not necessarily need to go to the hospital laboratory or outpatient clinic [179]. In addition, patients can communicate with contact nurses and physicians via a hospital-based chat function (Alltid Öppet) [179].

mittlerweile einige „Support-Leistungen“ außerhalb des KH-Settings möglich

4.5 Organisation of Breast Cancer Care in the Netherlands

4.5.1 Cancer Epidemiology and Cancer Care Expenditures

In the Netherlands, life expectancy at birth is 81.5 years, and 19.8% of the population are aged 65 and older. The country allocates 11.1% of its GDP to health expenditures [212]. In 2018, the per capita cost of cancer care was € 591, while the direct costs were € 308 [46]. The cancer incidence rate was 655 per 100,000 population, and the mortality rate was 267 per 100,000 in 2019. There were 52,864 new cancer cases in women, 30% of which were breast cancer [213]. In 2021, inpatient health expenditures amounted to € 986 per capita, with 3.0 acute care beds per 1,000 population [212]. Although inpatient cancer case rates were not reported, the Netherlands yielded an 87% five-year net survival rate for cancer [213].

11,1 % des BIP → Gesundheitsausgaben

Gesamtkosten Krebsbehandlung 591 € pro Kopf (2018)

KH-Gesundheitsausgaben € 986 pro Kopf (2021)

4.5.2 National Health Strategies and Programmes

The Dutch healthcare system is structured around four primary acts that ensure comprehensive health care coverage for all residents [212]:

4 Rechtsgrundlagen als Basis in NL:

- Health Insurance Act (“Zorgverzekeringswet”): Established in 2006, this act mandates that all residents obtain health insurance, including a government-defined benefits package. Insurers operate competitively and must accept all applicants, negotiating with providers based on quality and cost. The package covers primary care, specialist outpatient care, hospital care, maternal services, and more. Adults over 18 pay an annual deductible of at least € 385, with certain exemptions. Nearly the entire population (99.9%) is insured.
- Long-term Care Act (“Wet langdurige zorg”): This act provides a single-payer system for long-term care, managed regionally and focused on extensive, often residential, care with 24-hour availability.
- Social Support Act (“Wet maatschappelijke ondersteuning”): Funded through taxes and administered by municipalities, this act delivers social care services in home or small-scale settings.
- Youth Act (“Jeugdwet”): This act supports children and adolescents with a range of services, from preventive to specialised care, overseen by local authorities.

Krankenversicherungsgesetz (2006): regelt bspw. Primärversorgung, fachärztliche & KH-Versorgung etc.

Langzeitpflegegesetz: regionale Versorgung

Sozialhilfegesetz: Sozialfürsorge

Jugend(schutz)gesetz

Health care services in the Netherlands are predominantly delivered by private non-profit providers, with many physicians operating as self-employed professionals. The Public Health Act complements these schemes by addressing public health initiatives, including infectious disease prevention and control [212].

Gesundheitsversorgung weitestgehend durch private GDL erbracht

Between 2005 and 2010, the Netherlands launched the National Cancer Control Programme ("Nationaal Programma Kankerbestrijding"), which introduced a comprehensive array of initiatives focused on cancer prevention, diagnosis, treatment, follow-up care, psychosocial support, education, and research. Despite these efforts, the Netherlands has not established a comprehensive national cancer plan by the government. Instead, the Ministry of Health, Welfare, and Sport backs initiatives driven by health care professionals, researchers, and patient organisations that are consistent with the objectives of Europe's Beating Cancer Plan [23, 213].

NL hat keinen formalen Krebsplan aber ein nationales Programm zur "Krebskontrolle" und einzelne Initiativen

The Netherlands Cancer Collective ("Nederlands Kanker Collectief") coordinates the Dutch Cancer Agenda in partnership with various stakeholders dedicated to reducing cancer's impact in the Netherlands. A significant component of this agenda is the Cancer Survivorship Care Taskforce, an alliance that brings together health care professionals, hospital associations, researchers, policymakers, and patient organisations. This taskforce is focused on addressing the ongoing needs of cancer patients and survivors, particularly concerning their rights to return to work and to control the accessibility of their personal and health information, known as the "right to be forgotten" [213].

niederländisches Krebskollektiv & „Cancer Survivorship Care Taskforce" koordinieren die Krebsversorgung

The task force's goals include advising the Ministry of Health, Welfare, and Sport, raising public awareness of the issues faced by cancer patients and survivors, and improving the organisation of cancer care. Additionally, the task force promotes the development of regional oncological care networks and advocates for creating a comprehensive national cancer plan. Furthermore, since 2011, the quality assurance of radiotherapy departments has been governed by national standards set by the Dutch Society for Radiotherapy and Oncology in collaboration with other stakeholders such as the Integraal Kankercentrum Nederland (IKNL). Performance indicators for radiotherapy centres, particularly regarding timeliness, effectiveness, and safety, are reported annually to ensure transparency in care quality [213].

"Cancer Survivorship Care Taskforce" fördert Entwicklung regionaler onkologischer Versorgungsnetze

4.5.3 Health Care Infrastructure and Patient Journey

Standard Requirements for Cancer Care

SONCOS, the Dutch Foundation for Oncological Collaboration, sets standard requirements for cancer care [214]. These are widely implemented but are regarded as recommendations [215, 216]. The twelfth edition of their report ("Nomeringsrapport"), published in 2024, outlines evolving standards for high-quality oncology care. Initially released in December 2012, the report addresses the needs of surgical, medical, and radiation oncologists, aiming to improve patient care continuously. The standards are updated annually to incorporate technical innovations, scientific insights, and practical experiences, focusing on multidisciplinary approaches. They cover the necessary infrastructure, team compositions, and procedural requirements for effective cancer treatment.

SONCOS für onkolog. Versorgungsstandards zuständig

Standards werden jährlich angepasst

(infra)strukturelle & prozessualle Standards

The following outlines the general requirements for oncological care in the Netherlands [214]:

Standards umfassen:

- **Information and Organisation:**
  - Health care institutions must provide transparent information about their facilities and treatment options for oncology care.
  - Institutions are expected to promote healthy lifestyles, including having access to smoking cessation clinics for cancer patients.

Informations- & Organisationsstandards

  - Participation in national quality registrations and quality inspections approved by oncology professional groups is mandatory.
  - Each institution should have an oncology committee with representatives from all relevant medical, paramedical, and nursing disciplines.
- **Multidisciplinary Consultations (MDCs)/MDT conferences**:
  - Regular MDCs also known as MDT conferences are essential, with weekly meetings with representatives from all relevant specialities to discuss patient cases before and after treatment. Precise logistics, expertise, and responsibility agreements are necessary to ensure efficient consultations.

Standards hinsichtlich MDT-Konferenzen

- **Facilities:**
  - Adequate outpatient, day treatment, and inpatient facilities designed explicitly for oncology care are required. Qualified professionals, including specialised oncology nurses, must staff these.
  - Access to departments such as radiology, nuclear medicine, pathology, and clinical pharmacology, either on-site or through collaboration agreements, is essential.

Standards der onkolog. Versorgungseinrichtungen & Abteilungen

- **Treatment and Trials:**
  - Institutions must offer systemic oncology treatments and participate in clinical trials to improve treatment protocols and patient care.

allg. Versorgungsstandards & Studienstandards

The increasing number of cancer patients and the complexity of oncology care necessitate network-based medicine. Thus, two types of cancer care networks are available in the Netherlands: regional oncology networks and tumour-type networks. Regional oncology networks organise care at multiple levels, ensuring coherent and transparent service delivery. These networks are developed based on natural institutional collaborations, aligning with patient flow patterns in specific areas.

2 Typen von Krebsnetzwerken: regionale onkolog. & tumorspezifische Netzwerke

In the following, the standards for regional oncology networks are outlined [214]:

Standards der regionalen Netzwerke:

- Regional oncology networks must ensure compliance with SONCOS standards at the institutional level and facilitate smooth patient transitions within and between networks. Collaboration agreements should cover care quality, data exchange, financial arrangements, and governance.

Compliance mit SONCOS-Standards

- A joint network oncology committee is required to oversee and unify the quality policy and care across the network.

gemeinsames Netzwerkkomittee

On the contrary, tumour-type networks should organise care for specific tumour types, ensuring the best possible quality and continuity. These networks must establish shared visions and standardise care pathways according to national guidelines. Clear communication and data exchange protocols are necessary to support seamless care across the network [214].

tumorspezifische Netzwerke zuständig für entitätsspezifische Versorgungspfade

Additionally, SONCOS has formulated specific standards and requirements for treating breast cancer. Thus, a health care institution must meet the following conditions [214]:

brustkrebsspezifische SONCOS-Standards

- **Breast Cancer Team**: The team should consist of at least one breast care nurse and/or oncology nurse practitioner, two surgical oncologists, one plastic surgeon, two radiologists, one pathologist, one radiation oncologist, one medical oncologist, and one nuclear medicine specialist. All team members must have proven expertise in breast pathology, as

multidisziplinäres “Brustkrebs-Team” mit Expertise in Mammapathologie

specified in the National Breast Cancer Counselling Service (NABON, Nationaal Borstkanker Overleg Nederland) memorandum [217].

- **Outpatient Clinic**: There must be a recognisable breast cancer outpatient clinic.

Brustkrebsambulanz

- **Breast MRI**: Breast MRI should be available within defined timeframes for its performance, evaluation, and reporting by a radiologist or nuclear medicine specialist with the appropriate expertise.

Verfügbarkeit zeitnaher Bildgebung

- **Stereotactic Biopsies**: Stereotactic biopsy facilities should be available, with set periods for evaluation and reporting by a pathologist.

Verfügbarkeit stereotaktischer Biopsien

- **Nuclear Medicine Department**: Access to a nuclear medicine department capable of performing sentinel node procedures, with PET/CT availability, and the ability to administer therapy with bone-seeking radiopharmaceuticals and established service levels.

Abteilung Nuklearmedizin mit SLNB & PET/CT verfügbar

- **Pre-Operative Consultation**: There should be an option for pre-operative consultation with a plastic surgeon and a radiation oncologist.

prä-operative Beratung

- **MDT**: The following specialists must be present during the weekly MDT conference: surgical oncologist, medical oncologist, radiologist, radiation oncologist, pathologist, case manager, breast care nurse and/or oncology nurse and/or oncology nurse practitioner. There should also be the option to include a representative from the reference centre and the plastic surgeon in this consultation.

wöchentliche MDT-Konferenzen

- **Operating Room Facilities**: The institution must have an operating room with adequate facilities, including a gamma probe. Additionally, there should be an operating room suitable for prosthetic surgery.

adäquate Ausstattung des OP-Saals

- **Neo-Adjuvant Chemotherapy Pathway**: A defined care pathway for neo-adjuvant chemotherapy must exist.

klar definierte Behandlungspfade

- **Genetic Counselling and Testing**: Written agreements with recorded processing times must exist for genetic counselling and testing, including fast-track diagnostics.

genetische Beratung & Testverfahren

- **Fertility Preservation**: In the case of (neo-)adjuvant treatments, agreements must be in place regarding the timely referral for fertility preservation.

Fertilitätserhaltung

- **Oncoplastic Surgery**: The institution should perform oncoplastic surgeries, such as skin-sparing ablations with immediate reconstruction or oncoplastic-sparing surgeries.

onkoplastische Chirurgie

- **Participation in Audits**: The institution must take part in the Dutch Breast Cancer Audit/NABON Breast Cancer Audit.

Teilnahme an Audits

- **Surgery Volume**: At least 50 breast cancer surgeries must be performed per location per year.

Mindestmengen

- **Certified Surgical Oncologists**: Operations must be performed by a certified surgical oncologist.

zertifizierte onkolog. Chirurg*innen

Breast Cancer Patient Journey

Identification of Patients

The Dutch **National Breast Cancer Screening Programme**, initiated in 1990, is coordinated by the National Institute for Public Health and the Environment (RIVM) and targets women aged 50 to 75. Women in this age group are invited for a mammogram every two years. The programme operates through a logistical chain of public and private organisations. The Health Council

Identifikation von Pat. durch organisiertes nationales Screening-Programm & …

provides scientific advice to the Minister of Health, who makes decisions about screening programs. RIVM's Centre for Population Screening (RIVM-CPS) finances, coordinates, directs the programme, sets quality standards, and organises monitoring and evaluation. The IKNL conducts annual national monitoring to ensure quality and identify issues. The Breast Cancer Screening Programme Committee, established by RIVM-CPS, advises on national coordination, comprising experts from relevant professions and authoritative organisations [218].

Suspected breast cancer patients are generally referred to hospital outpatient clinics for further diagnostic procedures through three primary pathways. The first involves identification through routine **screening programs**. Alternatively, referrals may be made by **GPs** or **radiologists** who detect breast cancer **incidentally** [215].

… Zufallsbefunde bzw. Überweisung durch GP oder Radiolog*in

Diagnosis

In cases of suspected breast cancer, the initial assessment, including **physical examination**, is typically conducted by nurse practitioners, often within specialised "mama care" units of hospital outpatient clinics [215, 216]. Patients may also be referred directly to the radiology department of hospital outpatient clinics by their GP, who would have already performed a physical examination if a breast abnormality was detected. If a suspicious finding is identified, the patient is referred back to the nurse practitioner for further evaluation. Nurse practitioners are also responsible for coordinating necessary **blood tests, biopsies,** and **histological examinations** [215]. Upon completion of **diagnostic imaging** and **disease staging** in the hospital outpatient clinic, or if additional concerns arise, the patient is referred to a surgeon for further management [215, 216].

erste physische Untersuchung meist durch „Nurse Practitioners" in spitalsambulanten Spezialkliniken

koordinieren auch Blutabnahmen & histologische Untersuchungen

In the past, patients requiring **genetic testing** and **counselling** were referred to a large hospital in Maastricht, where the waiting period for an appointment could extend up to nine months, often disrupting timely decision-making regarding surgical interventions. To address this issue, the Netherlands introduced the DNA First initiative. Under this program, blood samples are collected at the local hospital outpatient clinics and sent to Maastricht, with results typically available within two weeks. Patients receive their results at home: those with no detected genetic issues receive a letter that includes guidance for family members. In contrast, those with detected mutations are scheduled for counselling at the hospital, effectively bypassing the extended waiting list. Additionally, an MDT reviews these results monthly via videoconference, ensuring comprehensive care and seamless coordination with genetic counsellors [215, 219].

"DNA First Initiative" zur Beschleunigung von Befunden aus genetischen Untersuchung

Pat. erhalten Ergebnisse & Informationen nach Hause

Treatment

Treatment Management

In the Netherlands, all newly diagnosed cancer cases are reviewed in **MDT conferences** within hospital outpatient clinics tailored to the specific type of cancer. Although not mandated by law but recommended by SONCOS, these meetings have been widely adopted among cancer care providers due to their critical role in treatment planning. The meetings involve a broad range of specialists, including medical oncologists, surgeons, radiation oncologists, pathologists, as well as cancer care nurses and nurse practitioners. Additional medical services may be consulted as necessary to support therapeutic decision-making.

Besprechung neuer Brustkrebsfälle in spitalsambulanten MDT-Konferenzen → SONCOS-Empfehlung

MDT-Konferenzbericht innerhalb weniger Tage an GP, um Kontinuität der Versorgung zu gewährleisten

Behandlungsplan wird mit Pat. besprochen

Following these meetings, a report is typically sent to the patient's GP within a few days to ensure continuity of care [213, 215, 216]. These MDTs generally convene twice a week in hospital outpatient clinics. Although the patient is not directly involved in these meetings, their **treatment plan** is formulated by considering both medical and, if necessary, social aspects of the patient's situation. MDT conferences are often conducted online to accommodate participants from various hospital types [213, 216]. The treatment plans are subsequently discussed with the patient. If surgery is required, coordination with a surgeon is arranged; if chemotherapy is needed first, patients are referred to an oncologist [215, 216].

kein formales geriatrisches Assessment

intravenöse Infusionen & Knochendichtemessung → spitalsambulanten Setting

Geriatric assessments are typically performed by geriatric personnel in hospital outpatient clinics based on specific indications rather than as a routine procedure [216]. **Blood samples, intravenous infusions,** and **bone density measurements** (if hormone therapy is administered) are organised within hospital outpatient clinics [215, 216]. Surgeons usually perform the sentinel lymph node biopsy during hospital or hospital outpatient clinic surgery. Before surgery, lymph nodes in the axilla are assessed using diagnostic techniques such as ultrasound, with a biopsy conducted if any nodes appear suspicious. If no signs of disease are detected in the axilla, the sentinel lymph node biopsy is undertaken concurrently with the breast surgery. A radioactive fluid is injected the day before surgery at the hospital outpatient clinic [213, 216].

Therapy Options

Übernachtung abhängig von Komplexität des Eingriffs

Entlassung koordiniert "Cancer Care Nurse"

Surgical procedures are performed at the hospital or in the hospital outpatient clinic. The length of hospital stays for surgical patients varies; those undergoing mastectomies with reconstruction typically stay overnight, while patients undergoing lumpectomies are usually discharged on the same day, provided there are no complications [215, 216]. Thus, cancer care nurses manage **discharge planning** in hospitals or hospital outpatient clinics [215, 216, 220].

Strahlentherapie in der Regel ambulant

The Netherlands have 21 radiation therapy centres, supported by approximately a dozen satellite centres. With about 8.5 radiation therapy centres per 1,000,000 inhabitants, the country ranks fourth among EU countries [213]. Proton therapy is available through privately funded initiatives, with three proton beam centres established: Holland Protonen Therapie Centrum, University Medical Centre Groningen, and Maastro Clinic. **Radiotherapy** is typically provided as an outpatient service or within hospital outpatient clinics. These radiotherapy departments are often part of a more extensive hospital network, serving both the main hospital and surrounding facilities. Secondary locations sometimes exist within peripheral hospitals, but these are usually integrated into the broader hospital services rather than functioning as standalone centres [216].

Chemotherapie mit 1-2 Tagen KH-Aufenthalt

endokrine Therapie auch zuhause möglich

Chemotherapy is usually administered over one or two days in hospital outpatient clinics, after which patients return home. Hospital admission is only necessary if complications, such as fever or severe illness, arise [215]. Although experimental initiatives in some areas have explored administering chemotherapy at home, this practice is not yet widespread. However, in some regions, specific **medicinal tumour therapies**, particularly endocrine therapies and tablet-based treatments, can be administered at home [215, 216].

Moreover, various home care organisations provide injections such as fulvestrant and bisphosphonate infusions at home. Home care teams, sometimes affiliated with hospitals, assist with these treatments. While patients may self-administer some injections, such as those for bone marrow support, more complex injections typically require GP or home care organisation assistance. Short infusions are often managed by home care organisations, helping to alleviate the demand for hospital outpatient clinics [215, 216].

häusliche Pflegeorganisationen & Pflegeteams assistieren

Patient Support and Follow-up Care

In the Netherlands, **fertility** and **genetic counselling**, along with **sexual health** services, are typically provided within hospital outpatient clinics. If a specific hospital does not offer fertility counselling, referrals can be made to larger hospitals. Depending on the patient's needs, **psycho-oncological care** services may be provided in an outpatient setting or hospital outpatient clinics. Due to limited staffing, the primary focus is identifying issues and referring patients to the appropriate specialists when necessary. However, in-house psychologists and **social workers** are generally available to support patients, with some outpatient services coordinated to provide care close to the patient's home [215, 216].

Fertilitätsberatung inkl. Beratung sexueller Gesundheit & genetische Beratung → Spitalsambulanzen

psychoonkolog. Beratung spitalsambulant & niedergelassen

Prosthetic device prescriptions are usually managed by the surgical department, often in collaboration with the "mama care" team and provided within the hospital outpatient clinic. Once prescribed, prosthetic devices can be collected from the outpatient setting [215, 216].

chirurgische Abteilung für Prothesen zuständig

Rehabilitation plays a crucial role following cancer treatment, particularly for breast cancer patients, who may undergo five to ten years of endocrine therapy. During the first year, nurse practitioners closely monitor these patients at appointments in hospital outpatient clinics, with follow-up visits every three months to manage side effects and help them adjust to post-treatment life. After the first year, visits typically occur annually in accordance with national guidelines. However, there is a growing trend towards more personalised follow-up schedules, particularly for patients at higher risk of recurrence, such as those with hormone receptor-positive disease [216]. **Physiotherapy** is provided both within hospital outpatient clinics and in outpatient settings. Specialised oncological training classes are also available nationwide, supported by a network of physiotherapists [215, 216].

Rehamaßnahmen & Follow-Up Care durch "Nurse Practitioners" überwacht

Physiotherapie wird spitalsambulant & niedergelassen angeboten

Palliative care in the Netherlands is primarily organised at the community level, with GPs and nurses leading home-based care. Most primary home care teams and nursing homes are equipped to offer end-of-life care. Palliative care specialists are called upon to provide additional support and expertise when necessary. Additionally, multidisciplinary specialist palliative care teams serving children and adults are available in every hospital outpatient clinic that provides cancer care. These teams adhere to national standards and guidelines, although variations in skill levels, procedures, and referral practices can sometimes affect timely access to palliative care [213, 215, 216, 220].

Palliativversorgung ist auf kommunaler Ebene organisiert → multidisziplinäre spezialisierte Teams

Breast reconstruction is performed by surgeons or plastic surgeons in a hospital setting with an overnight stay, ensuring that all aspects of post-cancer care are comprehensively addressed [216].

Brustrekonstruktion im stationären Setting

The described patient journey from diagnosis to follow-up, including the place of care provision, is depicted in Figure 4-7. Additionally, more detailed information on the place of health care provision and the involved health care professions can be found in the Appendix document.

"Patient Journey" Details in Abb. & Tab. im Appendix-Dokument

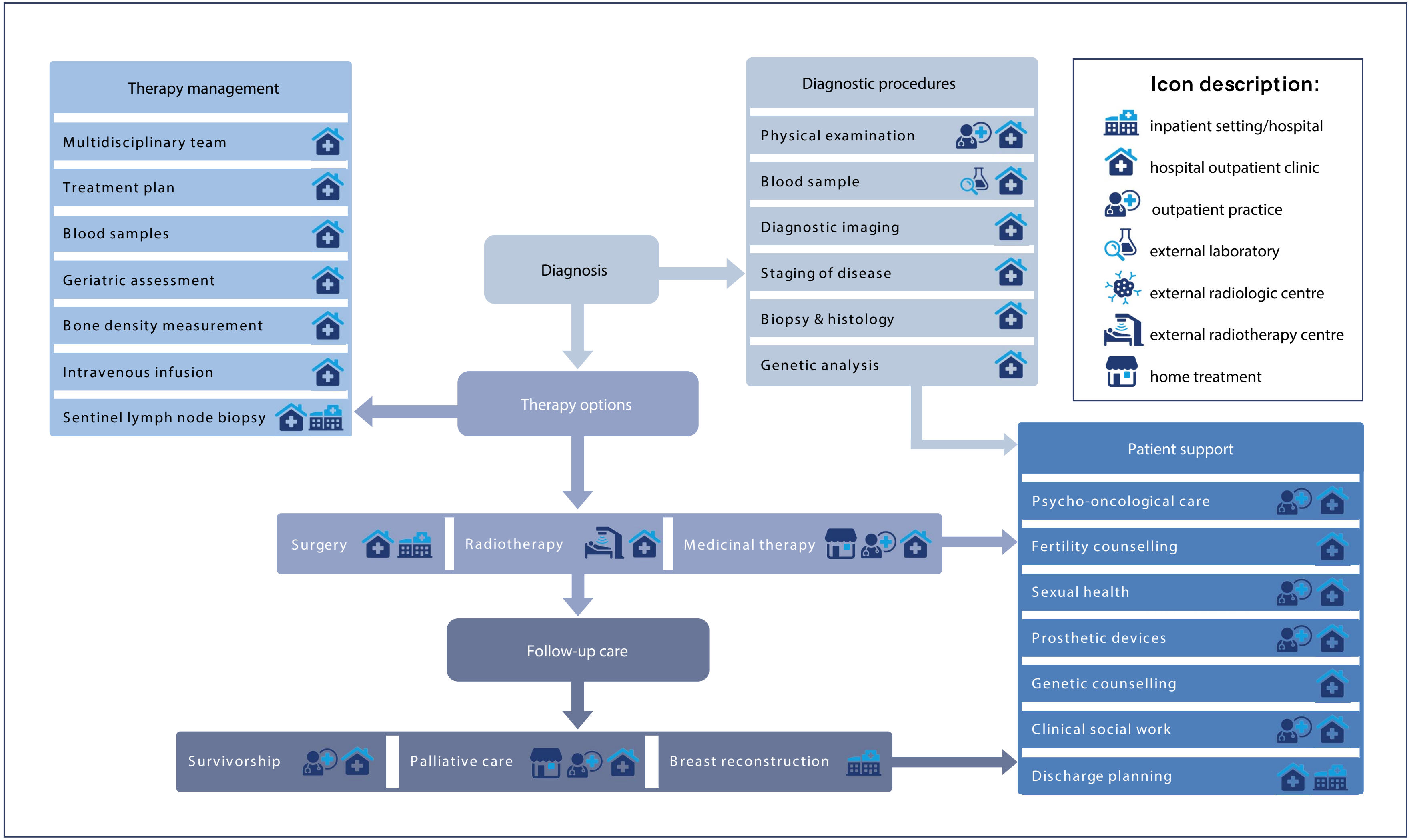


Figure 4-7: Patient journey and place of care provision in the Netherlands

4.5.4 Cross-Sectoral Care Coordination

Care Coordination

The increasing number of cancer patients and the complexity of oncology care necessitate network-based medicine. Thus, two types of cancer care networks are available in the Netherlands: regional oncology networks and tumour-type networks. Regional oncology networks organise care at multiple levels, ensuring coherent and transparent service delivery. These networks are developed based on natural institutional collaborations, aligning with patient flow patterns in specific areas.

netzwerkbasierte Krebsversorgung in NL

In the following, the standards for regional oncology networks are outlined [214]:

regionale onkolog. Netzwerke &

- Regional oncology networks must ensure compliance with SONCOS standards at the institutional level and facilitate smooth patient transitions within and between networks. Collaboration agreements should cover care quality, data exchange, financial arrangements, and governance.
- A joint network oncology committee is required to oversee and unify the quality policy and care across the network.

On the contrary, tumour-type networks should organise care for specific tumour types, ensuring the best possible quality and continuity. These networks must establish shared visions and standardise care pathways according to national guidelines. Clear communication and data exchange protocols are necessary to support seamless care across the network [214].

tumorspezifische Netzwerke für Koordination verantwortlich

Breast cancer surgeries are primarily performed in peripheral hospitals rather than academic institutions due to financial constraints, as insurers do not cover the higher costs of academic hospitals. This setup requires close collaboration between the two, with most patients from academic hospitals undergoing surgery at peripheral hospitals, except in particularly complex cases [216].

enge Kollaboration zwischen Unikliniken und peripheren KHs bei chirurgischen Leistungen

To maintain continuity of care, surgeons affiliated with both academic and peripheral hospitals often perform surgeries at the peripheral hospitals. This dual affiliation allows for a coordinated approach to patient treatment, with patients having appointments at both institutions. Academic hospitals provide ongoing consultancy services to peripheral hospitals, offering specialised expertise for complex cases through online consultations, usually conducted once or twice a week or as needed. MDT conferences are also held online, allowing teams from both academic and peripheral hospitals to connect and discuss patient cases while being physically present at their respective locations, ensuring integrated care management [216].

Unikliniken bringen Fachwissen in periphere KHs

Health Care Data

Electronic Health Records System

In the Netherlands, no single, unified EHR system is used across all hospitals, resulting in various electronic systems across different hospitals. For example, Epic is widely utilised and recognised internationally, while some hospitals use HiX as another electronic patient dossier system. This fragmentation means that hospitals may not have access to their complete medical history when patients receive treatment in different regions, such as in the

kein einheitliches eGA-System

Behandlungsinfos aus KHs werden an GPs übermittelt

north. Additionally, no integrated system connects hospital outpatient care with GPs. While efforts are made to manually send patient information to GPs to inform them about hospital treatments, this process is not yet facilitated through an electronic system. Although there are ongoing efforts to integrate pharmacy records with these hospital systems better, complete optimisation has not yet been achieved [215, 216].

GDLs müssen detaillierte klinische Dokumentation erstellen

Generally, health care providers are required to maintain detailed medical records for each patient, including examination findings, test results, diagnoses, and treatments. To ensure data security, these records must comply with the General Data Protection Regulation (GDPR). Patients have the right to access, amend, and request copies of their records. Records can only be shared with other health care providers with patient consent, and electronic sharing is mandated by law to enhance data exchange within the healthcare system [221].

NL wird Großteil von erhaltenen EU-Fördergeldern in Aufbau von Daten-Infrastruktur widmen

The Netherlands' healthcare system is poised to receive a substantial funding increase through the Recovery and Resilience Plan (RRP), part of the EU's broader strategy in response to the COVID-19 pandemic. The plan allocates € 172 million to health care, constituting about 4% of the Netherlands' total grant from the EU Recovery and Resilience Fund. Moreover, over 40% of these funds will be invested in creating a comprehensive national health data infrastructure, which will enhance the use of health data for policy development, clinical practice, and research [212].

Cancer Registry

niederländisches Krebsregister (NCR) für Versorgungs-Monitoring & -Planung

Since its establishment in 1989, the Netherlands Cancer Registry (NCR) has systematically collected comprehensive data on cancer patient care. It includes detailed information on diagnoses, tumour staging, characteristics, and subsequent treatments encompassing procedures and medications. The registry also monitors data related to diagnostics, follow-up care, and patient survival rates. Data collection is conducted by NCR data managers who, through agreements with hospitals, access and compile information directly from electronic medical records. Beyond clinical data, the NCR conducts surveys to assess cancer care capacity, focusing on staffing levels, equipment availability, and departmental productivity across various health care institutions involved in cancer care [213, 222].

NCR-Daten auch wichtig für internationale Forschungskooperationen

Insights derived from NCR data are crucial in informing decision-making processes across multiple sectors, including policy development, health care delivery, patient advocacy, and scientific research. Patient organisations actively shape the scope and objectives of data collection efforts. Furthermore, the NCR engages in international research collaborations, notably with the International Agency for Research on Cancer, and contributes anonymised data to the European Network of Cancer Registries [213].

Interoperabilität des NCR mit anderen Registern gegeben

To facilitate comprehensive nationwide data integration, the NCR employs a pseudonymised Citizen Service Number (BSN), enabling the linkage of cancer data across various local and national information systems, including municipal records, pharmacy databases, and central registries such as the death certificate information system. Additional data linkages can be established upon request, connecting to resources like the Nationwide Pathology Databank and the Patient-Reported Outcomes Following Initial Treatment and Long-term Evaluation of Survivorship (PROFILES) registry [213].

Developments and Trends

Education and Deployment of Cancer Nurses

Over the past decade, the number of nurses in the Netherlands has increased significantly, rising from 10.3 per 1,000 population in 2014 to 11.4 per 1,000 in 2021, which is nearly a third higher than the EU average. This growth reflects the expanding role of nurses in the healthcare system, with a notable shift towards advanced practice. A growing segment of nurses now take on tasks traditionally performed by physicians, opening up more opportunities for career advancement and specialised roles within the health care sector [212].

NL hat auf steigenden Bedarf an (gutausgebildeten) Krankenpflegekräften reagiert

Since 2012, nurse specialists in the Netherlands have been legally permitted to practice independently, a status that was formally approved in 2018. This legal recognition allows them to prescribe certain medications and perform specific non-surgical procedures, such as endoscopies. To achieve this level of practice, these nurses undergo a rigorous two-year Master's degree in Advanced Nursing Practice. This advanced training equips them with the necessary skills to manage complex patient care, particularly in specialised fields like oncology. Breast cancer nurse specialists, for example, are trained to lead patient care teams, develop treatment plans, and provide comprehensive care that includes both medical and psychosocial support for their patients [212, 223].

"Nurse Specialists" mit umfangreichen Kompetenzen & gesetzlich verankert

eigenes Master-Studium "Advanced Nursing Practice"

Despite the expansion in both the number and the scope of practice of nurses, the nursing workforce in hospitals remains under significant pressure. Shortages of nursing and home care staff have been persistent and were aggravated by the COVID-19 pandemic. The overall number of health care workers has sharply increased in recent years, making up 15% of the workforce. To address staffing shortages, hospitals have increasingly relied on freelance nurses. However, health insurers in the Netherlands have urged the government to improve working conditions for permanent employees and limit freelance nursing growth due to concerns about rising costs and potential impacts on the quality of care [212].

weiterhin erheblicher Arbeitsdruck trotz Personalausweitung

→ Verbesserung der Arbeitsbedingungen

Digital Decision Aids

In the Netherlands, decision aids ("Keuzehulpen") are increasingly used to support shared healthcare decision-making, including breast cancer care. These online tools provide personalised information about diagnoses and treatment options, outlining the pros and cons to help patients understand their choices. Patients complete the decision aid before consultations, allowing them to clarify their preferences and discuss them with health care providers. This approach improves patient satisfaction and adherence to treatment by fostering active participation in decision-making [215, 224].

vermehrter Einsatz von elektronischen Entscheidungstools

4.6 Organisation of Breast Cancer Care in Belgium

4.6.1 Cancer Epidemiology and Cancer Care Expenditures

Belgium's life expectancy at birth is 81.8 years, and 19.5% of the population is 65 and older. The country allocates 11.1% of its GDP to health expenditures [126]. In 2018, the total cost of cancer care was € 577 per capita, of which € 284 were direct costs [46]. Belgium reported a cancer incidence rate of 640 per 100,000 population and a mortality rate of 229 per 100,000 in 2019. Among women, there were 34,666 new cancer cases, with breast cancer accounting for 34% of these [225]. In 2021, inpatient health expenditures reached € 1,533 per capita, with 5.5 acute care beds per 1,000 population [126]. While inpatient cancer case rates were not reported, Belgium has an 86% five-year net survival rate for cancer [225].

11,1 % des BIP
→ Gesundheitsausgaben

Gesamtkosten
Krebsbehandlung
577 € pro Kopf (2018)

KH-Gesundheitsausgaben
€ 1.533 pro Kopf (2021)

4.6.2 National Health Strategies and Programmes

The Belgian healthcare system originated from the 19th-century voluntary mutual-aid organisations formed by workers during industrialisation to protect against disease, unemployment, and incapacity. The Social Security Act of 28 December 1944 established the first compulsory social security system for salaried workers, including mandatory health insurance. Since then, the system has evolved towards universal coverage (currently 99%), progressively including non-workers, vulnerable individuals, self-employed persons, and civil servants. Generally, health care provision adheres to principles such as independent medical practice, direct patient access (without gatekeeping), freedom to choose health care providers and facilities (including hospitals), and the concept of therapy freedom, allowing physicians to independently determine treatments. Additionally, the system primarily operates on a fee-for-service payment model. However, the use of fixed payments has recently increased [226].

universelle
Gesundheitsversorgung

freie GDL-Wahl & kein
Gatekeeping

Over the past decades, Belgium has evolved into a federal state through six state reforms. These reforms partially transferred a broad range of competencies, including health, to the federated entities (the regions). The regions are now responsible for establishing hospital licensing norms and managing public health initiatives such as health promotion, disease prevention, vaccinations, and screening programs for breast, colorectal, and cervical cancer [226, 227].

Gesundheitsregion
→ Prävention,
Gesundheitsförderung &
Angebote wie Screening-
Programme zuständig

In 2009, Belgium adopted an NCP with 78 measures to improve cancer care through a multidisciplinary approach, psychosocial support, and data collection via the Belgian Cancer Registry. The Cancer Centre at Sciensano monitors progress and provides advice. A 2012 evaluation found the plan largely successful but identified areas needing improvement, such as care coordination, socio-professional reintegration, blood banks, care quality, and personalised medicine. Thematic working groups were established to address these issues. From 2015 to 2019, additional measures focused on molecular diagnostics, care for rare conditions, and professional reintegration of patients. As of 2022, while no new cancer plan is being discussed, authorities are considering further actions to improve access to cancer care, including patient affordability, addressing cancer in children and young adults, and further developing care concentration [225].

Implementierung des NCP
mit 78 Maßnahmen (2009)
von Sciensano überwacht
und begleitet

aktuell keine neuer NCP
aber Prüfung von
Maßnahmen zur
Verbesserung des
Versorgungszugangs

A decisive moment in breast cancer care was the enactment of the Royal Decree on January 1, 2008, which established recognition standards for breast clinics based on the EUSOMA guidelines. This decree specified that accreditation was granted at the hospital site (campus) level, not the entire hospital. One essential standard was a minimum volume of 150 new breast cancer diagnoses annually, with a two-year transition period during which the minimum was set at 100. Exceptions were made for centres without another breast clinic within a 50 km radius, maintaining the minimum at 100 even after the transition [227].

seit 2008 Brustkrebsversorgung auf Basis von EUSOMA-LL in einigen Kliniken

4.6.3 Health Care Infrastructure and Patient Journey

Standard Requirements for Cancer Care

Considering the EUSOMA volume norm, only 14 out of 108 hospitals initially met the required case volume, with 44 hospitals treating fewer than 50 new invasive breast cancer cases annually [226, 228]. By 2008, 41 hospital campuses had received breast clinic recognition based on the enactment of the Royal Decree on January 1, increasing to 53 by December 2013. The main outlines and adaptions of the Royal Decrees from 2007 and 2013 are outlined in Table 4-8.

zu Beginn haben nur wenige Kliniken die Mindestmengen erfüllt

The Royal Decree of December 15, 2013, which took effect on January 3, 2014, introduced the distinction between “coordinating breast clinics” and “satellite breast clinics” which are defined as follows [227]:

Unterscheidung zwischen …

- The coordinating specialised oncological care program for breast cancer (“coordinating breast clinics”) encompasses comprehensive patient care, including diagnosis, multidisciplinary consultations, treatment, rehabilitation, and follow-up for patients with breast malignancies. Each coordinating breast clinic is required to diagnose a minimum of 125 new cases of breast cancer annually.

koordinierende Brustkliniken & …

- The specialised oncological care programme for breast cancer (“satellite breast clinics”) consists of a package of patient care comprising the diagnosis, the multidisciplinary treatment, rehabilitation and follow-up of patients with malignant diseases of the breast(s). The specialised oncological care programme for breast cancer diagnoses annually at least 60 new breast cancers and has a formal collaboration with a coordinating breast clinic.

„Satelliten-Brustkliniken“

Additionally, the Royal Decree of April 19, 2014, effective January 2, 2014, lowered the minimum annual volume per surgeon from 50 to 30 breast surgeries to ensure access to care. Despite the legislative intent to centralise specialised breast cancer care in dedicated clinics, many patients continue to be treated outside these recognised centres. In 2018, approximately 20% of patients diagnosed with breast cancer, including DCIS and invasive breast cancer (IBC), were treated at facilities not recognised for breast cancer care [227].

trotz Zentralisierungsbestrebungen immer noch wesentlicher Pat.-Anteil außerhalb von Brustkrebszentren behandelt

Table 4-8: Recognition criteria for breast clinics – main outlines and adaptions (adapted from Leroy et al. [2023])

Royal Decree Dates	Main outlines & adaptions for recognition criteria for Belgian breast clinics

Royal Decree of 26 April 2007	▪ Care program: A campus qualifies as a breast clinic only if it includes an oncology care program.
	▪ Minimal volume: A breast clinic must handle a minimum annual caseload of at least 150 new breast cancer diagnoses (with a transition period where 100 new diagnoses per year are acceptable).
	▪ A specialist in surgery or gynaecology, a specialist in medical oncology, or a specialist in radiation oncology carries out the medical coordination of the breast clinic. This individual must work full-time at the hospital and dedicate at least eight half-days per week to breast cancer treatment.
	▪ Additionally, a breast clinic must have the following medical specialists, each with a minimum annual caseload and at least three years of experience:
	  ▫ Two specialists in surgery or gynaecology with specific expertise in breast cancer surgery (minimum annual caseload: 50 surgical interventions)
	  ▫ Two medical specialists in X-ray imaging are proficient in mammography and breast ultrasound and are skilled in breast biopsy techniques (minimum annual volume: 1000 mammography's).
	  ▫ One medical specialist in anatomical pathology is available on-site and present during surgical procedures at the campus.
	  ▫ One medical specialist in radiation oncology.
	  ▫ One medical specialist in medical oncology who dedicates at least eight half-days per week at the hospital hosting the breast clinic.
	  ▫ One medical specialist in plastic, reconstructive, and aesthetic surgery with experience in treating breast cancer patients.
	▪ A nurse coordinator should oversee the nursing care of breast cancer patients.
	▪ The breast clinic must include a psychologist to ensure psychosocial support for patients throughout all stages of their illness.
	▪ Physiotherapists specialising in preventing postoperative and post-radiotherapeutic lymphoedema and shoulder stiffness must be available.
	▪ A multidisciplinary consultation must occur weekly for all newly diagnosed patients and before any treatment begins:
	  ▫ Each multidisciplinary consultation must include at least one physician from each medical discipline involved in the breast clinic (as mentioned above), along with a nurse and a psychologist. If necessary, a plastic surgeon should also be present.
	  ▫ A report is generated for each multidisciplinary consultation. This report includes a detailed description of the primary treatment recommended for the patient and outlines the proposed medical follow-up plan.
	▪ In addition to the registration requirements specified for oncological care programs, breast clinics must also register the following (in coded form):
	  ▫ The results of analyses concerning hormonal receptors (ER and PR).
	  ▫ The results of analyses concerning HER2 antigens.
	▪ On the site (campus) of the breast clinic, sufficient ambulatory consultations must be organised to ensure that:
	  ▫ Every new patient with suspected or confirmed breast cancer is seen within five days.
	  ▫ To provide multidisciplinary advice during these consultations, a medical specialist in surgery or gynaecology, a medical specialist in radiology, a medical specialist in radiotherapy, and a medical specialist in medical oncology must be present on campus, ideally within the same unit.
	  ▫ During these consultations, it must be possible to perform a clinical examination, the necessary medical imaging examinations, and the collection of breast biopsies.
	  ▫ The diagnosis and treatment plan is communicated to the patient within a maximum of five working days from the first contact. During these consultations, a nurse experienced in the management of breast cancer and the psychologist(s) of the breast clinic must be available.
	▪ The surgical infrastructure must be organised to ensure that:
	  ▫ The surgical intervention can, if indicated, take place within 15 working days from the moment the patient is informed about the procedure.
	  ▫ The reconstruction, if indicated, does not cause a delay in the breast surgery.
	▪ The breast clinic must also ensure that radiotherapy can be offered within three weeks after breast surgery if no systemic treatment is required.

Royal Decree Dates	**Main outlines & adaptions for recognition criteria for Belgian breast clinics**
Royal Decree of 15 December 2013	Coordinating breast clinics

	■ Reduction of the minimal annual threshold to at least 125 new breast cancer diagnoses.
	■ Appointment of at least a half-time psychologist with significant experience in counselling patients with breast cancer. In the case of a formal collaboration with a satellite breast clinic, the appointment of an additional 0.25 full-time equivalent (FTE) psychologist is required.
	■ Opening of a rehabilitation program that includes physical, psychological, and social rehabilitation.
	■ Provision of the necessary equipment and infrastructure so that:
	  ■ Every patient who presents at the coordinating breast clinic is seen within five days during a multidisciplinary consultation, with the availability of a medical specialist in surgery, a medical specialist in radiotherapy, and a medical specialist in oncology.
	  ■ The care plan can be initiated within ten working days after the diagnosis has been made.
	■ Submission of a five-year report, including hospital mortality data, to the Minister responsible for public health.

	Satellite breast clinics
	■ Must have a minimal annual threshold of at least 60 new breast cancer diagnoses. ■ A formal collaboration agreement must be reached with a coordinating breast clinic, which provides medical coordination and chairmanship for the multidisciplinary consultation. ■ Must fulfil the exact medical and rehabilitation staffing requirements as the coordinating breast clinics. ■ Must appoint a half-time breast nurse and a half-time psychologist.

Abbreviations: ER … Oestrogen receptor, FTE … Full-time equivalent, HER2 … Human epidermal growth factor receptor 2, PR … Progesterone receptor

As of 1 September 2022, Belgium had 51 coordinating and 20 satellite breast clinics. These clinics are not evenly distributed nationwide. The distribution somewhat corresponds to the incidence of breast cancer. For example, Brussels, which has a very high incidence of breast cancer, consequently, has a high concentration of coordinating breast clinics. Conversely, the province of Luxemburg in southern Belgium, where the incidence of breast cancer is very low, has neither coordinating nor satellite breast clinics [227].

51 koordinierende Brustkliniken & 20 „Satelliten-Brustkliniken" aber regional nicht gleichmäßig verteilt

Breast Cancer Patient Journey

Belgian breast cancer patients follow several steps in their care journey. A general patient pathway or CCP, as proposed by the Belgian Health Care Knowledge Centre (KCE) in 2013, is displayed in Figure 4-8. The KCE report further recommends that every woman diagnosed with breast cancer should have access to a breast care nurse specialist. The nurse specialist provides information and support throughout the diagnosis, treatment, and follow-up stages to ensure continuous care and address physical and emotional needs [229].

Belgian Health Care Knowledge Centre (KCE) hat CCP vorgeschlagen

Implementierung von "Nurse Specialist" auch empfohlen

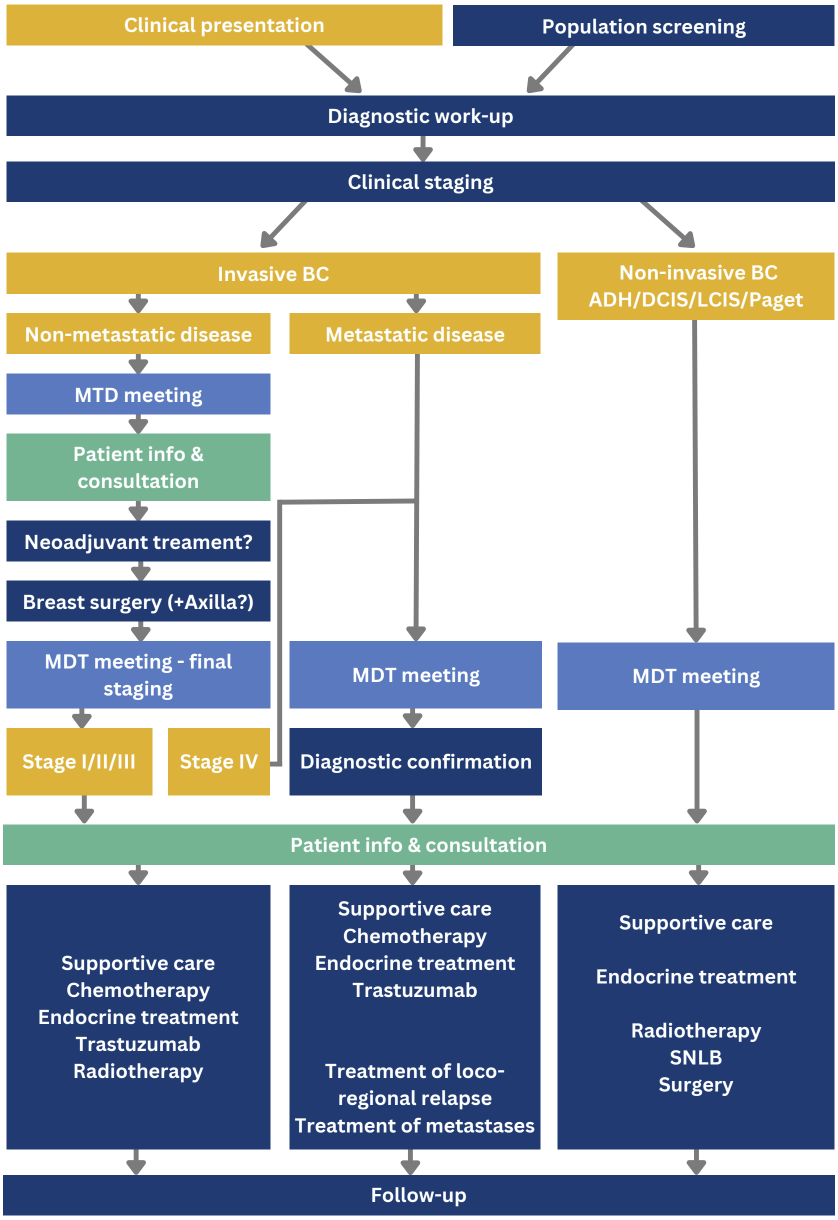


Figure 4-8: General breast cancer patient pathway in Belgium (adapted from Wildiers et al. [2013], own depiction)

Identification of Patients

Identifikation von Pat. durch organisiertes Screening, GP Überweisung & Zufallsbefunde

In Belgium, potential breast cancer patients are typically identified through organised **screening programs**, referrals from **GPs**, or **incidental findings** during diagnostic workups for other conditions. In addition to the national screening programme, GPs play an important role in recognising symptoms and guiding patients through further diagnostic procedures, ensuring timely and accurate identification of breast cancer [230].

wesentliche regionale Differenzen in der Screening-Teilnahme

Since 2001, a population-based breast cancer **screening** programme has been launched in the Flemish region (northern region), in 2002 in Brussels (capital region), and in the Walloon region (southern region). Women aged 50 to 69 are invited to have a screening mammography every two years. In 2016, the program's coverage was 33.2%, with significant regional differences: 50.7% in the Flemish region, 10.9% in Brussels, and 6.8% in the Walloon region. When including mammograms performed outside the organised screening program, the coverage increased to 61.8%, with smaller regional disparities: 67.4% in the Flemish region, 52.9% in Brussels, and 53.9% in the Walloon region [226]. Despite this, the overall coverage remains well below the European target of offering breast, cervical, and colorectal cancer screening to 90% of the target population by 2025 [231]. Overall, participation in the screening program across Belgium remained nearly consistent between 2019 and 2021, with an average participation rate of 31.3% (32.2% in 2019, 30.3% in 2020, and 31.5% in 2021) [232].

Diagnosis

Following a breast cancer diagnosis, patient care typically begins with a gynaecologist at a hospital outpatient clinic, ideally within a recognised breast cancer clinic, which is the case for approximately two-thirds of breast cancer patients. The gynaecologist, serving as the primary point of contact, performs a comprehensive assessment, including **physical examinations** and referrals to various tests, such as **blood samples** and **diagnostic imaging**, tailored to the disease stage [230]. As needed, the breast cancer clinic requests additional diagnostic procedures for disease staging and genetic analyses. Alongside hospital outpatient clinics, private radiology practices can conduct **diagnostic imaging** (excluding CT scans), and external laboratories are available for blood sample analysis. If **biopsies** were not previously obtained at screening centres, they are performed at the hospital outpatient clinic [230, 233].

physische Untersuchung, Blutabnahme & Bildgebung durch Gynäkolog*in nach erster Diagnose

auch private Radiologie-Zentren sind involviert

Biopsien → spitalsambulanten Setting

Several gene expression profiling (GEP) tests, such as Oncotype DX and MammaPrint, are available in Belgium to estimate the risk of cancer progression or recurrence. However, due to insufficient evidence, the widespread use of these tests is not supported by an HTA report from the KCE institute. A pilot project launched in 2019 aims to regulate GEP test usage, control costs, and gather additional data on treatment decisions by restricting access to reimbursed GEP tests. This project is limited to early-stage patients (tumour size <5 cm, HER2-negative, ER and/or PR positive, and up to three positive lymph nodes) treated at hospitals with agreements from the National Institute for Health and Disability Insurance (RIZIV-INAMI), involving only designated coordinating and satellite breast clinics [227].

Genexpressionsanalysen verfügbar, aber nicht standardmäßig

Treatment

Treatment Management

After completing all diagnostic procedures, the patient's case is presented at **MDT** conferences in the hospital outpatient clinics [230, 233]. The use of MDTs has significantly increased since the introduction of MDT-specific nomenclature codes in 2003. By 2015, 87.5% of cancer patients were discussed by MDTs, compared to 51% in 2004. Although there are variations by cancer type – with breast cancer having the highest MDT discussion rate at 95.7% and malignant melanoma the lowest at 70.5% – these differences have decreased over time. Regional disparities, initially notable in 2004, also lessened by 2015, with Flanders having a slightly higher MDT discussion rate (88.7%) compared to Brussels (87.8%) and Wallonia (85.1%) [228].

nach Diagnose werden Fälle in MDT-Konferenzen besprochen

~96 % der Brustkrebspat. in MDT-Konferenzen besprochen (2015)

MDT meetings in hospital outpatient clinics are attended by various specialists, including surgeons, medical oncologists, radiotherapists, pathologists, gynaecologists, and radiologists. The team reviews all test results and discusses treatment options. Subsequently, the **treatment plan** is reviewed with the patient pre- and post-surgery. Follow-up care includes assessments like **bone density scans**, further **blood samples** and the management of central catheters as needed [230, 233]. **PICC** lines for chemotherapy are typically inserted by anaesthesiologists in the hospital outpatient clinic on the day of the first chemotherapy session, as required [230]. A **geriatric assessment** is also routinely conducted for patients over 75 years in the hospital outpatient clinic [233].

nach MDT-Konferenzen wird Behandlungsplan mit den Pat. besprochen (prä- & post-OP)

PICC-Katheter → erster Chemotherapietag

routinemäßiges geriatrisches Assessment

Therapy Options

Most **surgeries**, including reconstruction and sentinel lymph node biopsies, typically involve an overnight stay in the hospital (inpatient). However, there is a growing trend towards minimising hospital stays, as demonstrated by breast-conserving surgery and sentinel lymph node biopsies, which can now be performed in hospital outpatient clinics without requiring an overnight stay [230, 233].

Großteil der OPs stationär mit 1 Übernachtung aber Trend Richtung „Ambulantisierung"

In EUSOMA-accredited cancer centres, adherence to EUSOMA guidelines is essential, particularly regarding the involvement of plastic surgeons in the surgical care of breast cancer patients. These guidelines emphasise the importance of offering immediate **breast reconstruction** following mastectomy. Consequently, surgical teams in these centres typically include gynaecologists, general surgeons, and plastic surgeons. This multidisciplinary approach ensures that at least 40% of mastectomy patients are offered immediate reconstruction, as required by the guidelines [26]. It is crucial, however, that the reconstruction does not delay the breast surgery [227].

Brustrekonstruktion sollte unmittelbar nach Mastektomie angeboten werden (EUSOMA-LL)

Systemic treatments, including antibody therapy and most adjuvant and palliative therapies, are primarily administered in hospital outpatient clinics, with patients typically arriving in the morning or afternoon and returning home in the evening. However, there are ongoing initiatives to transition some therapeutic options to home settings (see section Developments and Trends) [230, 233].

systemische Therapien größtenteils spitalsambulant

Radiotherapy is administered in specialised centres within both public and private hospital clinics without requiring overnight stays [230, 233]. Previously unavailable in Belgium, proton beam therapy necessitated travel to neighbouring countries for patients seeking this treatment. However, with the completion of the Leuven Proton Therapy Centre, which began treating patients in July 2020, Belgium has introduced proton therapy domestically. Additionally, discussions are ongoing regarding the establishment of a second proton therapy centre in Belgium. Belgium has 9.9 radiotherapy centres per million inhabitants, above the EU average of 8.9. Despite this, radiotherapy is underutilised. A study showed that only 37% of cancer patients received external beam radiation therapy within five years of diagnosis, compared to the optimal utilisation rate of 53%. As a result, more than one in four Belgian cancer patients did not receive necessary radiotherapy, with significant variations between cancer types [225, 234].

Strahlentherapie in spezialisierten Zentren

mittlerweile auch Möglichkeit der Protonentherapie in BE

Patient Support and Follow-up Care

The Royal Decree mandates the inclusion of a clinical psychologist, psychiatrist, and social worker in cancer care programs; however, their roles are not clearly defined or consistently maintained. Since 2017, health insurance has covered psychological support for cancer patients, with expanded coverage in 2020 to include sessions for children under 18 and adults over 65 [225]. **Psycho-oncological care** is provided both in hospital outpatient clinics by paramedical teams and in various outpatient settings or at home by psychologists [230, 233]. Due to inconsistent recording of psycho-oncological services, it is not possible to determine the proportion of oncology patients receiving psycho-oncological support. An evaluation under the NCP found that approximately 40% of patients require psychosocial support, yet only 30% of those in need actively receive it [225].

psychoonkologische Versorgung → spitalsambulanten & niedergelassenen Setting

genaue Zahlen zu Inanspruchnahme nicht verfügbar

Fertility counselling is routinely offered by fertility specialists in hospital outpatient clinics to premenopausal patients upon diagnosis, providing guidance on preservation options [230, 233]. **Sexual health** counselling is also available through consultations with sexologists and gynaecologists in these clinics [233]. Additionally, cancer nurses play a crucial role in offering support and recommending resources such as **wigs and prostheses**, which can be obtained with a prescription. **Social workers** also contribute significantly to patient support within hospital outpatient clinics. Physicians in the inpatient setting typically manage **discharge planning** for breast cancer patients [230, 233].

Fertilitätsberatung & Beratung zur sexuellen Gesundheit spitalsambulant

Sozialarbeit auch wichtige Säule bei Pat.-Betreuung

Genetic counselling is conducted according to guidelines established by the Belgian Society of Genetics; however, not all patients may require counselling. At academic hospitals equipped with genetic centres, counselling sessions are held onsite. In hospitals lacking these facilities, a visiting physician or genetic counsellor may provide genetic counselling from a specialised centre, or patients may be referred to academic centres where genetic counselling services are available, ensuring access to comprehensive and tailored care [230, 233].

genetische Beratung in Unikliniken & durch „Gast-Genetiker*innen" in Kliniken ohne Expertise

Post-treatment surveillance in hospital outpatient clinics typically includes annual mammograms, with or without accompanying ultrasound, for the first ten years to detect any potential recurrence or new primary cancers. Follow-up appointments are scheduled every three to four months during the first two years after diagnosis, every six months until five years, and annually thereafter. Additionally, programs are available to assist in the **socio-professional reintegration** of patients who have completed breast cancer treatment. These initiatives, offered in hospital outpatient clinics and other outpatient settings, aim to support a return to daily life and work by addressing physical and psychological recovery needs. Physiotherapy is advised to address mobility impairments following axillary clearance, and specialised services are available for the management of lymphedema, a frequent complication of breast cancer treatments [229, 230, 233].

Follow-Up-Termine nach Behandlung alle 3-4 Monate (innerhalb der ersten 2 Jahre)

sozio-professionelle Wiedereingliederungs-programme verfügbar

In Belgium, **palliative care** responsibilities are divided between the federal state and the regions. The federal government handles funding for inpatient palliative care and medication reimbursement and operates a Palliative Care Evaluation Unit that issues biennial reports. Regional governments manage and finance palliative care associations, multidisciplinary support teams, and day centres. Established in 1995, palliative care networks (15 in Flanders, one in Brussels, eight in Wallonia, and one in the German-speaking community) promote cooperation among institutions and health professionals.

Zuständigkeiten der Palliativversorgung zwischen Bundesstaat & Regionen aufgeteilt

These networks cover specific geographic areas and are tasked with public education, partner collaboration, professional training, volunteer support, data collection, and service evaluation [225].

spezialisierte Palliativversorgung im KH & Palliativversorgung zuhause verfügbar

Generally, every patient has the right to end-of-life **palliative care**, which a GP, specialist, relatives, or any concerned health professional can initiate. Hospitals provide two palliative care options: specialised units offering comprehensive, multidisciplinary care and a palliative function to support patients not in specialised units. Palliative care is also available at home and is provided by over 20 care units outside the hospital [225, 230, 233]. In 2015, 53% of terminal cancer patients received palliative care, with higher rates in Flanders. However, 18.4% died within a week of initiation, underscoring the need for timely care. About 8.9% of patients received chemotherapy in their last two weeks, with higher rates in Wallonia. While 63% of cancer patients died in hospitals, only 23.1% died at home, though recent trends indicate a decrease in hospital deaths and an increase in residential care deaths. New criteria introduced in 2018 aim to improve the timing and quality of palliative care [228].

"Patient Journey" Details in Abb. & Tab. im Appendix-Dokument

The described patient journey from diagnosis to follow-up, including the place of care provision, is depicted in Figure 4-9. Additionally, more detailed information on the place of health care provision and the involved health care professions can be found in the Appendix document.

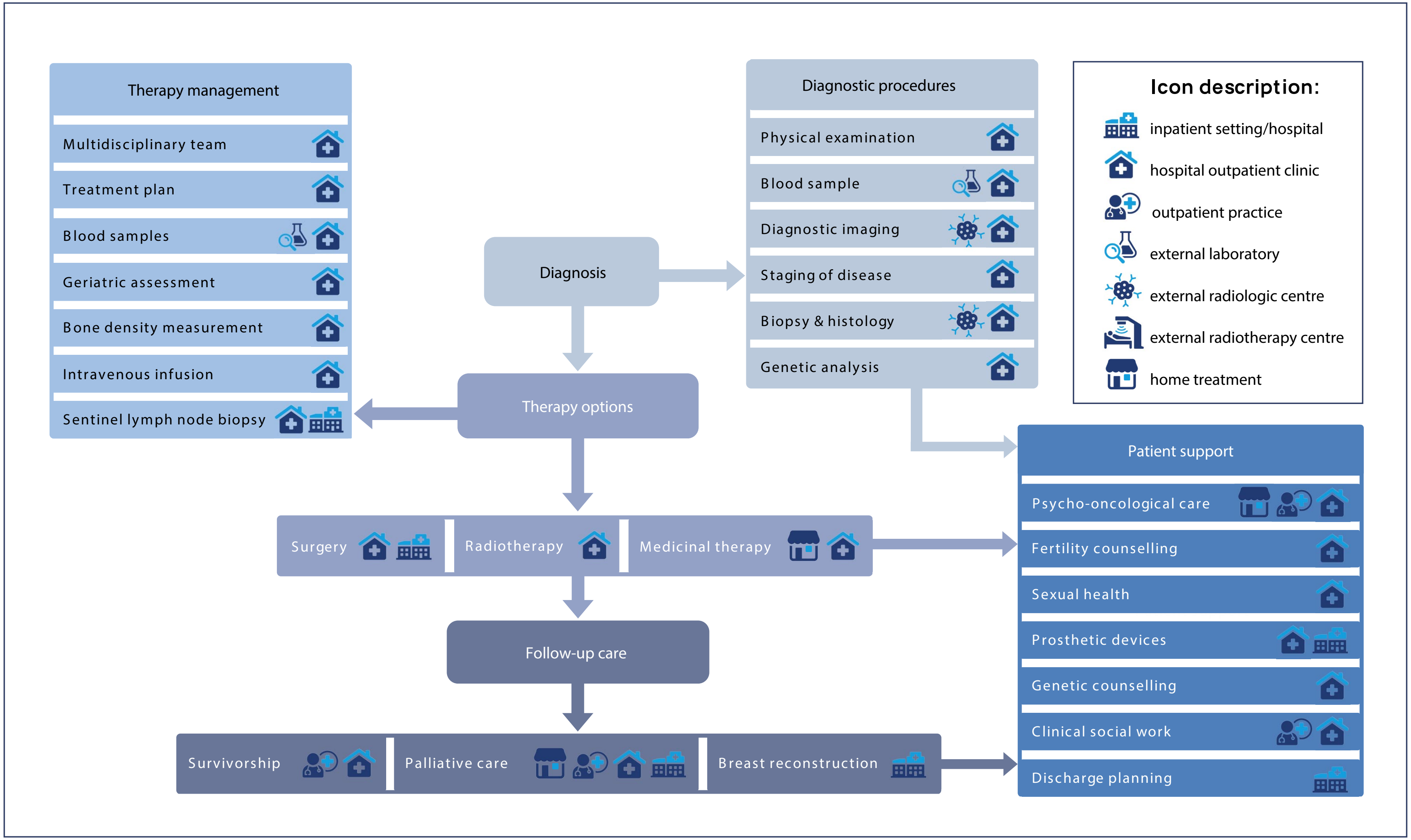


Figure 4-9: Patient journey and place of care provision in Belgium

4.6.4 Cross-Sectoral Care Coordination

Care Coordination

fachärztliche Versorgung inkl. Krebsversorgung hauptsächlich durch KH-Ambulanzen angeboten

In Belgium, the federal authorities are tasked with regulating SHI, health products, and health professions. They also oversee the allocation of budgets for ambulatory and hospital care. Conversely, the regions and communities (federated entities) are responsible for health promotion and prevention, organising primary care services, managing social services and community care, financing hospital infrastructure and major medical equipment, and establishing standards for hospital licensing. Regular inter-ministerial conferences are held to facilitate collaboration and coordination across these different levels. Regarding care provision, primary care physicians in Belgium are primarily self-employed, while specialist care is mainly offered through hospital outpatient departments, with additional services available in private practices [212].

MDT koordinieren Pat.-Versorgung & übergeordnete Organisation & Koordination basierend auf „Multi-Campus-Ansatz“

Besides the coordination of care through the MDT, the organisation and coordination of breast cancer care within hospitals in Belgium involve a multi-campus approach, where different campuses may have varying levels of recognition and specialisation. Specifically, hospitals can designate one campus as a coordinating breast clinic, another as a satellite breast clinic, and a third as a campus without formal recognition for breast cancer care. Over time, various forms of collaboration between these campuses and hospitals have been established. These collaborations range from meeting the minimal requirements defined in the Royal Decree to having entire medical and paramedical teams travel between campuses to provide consistent care across both recognised and non-recognised sites [212]. Additionally, as stipulated by the Royal Decree, the nursing care of patients with breast cancer should be overseen by a dedicated nurse coordinator [227].

Health Care Data

Electronic Health Records System

KHs & private Radiologie-Zentren haben eigenes eGA-System aber zentraler Mechanismus erleichtert den Zugang & Austausch von Pat.-Berichten

In Belgium, hospitals and private radiology centres maintain individual EHR systems. However, a centralised mechanism facilitates access to reports across these institutions. This system operates through a central repository known as the “eHealth Platform”, which does not store reports directly but instead contains links to the reports stored on individual institutions’ servers. When a health care provider needs to access a patient’s history from another hospital or private radiology centre, they can use their own electronic medical record system to access a page with a link to the relevant report. This setup helps prevent unnecessary duplication of tests and treatments by enabling providers to check if procedures have already been performed elsewhere [230, 235, 236].

Zugang zu KH-Berichten für GP möglich, doch nur im PDF-Format bereitgestellt

This centralised access primarily facilitates hospital interactions and may not be uniformly extended to the outpatient sector. In the outpatient setting, health care providers can also retrieve reports from private radiology centres and laboratory results from private labs. They may access summaries of a patient’s health status compiled by GPs, though the completeness of this information can vary [230]. Access to hospital reports for GPs is available, but these are typically provided in PDF format. This format does not use the SNOMED CT coding language employed internally within hospital systems like EPIC. As a result, while hospital reports are structured with SNOMED CT codes for internal use, external physicians, such as GPs, receive the finalised reports in a more accessible format like PDF [235, 236].

Enacted in Belgium in February 2020, the Right to be Forgotten Act empowers individuals to exert control over their personal data, including health information. This legislation is designed to enhance insurance accessibility for cancer survivors by permitting the removal of specific health data from public records. It applies to insurance for both mortgage loans related to home acquisition or renovation and business loans [225].

seit 2020 gilt Gesetz über das Recht auf Vergessen werden

Cancer Registry

Cancer registration in Belgium started in the 1950s with health insurance funds collecting data, leading to the National Cancer Registry ("Nationaal Kankerregister", NKR) in 1983, managed by Belgian Work against Cancer. Despite these efforts, under-reporting led to additional initiatives in Flanders in the late 1980s, supported by the Flemish government from 1994 to 2005. Coordinated by the Vlaamse Liga tegen Kanker (now Kom op tegen Kanker), this network gained international recognition in 2001 when its data were included in the IACR's Cancer Incidence in Five Continents. The introduction of mandatory registration in 2003 and standardisation efforts led to the establishment of the Belgian Cancer Registry (BCR) on June 28, 2005. Officially inaugurated on May 17, 2006, the BCR combines previous initiatives to create a comprehensive cancer registration system for Belgium, offering valuable insights both nationally and internationally [226, 237].

seit 2008 verpflichtende Meldung von Daten in das belgische Krebsregister (BCR)

The BCR manages cancer data across Belgium, focusing on comprehensive collection, validation, and analysis while ensuring robust data protection. Its primary aim is to map cancer epidemiology and use research to improve patient outcomes and quality of life. The BCR relies on mandatory registration from hospitals and pathology laboratories to maintain a thorough databank essential for evaluating cancer prevention, early detection, diagnosis, treatment, and follow-up. Through systematic data collection and international collaboration, the BCR contributes to global cancer research by reporting to organisations such as the International Agency for Research on Cancer (IARC), the World Health Organisation (WHO), and the European Network of Cancer Registries – Joint Research Centre (ENCR-JRC). Operating as a Public Benefit Foundation, the BCR conducts in-house and collaborative research with various stakeholders while adhering to strict privacy and data protection standards as outlined in Article 39 of the health-related act ratified on 13 December 2006 [237].

Hauptzwecke des BCR:

Krebsepidemiologie & Nutzung zur Verbesserung der Behandlungsergebnisse & Lebensqualität der Pat.

Developments and Trends

Home-Based Cancer Treatment Initiatives

Belgium has introduced several initiatives to facilitate home-based cancer treatments, including certain antibody therapies, chemotherapy, antihormone injections, and supportive treatments. These therapies are administered at home by nurses in accordance with a legally specified list of reimbursed products. While these nurses are not required to be hospital staff, there is ongoing debate about whether hospital clinic staff should manage these treatments directly [230, 233].

einige Initiativen zur häuslichen Krebsbehandlung gestartet

The "Wit-Gele Kruis" offers one program that provides oncological treatments for patients evaluated as suitable as home treatment by their oncologist or haematologist. This service involves collaboration between hospital and home care teams, where trained oncology nurses administer treatments, monitor

"Wit-Gele Kruis":

Kollaboration zwischen KH, häuslichem Pflegeteams & Pat.

patients, and report back to the hospital. Initial therapies are conducted in the hospital to ensure patient safety before transitioning to home care [238].

Another initiative was the three-year pilot project conducted by UZ Leuven, which was completed in December 2020. This project focused on administering breast cancer treatment at home or through GPs as part of a federal initiative to reduce hospital visits and enhance patient experiences. The project involved collaboration with the White-Yellow Cross for Vlaams-Brabant and the GP association Khobra, concentrating on a subcutaneously injected treatment with minimal side effects. Initial administration and monitoring were carried out in the hospital, while subsequent doses were managed by trained nurses or GPs selected by the patients [239].

weiteres Projekt durch UZ Leuven initiiert:

Brustkrebsbehandlungen zu Hause oder bei GPs Verringerung von KH-Aufenthalten

The pilot project provided specialised training for nurses across Flanders, allowing patients the flexibility to choose their own GPs or home nurses. The initiative reduced hospital visits and improved the treatment experience for patients. Future plans include further training for primary care providers, quality control enhancements, and enhanced electronic data sharing. Pending government approval, UZ Leuven aims to expand home treatment options for breast cancer and other oncological conditions [239].

Ergebnisse des Pilotprojekts: weniger KH-Aufenthalte & bessere Behandlungserfahrung für Pat.

Patient-Reported Experience Measurements (PREMs)

Several local initiatives in Belgium focus on measuring patient-reported experience measurements (PREMs). A project led by a private consulting company assesses patient experiences across 17 hospitals in Brussels and Wallonia. In Flanders, many hospitals participate in the Flemish Indicators Initiative, which utilizes patient survey questionnaires on a voluntary basis. Additionally, developments in PROMs and PREMs include a project organised by Sciensano and a new initiative by the Vlaams Instituut voor Kwaliteit van Zorg (VIKZ) focusing on lung and rectal cancer [225, 230].

zudem auch einige lokale Initiativen zu Messungen von Pat. gemeldeten Erfahrungen (PREMs)

5 Results: Comparison of Breast Cancer Care across selected European Countries

5.1 Comparison of Cancer Epidemiology and Cancer Care Expenditures across selected European countries

The European Union's average life expectancy is 80.7 years, with 21.1% of the population aged 65 or older. On average, 10.9% of GDP is allocated to healthcare expenditures. The average cancer incidence is 569 per 100,000, with breast cancer representing 29% of new cases among women. The five-year net survival rate for cancer is 83% [2, 46]. In 2021, inpatient health expenditures averaged € 1,092 per capita, with 4.8 acute care beds per 1,000 population [5]. An overview of cancer epidemiology and cancer care expenditures in selected European countries is summarised in Table 5-1, based on the State of Health in the EU's Country Health Profiles and Country Cancer Profiles.

EU: ∅ 10,9 % des EU-BIP → Gesundheitsausgaben

∅ KH-Gesundheitsausgaben € 1.092 pro Kopf (2021)

Austria and Germany allocate a larger share of GDP to healthcare (11.5% and 12.8%, respectively) and maintain higher acute care bed densities (6.9 and 7.8 beds per 1,000) compared to the EU average [5, 63]. Austria's cancer incidence (488 per 100,000) is the lowest among the identified countries. Its five-year survival rate (85%) is comparable to Belgium and Denmark, though lower than the Netherlands (87%) and Sweden (89%) [2, 5, 62]. Austria's per capita cancer care cost (€440) is lower than Belgium, the Netherlands, and Denmark but higher than Sweden. Inpatient health spending (€1,387 per capita) is higher than in the Netherlands, Sweden, and Denmark but lower than in Belgium [5, 63, 126, 175, 212, 240].

Gesundheitsbudget AT & DE & Bettendichte > EU-∅

Krebsinzidenz: AT < SE < DE < BE < NL < DK

Table 5-1: Overview of cancer epidemiology and cancer care expenditures for six European countries

Metric	Selected EU countries						EU-mean	Sources
	Austria	Germany	Denmark	Belgium	Netherlands	Sweden		
Health care expenditures & inpatient care								
Health expenditures as a % of GDP (2021)	11.5%	12.8%	10.5%	11.1%	11.1%	11.2%	10.9%	[5], [63],[126], [240], [212], [175]
Total cost of cancer in EUR per capita PPP (2018)	488	562	680	577	591	413	378*	[46]
Direct costs of cancer care in EUR (2018)[1]	289	308	259	284	308	187	195*	[46]
Health expenditures for the inpatient sector in EUR (2021)	1,387	1,358	1,069	1,533	986	957	1,092	[5], [63],[126], [240], [212], [175]
Acute bed number per 1,000 population (2021)	6.9	7.8	2.5	5.5	3.0	2.1	4.8	[5], [63],[126], [240], [212], [175]
Epidemiology & Cancer burden								
Life expectancy at birth in years (2022)	81.1	80.7	81.3	81.8	81.7	83.1	80.7	[5], [63],[126], [240], [212], [175]
Population aged 65 and over (2022)	19.2%	22.1%	20.3%	19.5%	19.8%	20.3%	21.1%	[5], [63],[126], [240], [212], [175]
Cancer incidence per 100,000 population (2020)	488	571	688	640	655	557	569	[2], [62], [61], [225], [213], [176]
New cancer cases in women, % breast cancer (2020)	21,040; 28%	249,323; 28%	19,267; 26%	34,666; 34%	52,864; 30%	26,228; 29%	1,237,588; 29%	[2], [62], [61], [225], [213], [176]
Cancer mortality per 100,000 population (2019)	230	244	283	229	267	217	247	[2], [62], [61], [225], [213], [176]
Five-year net survival in breast cancer (2010-2014)	85%	86%	86%	86%	87%	89%	83%	[2], [62], [61], [225], [213], [176]

Note:

** … European mean*

Abbreviations: EU … European, EUR … Euro, GDP … Gross Domestic Product (defined as expenditures on cancer that are made within the healthcare system).

5.2 Comparative Analysis of Breast Cancer Patient Journey across selected European Countries

5.2.1 Identification of Patients

In all examined countries, patients are identified either by organised screening programmes, referrals from GPs, or incidental findings during diagnostic workups for other conditions.

identifizierte Länder haben ähnliche Identifikationsstrategien

5.2.2 Diagnosis

Different health care infrastructures are used for diagnostic procedures across the investigated European countries, as illustrated in Figure 5-1. **Physical examinations** are typically conducted within hospital outpatient clinics and outpatient practices in Austria, Denmark, Sweden, and the Netherlands. In contrast, Belgium relies solely on hospital outpatient clinics, while Germany employs a broader range, including hospital outpatient clinics, external radiologic centres, and practices of outpatient haematologists and oncologists. Regarding **blood sampling**, Austria, Belgium, and the Netherlands primarily rely on both external and internal laboratories within hospital outpatient clinics. In Denmark, blood sampling for breast cancer patients is exclusively provided in hospital outpatient clinics, whereas Sweden integrates home treatment alongside hospital outpatient clinics and external laboratories. Germany adopts a diverse approach involving hospital outpatient clinics, external laboratories, and practices of outpatient haematologists and oncologists.

physische Untersuchung: spitalsambulant & niedergelassen in AT, DK, SE & NL

BE nur spitalsambulant & DE in mehreren Settings

Blutproben: AT, BE & NL durch ext. & spitalsambulante Labors

Blutabnahme in SE auch zuhause möglich

Different health care structures are utilised for **diagnostic imaging** across the investigated countries. Austria, Belgium, Denmark, and Sweden predominantly provide diagnostic procedures for breast cancer patients within hospital outpatient clinics and external radiologic centres. Germany adopts a mixed approach, incorporating hospital outpatient clinics, external radiologic centres, and outpatient practices. In contrast, the Netherlands primarily offers diagnostic procedures for breast cancer patients in hospital outpatient clinics. **Disease staging** is mainly conducted in hospital outpatient clinics in Belgium, Sweden, and the Netherlands. Denmark and Austria also perform these procedures in external radiologic centres, while Germany also integrates outpatient practices.

Bildgebung: AT, BE, DK & SE durch externe Zentren & spitalsambulant

Staging: spitalsambulant in BE, SE, & NL; in AT & DK auch in externen Zentren

Staging & Bildgebung in DE auch niedergelassen

In Austria, Sweden, and the Netherlands, **biopsy and histology** are primarily conducted in hospital outpatient clinics. Germany extends its approach by incorporating external radiologic centres and outpatient oncologist practices. In contrast, Belgium and Denmark utilise both hospital outpatient clinics and external radiologic centres for these procedures. Regarding the location of health care provision for **genetic analyses**, four out of six investigated countries (Belgium, Denmark, Sweden, and the Netherlands) offer these services exclusively in hospital outpatient clinics. Conversely, Austria and Germany also utilise external laboratories for genetic analyses.

Biopsien & Histologie: spitalsambulant in AT, SE, NL, BE & DK; BE, NL & DE auch in ext. Zentren & in DE zudem niedergelassen

genetische Analyse in 4 Staaten ausschließlich spitalsambulant

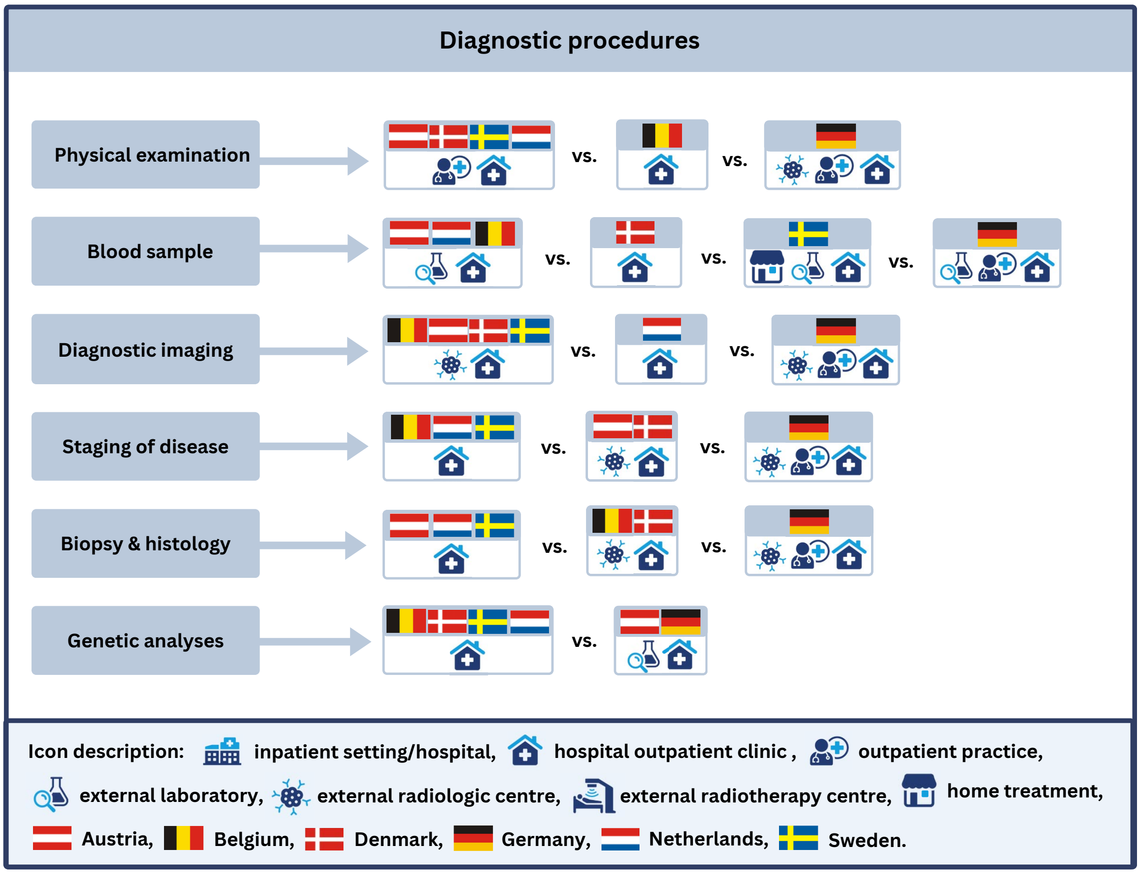


Figure 5-1: Comparison of utilised health care infrastructures for diagnostic procedures across six European countries

5.2.3 Treatment

Therapy Management

Several patterns and distinctions emerge when comparing the health care infrastructures utilised for therapy management across six European countries (Figure 5-2). Austria, Belgium, Denmark, the Netherlands, and Sweden predominantly conduct **MDT conferences** and develop **treatment plans** within hospital outpatient clinics. Germany, however, expands this approach by incorporating expertise from external radiologic centres in the MDT conference and practices of outpatient haematologists and oncologists in the MDT conference and treatment plan.

spitalsambulante MDT-Konferenzen in allen Staaten

DE auch Einbindung von niedergelassenen Ärzt*innen für HMO

For **blood sampling**, Denmark and the Netherlands primarily rely on hospital outpatient clinics, while Belgium and Austria utilise both external laboratories and hospital outpatient clinics. Sweden adopts a distinctive approach by integrating home treatment in addition to hospital outpatient clinics and external laboratories. In contrast, Germany employs a broader infrastructure, incorporating hospital outpatient clinics, external laboratories, and outpatient oncology practices. **Bone density** measurements are typically performed within hospital outpatient clinics across most countries, with Austria and Germany extending these services to include external radiologic centres, and Germany also offering them in outpatient oncologist practices.

Blutproben während Behandlungsphase vergl. mit Diagnosephase

Knochendichtemessung typischerweise spitalsambulant → DE & AT auch durch ext. Labore → DE auch niedergelassen

Geriatric assessments are not systematically conducted in all countries but are rather conducted needs based. However, if geriatric assessments are necessary, they are primarily conducted in hospital outpatient clinics in four of the examined countries (Belgium, Austria, Sweden, and the Netherlands). However, Denmark additionally provides this service in the inpatient setting, while Germany involves outpatient haematologists, oncologists, and hospital outpatient clinics.

geriatrisches Assessment vorwiegend spitalsambulant, nur bedarfsorientiert & nicht systematisch

Regarding **intravenous infusions** (such as PICC lines and Port catheters), Belgium, Sweden, and the Netherlands primarily perform this procedure in hospital outpatient clinics, while Austria, Denmark, and Germany also incorporate inpatient settings. **Sentinel lymph node biopsies** are generally conducted in Austria, Belgium, Denmark, Germany, and the Netherlands inpatient settings. Additionally, these procedures are offered in hospital outpatient clinics in Belgium, Denmark, and the Netherlands. Notably, Sweden performs sentinel lymph node biopsies exclusively in outpatient settings.

Infusionen: in BE, SE & NL spitalsambulant & stationär in AT, DK & DE; SLNB: AT, BE, DK, DE & NL stationär & spitalsambulant in BE, DK, NL: SE ausschließlich niedergelassen

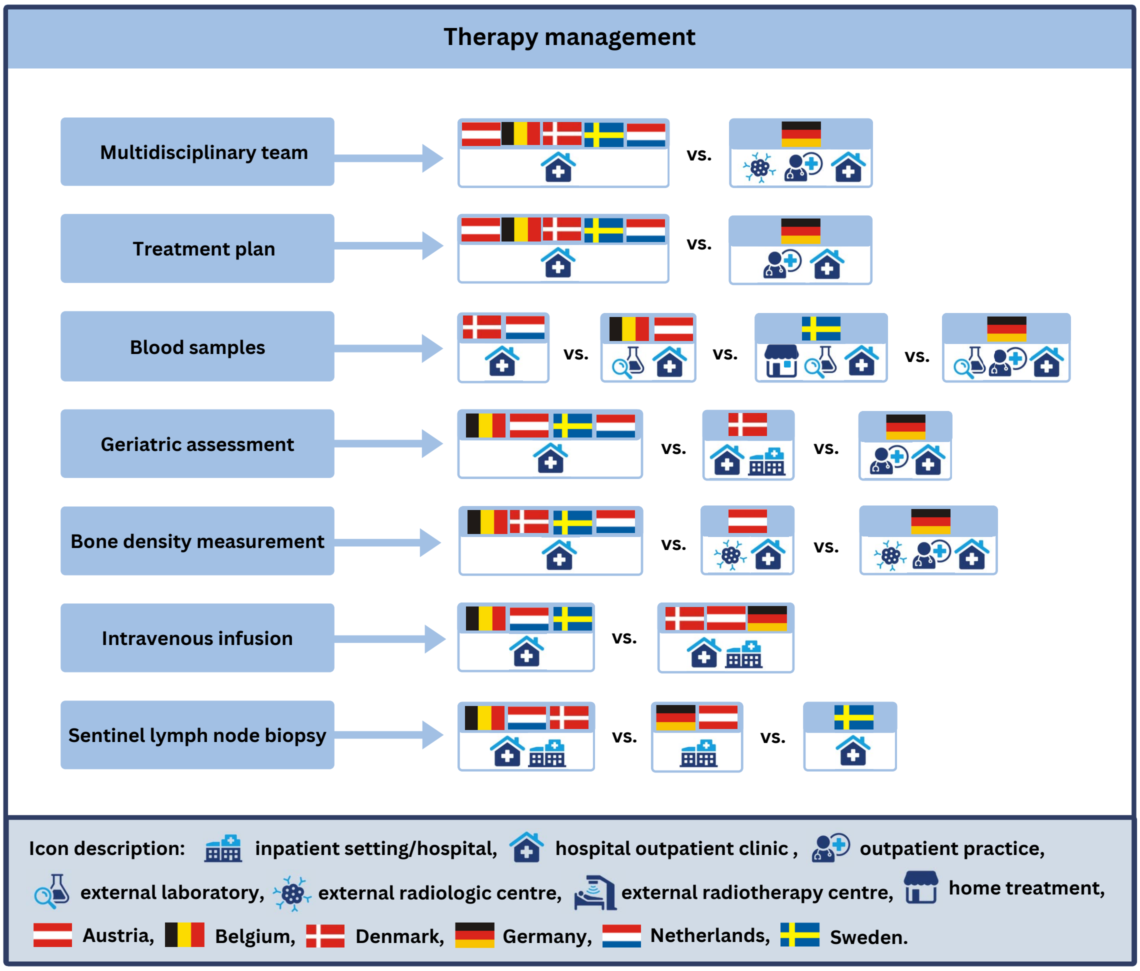


Figure 5-2: Comparison of utilised health care infrastructures for therapy management across six European countries

Therapy Options

The analysis of therapy options across six European countries reveals both similarities and differences in the infrastructures used for breast cancer treatment, particularly in surgery, radiotherapy, and medicinal therapy (Figure 5-3). In Austria and Germany, **breast cancer surgery** is exclusively conducted in hospitals, with patients requiring at least one overnight stay. In contrast, Belgium, Denmark, and the Netherlands perform surgeries in both inpatient settings and hospital outpatient clinics, depending on the severity of the intervention. Uniquely, Sweden conducts all surgeries exclusively in hospital outpatient clinics without requiring overnight stays.

Brust-OPs: AT & DE ausschließlich stationär

BE, DK & NL abhängig vom OP Schweregrad

in SE ausschließlich auf spitalsambulanter Basis

Radiotherapy services vary across the six European countries examined. Austria, Belgium, Denmark, and Sweden primarily depend on hospital outpatient clinics to deliver radiotherapy. Germany broadens these services by incorporating external radiotherapy centres and outpatient haematologists and oncologists. The Netherlands employs a mix of hospital outpatient clinics and external radiotherapy centres. Furthermore, **medicinal therapy** is generally administered in hospital outpatient clinics in Austria and Sweden. However, in the Netherlands and Denmark, these therapies are also provided in hospital outpatient clinics, external outpatient practices, and through home treatment. Belgium and Germany further diversify by including options such as home treatment or outpatient haematologist and oncologist practices.

Radiotherapie-Settings variieren über identifizierte Länder

medikamentöse Therapien in BE & DE teilweise zuhause möglich

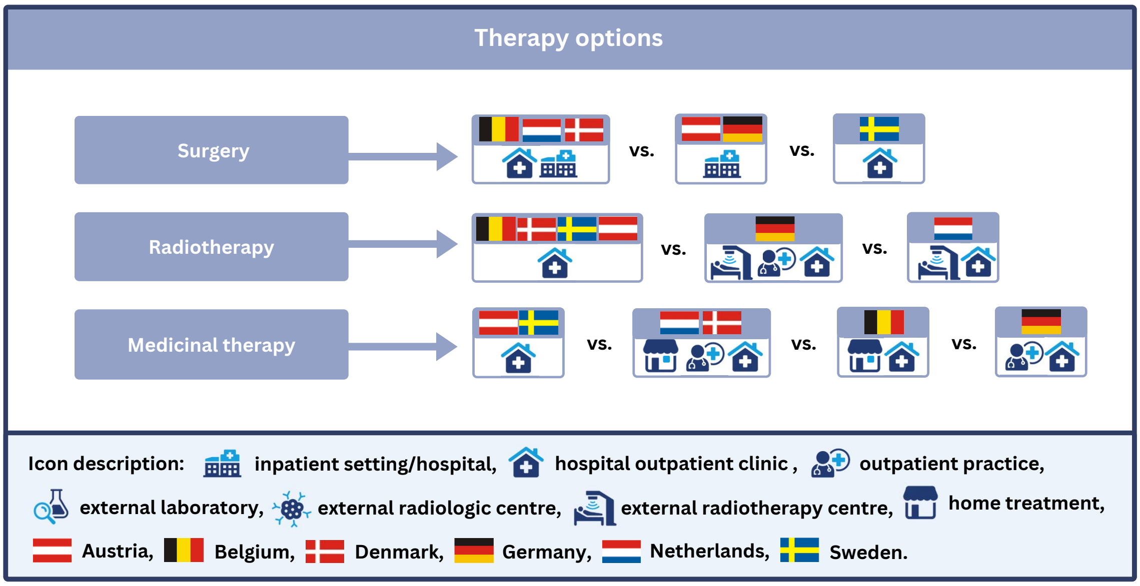


Figure 5-3: Comparison of health care infrastructures used for administering breast cancer therapy across six European countries

5.2.4 Patient Support and Follow-up Care

Patient Support

The analysis of patient support services for breast cancer care across six European countries highlights commonalities and unique approaches (Figure 5-4). **Psycho-oncological care** is consistently provided in hospital outpatient clinics in all countries. Outpatient practices also offer these services in all countries except Sweden. Notably, Belgium integrates home treatment into its psycho-oncological care provision. **Fertility counselling** shows a consistent pattern, with all countries offering this service in hospital outpatient settings. Additionally, Austria and Germany involve outpatient practices for fertility counselling.

psychoonkolog. Versorgung vorwiegend spitalsambulant, BE zudem zuhause

Fertilitätsberatung vorwiegend spitalsambulant

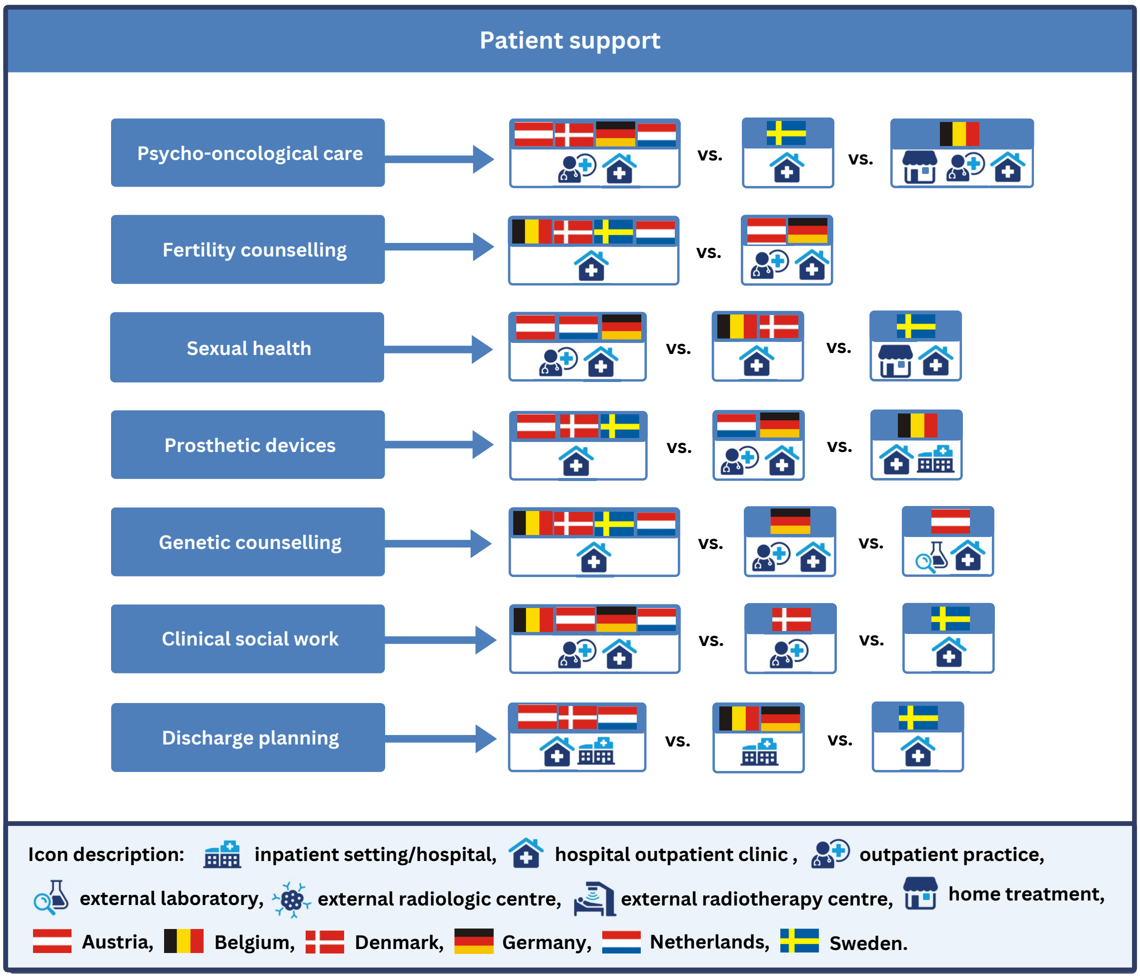


Figure 5-4: Comparison of utilised health care infrastructures for patient support across six European countries

Sexual health services exhibit varying approaches across the six European countries. While all countries offer this service in hospital outpatient clinics, additional health care structures are involved in some countries, such as outpatient practices in Austria, the Netherlands, and Germany or home treatment in Sweden. **Prosthetic devices** are generally managed within hospital outpatient clinics across all countries, with Belgium extending these services to in-

Beratung sexueller Gesundheit variiert hinsichtlich des Settings

Prothesenmanagement meist spitalsambulant

patient settings and Germany and the Netherlands involving outpatient practices. **Genetic counselling** is consistently provided in hospital outpatient clinics, but Germany also utilises outpatient haematologist and oncologist practices, and Austria incorporates external laboratories.

genetische Beratung spitalsambulant & in DE auch niedergelassen

In terms of **clinical social work**, all countries utilise hospital outpatient clinics, except Denmark, where this service is exclusively provided in outpatient settings. Belgium, Austria, Germany, and the Netherlands also offer social services within outpatient settings. **Discharge planning** is managed in both hospital outpatient clinics and inpatient settings in Austria, Denmark, and the Netherlands, while Germany and Belgium primarily rely on inpatient settings. In contrast, Sweden mainly manages discharge planning through hospital outpatient clinics.

Sozialarbeit nur in DK exklusiv im niedergelassenen Setting organisiert: Entlassungsmanagement nur in SE ausschließlich spitalsambulant

Follow-up Care

The analysis of follow-up care services across six European countries reveals both common practices and distinct approaches in the health care infrastructure used for breast cancer patients (Figure 5-5). In Belgium, Denmark, and the Netherlands, **survivorship care** is provided through a combination of home treatment, hospital outpatient clinics, and inpatient settings. In contrast, Germany and Sweden offer survivorship care solely in outpatient settings. In Austria, these services are provided across multiple sectors, including hospital outpatient clinics, outpatient settings, and home treatment.

Follow-Up-Care weist über Länder hinweg Gemeinsamkeiten aber auch Unterschiede auf

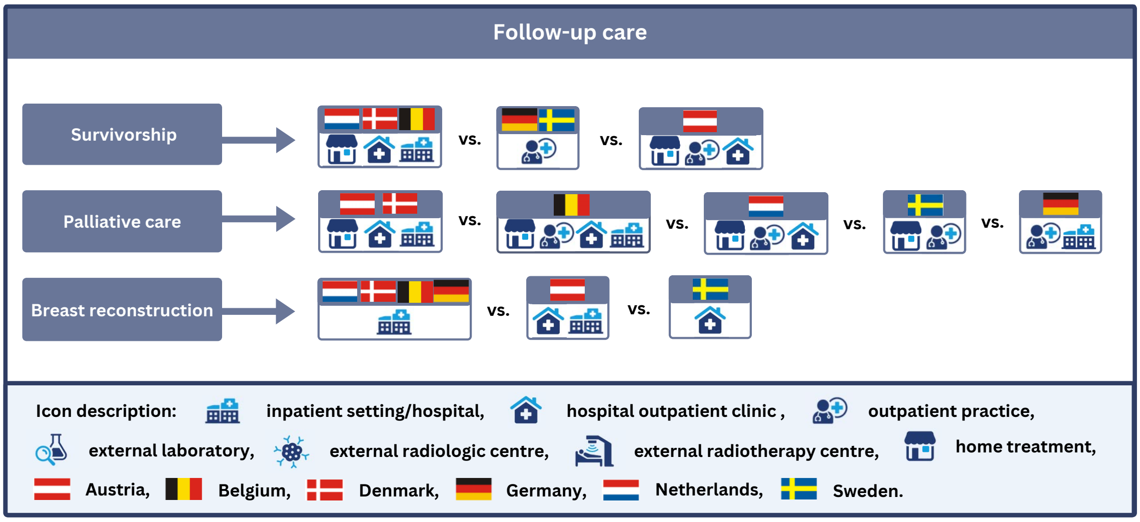


Figure 5-5: Comparison of utilised health care infrastructures for follow-up care across six European countries

Palliative care is delivered through various health care infrastructures across the investigated countries. Austria and Denmark provide it across three main settings: home treatment, hospital outpatient clinics, and inpatient facilities. Belgium offers the most comprehensive range, including home treatment, outpatient practices, hospital outpatient clinics, and inpatient settings. In Germany, palliative care is primarily delivered through outpatient haematologist and oncologist practices and inpatient settings. The Netherlands combine home treatment, hospital outpatient clinics, and outpatient practices, while Sweden focuses on home treatment and outpatient practices, notably excluding inpatient care.

Palliativversorgung: in AT & DK zuhause, spitalsambulant & stationär: BE in mehreren Sektoren

in SE stationäre Palliativversorgung vereinzelt

For **breast reconstruction** surgeries, Denmark, Belgium, Germany, and the Netherlands conduct these procedures in the inpatient setting. In contrast, Austria provides surgeries additionally in hospital outpatient clinics, and Sweden exclusively in hospital outpatient clinics.

Brustrekonstruktion vorwiegend
→ stationären Setting

6 Discussion

6.1 Summary of Results on the Breast Cancer Patient Journey

The analysis of breast cancer care across six European countries – Austria, Belgium, Denmark, Finland, the Netherlands, and Sweden (Table 6-1) – reveals both centralised and decentralised systems in diagnostics, therapy management, patient support, and follow-up care. The comparison spans various settings, including inpatient and outpatient care, hospital outpatient clinics, home treatment, and external laboratories or radiology centres. The study was informed by consultations with 17 healthcare experts from six countries, with feedback gathered through virtual meetings and written responses.

dezentralisierte & zentralisierte Ansätze in der Krebsversorgung in identifizierten Ländern

Expert*inneninfos (n=17) als Basis für den Bericht

The following sections outline the key findings regarding breast cancer care across the countries:

zentrale Ergebnisse der Analyse:

- *Identification of patients:* No significant differences were found in how breast cancer patients are identified across the examined countries. All countries have organized screening programmes to ensure systematic detection. Breast cancer cases are also identified through GP referrals or incidental findings during diagnostic workups for other conditions.

keine wesentlichen Unterschiede bei Identifikationsstrategien von Krebspat.

- *Diagnosis:* Physical examinations are mainly conducted in hospital outpatient clinics and outpatient practices, with Belgium relying solely on hospital clinics. Germany takes a broader approach, using external radiologic centres and outpatient oncologists. Diagnostic imaging is typically done in hospital outpatient clinics and external centres, except in the Netherlands, where it is solely provided in hospital outpatient clinics. Biopsies, histology, and genetic analyses follow similar patterns, with Germany additionally using outpatient oncologists.

physische Untersuchung & Bildgebung vorwiegend spitalsambulant, aber auch in externen Zentren

Settings von Biopsien & genetische Analyse ähnlich wie Bildgebung

- *Therapy options and management:* MDTs are generally held in hospital outpatient clinics, though Germany also involves outpatient oncologists. Blood sampling and bone density measurements vary, with Germany extending consultations to outpatient oncologists. Surgeries differ widely, with Sweden conducting all procedures in hospital outpatient clinics without overnight stays, while other countries use both hospital outpatient clinics and inpatient settings. Radiotherapy and medicinal therapy are mainly provided in hospital outpatient clinics, with some countries incorporating home treatment and outpatient practices.

MDT-Konferenzen primär spitalsambulant

Radiotherapie & medikamentöse Therapien meist spitalsambulant, aber auch Home-Treatment

- *Patient support and follow-up care:* Hospital outpatient clinics primarily offer psycho-oncological care, fertility, and genetic counselling. Clinical social work varies, with Denmark providing it only in outpatient settings, while other countries use a combination of care infrastructures. Follow-up care differs, with Germany and Sweden focusing on outpatient care while others use a mix of home treatment, outpatient, and inpatient settings. Breast reconstruction surgeries are mainly inpatient, except in Sweden, where they are done in hospital outpatient clinics.

psychoonkolog. & weitere Beratungsleistungen meist spitalsambulant

Möglichkeit des Home-Treatments teils auch bei Follow-Up-Care

Table 6-1: Country comparison of healthcare settings for medical services throughout the breast cancer patient journey

Health care services for breast cancer patients	**Health care infrastructure**				
	Inpatient setting	**Hospital outpatient clinic**	**Outpatient setting**	**Home treatment**	**Ext. laboratory/radiology**
Diagnosis					
Physical examination		🇧🇪 🇩🇰 🇩🇪 🇦🇹 🇸🇪 🇳🇱	🇩🇰 🇩🇪 🇦🇹 🇸🇪 🇳🇱		🇩🇪
Blood sample	🇸🇪	🇧🇪 🇩🇰 🇩🇪 🇦🇹 🇸🇪 🇳🇱	🇩🇪	🇸🇪	🇧🇪 🇩🇪 🇦🇹 🇸🇪 🇳🇱
Diagnostic imaging techniques		🇧🇪 🇩🇰 🇩🇪 🇦🇹 🇸🇪 🇳🇱	🇩🇪		🇧🇪 🇩🇰 🇩🇪 🇦🇹 🇸🇪
Staging of disease		🇧🇪 🇩🇰 🇩🇪 🇦🇹 🇸🇪 🇳🇱	🇩🇪		🇩🇰 🇩🇪 🇦🇹
Biopsy for diagnosis		🇧🇪 🇩🇰 🇩🇪 🇦🇹 🇸🇪 🇳🇱	🇩🇪		🇧🇪 🇩🇰 🇩🇪
Genetic analysis of the tumour		🇧🇪 🇩🇰 🇩🇪 🇦🇹 🇸🇪 🇳🇱			🇩🇪 🇦🇹
Patient support					
Psycho-oncological care		🇧🇪 🇩🇰 🇩🇪 🇦🇹 🇸🇪 🇳🇱	🇧🇪 🇩🇰 🇩🇪 🇦🇹 🇳🇱	🇧🇪	
Fertility counselling		🇧🇪 🇩🇰 🇩🇪 🇦🇹 🇸🇪 🇳🇱	🇩🇪 🇦🇹		
Sexual health		🇧🇪 🇩🇰 🇩🇪 🇦🇹 🇸🇪 🇳🇱	🇩🇪 🇦🇹 🇳🇱	🇸🇪	
Prosthetic devices	🇧🇪	🇧🇪 🇩🇰 🇩🇪 🇦🇹 🇸🇪 🇳🇱	🇩🇪 🇳🇱		🇦🇹
Genetic counselling		🇧🇪 🇩🇰 🇩🇪 🇦🇹 🇸🇪 🇳🇱	🇩🇪		🇦🇹
Clinical social work		🇧🇪 🇩🇪 🇦🇹 🇸🇪 🇳🇱	🇧🇪 🇩🇰 🇩🇪 🇦🇹 🇳🇱		
Discharge planning	🇧🇪 🇩🇰 🇩🇪 🇦🇹 🇳🇱	🇩🇰 🇦🇹 🇸🇪 🇳🇱			
Therapy management					
Multidisciplinary team		🇧🇪 🇩🇰 🇩🇪 🇦🇹 🇸🇪 🇳🇱	🇩🇪		🇩🇪
Treatment plan		🇧🇪 🇩🇰 🇩🇪 🇦🇹 🇸🇪 🇳🇱	🇩🇪		
Blood samples		🇧🇪 🇩🇰 🇩🇪 🇦🇹 🇸🇪 🇳🇱	🇩🇪	🇸🇪	🇧🇪 🇩🇪 🇦🇹 🇸🇪
Geriatric Assessment	🇩🇰	🇧🇪 🇩🇰 🇩🇪 🇦🇹 🇸🇪 🇳🇱	🇩🇪		
Bone density measurement		🇧🇪 🇩🇰 🇩🇪 🇦🇹 🇸🇪 🇳🇱	🇩🇪		🇩🇪 🇦🇹
Intravenous infusion	🇩🇰 🇩🇪 🇦🇹	🇧🇪 🇩🇰 🇩🇪 🇦🇹 🇸🇪 🇳🇱			
Sentinel lymph node biopsy	🇧🇪 🇩🇰 🇩🇪 🇦🇹 🇳🇱	🇧🇪 🇩🇰 🇸🇪 🇳🇱			
Therapy options					
Surgery	🇧🇪 🇩🇰 🇩🇪 🇦🇹 🇳🇱	🇧🇪 🇩🇰 🇸🇪 🇳🇱			
Radiotherapy		🇧🇪 🇩🇰 🇩🇪 🇦🇹 🇸🇪 🇳🇱	🇩🇪		🇩🇪 🇳🇱
Medicinal tumour therapy		🇧🇪 🇩🇰 🇩🇪 🇦🇹 🇸🇪 🇳🇱	🇩🇰 🇩🇪 🇳🇱	🇧🇪 🇩🇰 🇳🇱	
Follow-up care					
Survivorship care	🇧🇪 🇩🇰 🇳🇱	🇧🇪 🇩🇰 🇦🇹 🇳🇱	🇩🇪 🇦🇹 🇸🇪	🇧🇪 🇩🇰 🇦🇹 🇳🇱	
Palliative Care	🇧🇪 🇩🇰 🇩🇪 🇦🇹	🇧🇪 🇩🇰 🇦🇹 🇳🇱	🇧🇪 🇩🇪 🇸🇪 🇳🇱	🇧🇪 🇩🇰 🇦🇹 🇸🇪 🇳🇱	
Breast reconstruction	🇧🇪 🇩🇰 🇩🇪 🇦🇹 🇳🇱	🇦🇹 🇸🇪			

Abbreviations & icon description: ext … external, 🇦🇹 … Austria, 🇩🇪 … Germany, 🇩🇰 … Denmark, 🇸🇪 … Sweden, 🇳🇱 … the Netherlands, 🇧🇪 … Belgium

6.2 Comparative Country Overview – Cancer Care Models

Breast cancer care across European countries varies in terms of hospital infrastructure, treatment strategies, and patient outcomes. Some countries have introduced minimum volume standards to ensure that hospitals treating cancer patients maintain the necessary expertise, particularly for surgeries. This regulatory approach aims to improve patient outcomes by concentrating treatment in higher-volume institutions.

Unterschiede aber auch Gemeinsamkeiten in der Krebsversorgung (Behandlungsstrategien, Infrastruktur & Standards)

This chapter examines three models of breast cancer care, with emphasis on the degree of centralisation as well as regulatory and organisational structures that characterise each cancer care model.

3 Versorgungsmodelle

The **centralised specialist model** concentrates on breast cancer care in a limited number of highly specialised centres. These centres are typically accredited and subject to strict minimum volume requirements for surgeries and treatments, ensuring that only facilities with extensive experience handle complex cases. National cancer plans often promote centralisation by setting volume and quality standards, with certifications issued by bodies such as EUSOMA, OECI or the ÖZK [16, 24, 27]. Most care, including diagnostics, treatments, and follow-ups, is handled by specialist oncologists and trained cancer nurses within these centres (e.g., Denmark, Austria and Belgium). However, how many patients are actually treated in certified centres is often unclear.

zentralisiertes Fachärzt*innenmodell: Versorgung findet in einer begrenzten Anzahl hochspezialisierter Zentren statt

A second approach is a **decentralised model** with certification, where care is distributed across a larger number of hospitals but with rigorous certification systems in place to ensure quality control, particularly for surgeries and care coordination. Although decentralised, hospitals and surgeons must meet specific quality and volume standards to maintain certification. National regulations, such as the DKG in Germany, enforce these standards [76]. Outpatient care also plays a significant role, with oncologists who can provide most of the medical services along the breast cancer patient journey in an outpatient setting (e.g., Germany).

dezentrales Modell mit Zertifizierungsvoraussetzungen

The third approach is the **networked-based or integrated care model**, which combines centralised specialist centres with decentralised elements. This system provides high-end treatments at specialist centres, while regional hospitals and outpatient services manage follow-ups and less complex cases. Interdisciplinary collaboration and flexible accreditation standards allow for multiple tiers of care facilities within the network. Non-specialist hospitals or home-care teams may handle certain treatments with nurse practitioners coordinating care between institutions (e.g., The Netherlands and Sweden).

vernetztes bzw. integriertes Versorgungsmodell: „Mix" aus ersten beiden Modellen

These models reflect varying degrees of centralisation and specialisation, yet all aim to ensure high-quality care through regulation, accreditation, and collaborative networks. Each country generally aligns with one of these models based on its national cancer strategy and healthcare infrastructure. However, many countries blend elements from different models to better fit their healthcare needs and resources. For example, some regions may provide more decentralised care due to special certifications, even if the national trend leans toward a centralised system

Modelle schließen sich nicht aus & Länder können Charakteristika aus mehreren Modellen aufweisen

6.3 Challenges and Dynamics in the Centralisation and Decentralisation of Cancer Care

The coordination of cancer care is essential for improving health care quality and access. Centralisation of cancer centres, where minimum volume standards concentrate expertise, ensures high standards of care. However, balancing centralisation with equitable access, particularly in underserved regions, remains a challenge. Cross-sectoral care networks help bridge these gaps, enabling better cooperation between hospitals, outpatient services, and specialised centres as care increasingly shifts toward outpatient and home-based models. Ensuring coordination across sectors is vital to prevent gaps in care and maintain quality [241, 242].

Gleichgewicht von hochwertiger Krebsversorgung & gerechtem Zugang ist eine Herausforderung

→ sektorübergreifende Koordinierung essenziell

6.3.1 Hospitalisation versus Hospital Outpatient Care

The analysis of hospitalisation and inpatient stays for breast cancer care reveals considerable variation in care organisation, particularly regarding surgeries and tumour therapies (Figure 5-3), across the six examined countries. These differences reflect broader healthcare policies, resource allocation, healthcare system efficiency, and patient management approaches.

Unterschiede aufgrund system- & länderspezifischer Charakteristika

Countries with **centralised specialist models** often rely heavily on inpatient stays for breast cancer surgeries (e.g., Austria), which contributes to higher health care costs and increased capacity strain [48, 66, 81]. In contrast, **network-based or integrated care models**, such as those in Sweden, primarily utilize hospital outpatient clinics for breast cancer surgeries, eliminating the need for overnight stays [179, 196]. This shift towards outpatient care aims to alleviate the burden on hospitals and improve resource efficiency. Additionally, some countries – such as Denmark, the Netherlands, and Belgium – adopt intermediate models that balance inpatient care with the growing use of hospital outpatient clinics for less complex surgical procedures [145-147, 215, 216, 230, 233].

zentralisierte Modelle mit stationären Aufenthalten bei Brust-OPs

Brust-OPs in vernetzten Modellen wie in SE mittlerweile tagesklinisch/spitalsambulant

These findings highlight the varying degrees to which healthcare systems have adopted **decentralised care models** for managing hospital stays, particularly in breast cancer care. While countries with more inpatient stays may offer comprehensive post-operative care, increasing evidence supports the effectiveness of outpatient care. Studies, such as those by Susini et al. [2019] and Duriaud et al. [2018], demonstrate that same-day discharge for breast cancer surgery is safe, with high patient satisfaction, reduced anxiety, low readmission rates, and significant cost savings [243, 244]. A systematic review by Marla and Stallard [2009] further confirms that day surgery leads to faster psychological recovery and lower costs [245]. However, the success of outpatient models depends on well-coordinated follow-up care and effective post-surgical monitoring to address potential complications early.

Hinweise, dass Entlassungen am selben Tag bei Brustkrebs-OPs sicher sind

Erfolg ambulanter Modelle abhängig von gut koordinierter Nachsorge & Monitoring

6.3.2 Cross-Sectoral Care

Cross-Sectoral Care in Decentralised and Network-Based Cancer Care Models

The majority of countries rely on hospital outpatient clinics for cancer care, with Germany being an exception due to its relatively **decentralised care model**. In Germany, outpatient oncologists manage much of the cancer care, but this model faces challenges, particularly in recruiting specialists and maintaining expertise across multiple tumour types [66]. Despite these challenges, MDT conferences and interdisciplinary collaboration have been expanded, improving care coordination and outcomes for complex cases. However, conflicts between the outpatient and inpatient sectors can affect treatment decisions and referral processes [101, 246-248].

spitalsambulante Versorgung in Großteil der Länder

Ausnahme DE: zusätzlich niedergelassene Hämatologen & Onkologen & …

The implementation of the ASV model in Germany, designed to improve cross-sectoral care, has been slow due to administrative burdens and reimbursement challenges. Nonetheless, ASV could enhance regional outcomes by fostering closer collaboration between outpatient and inpatient providers, ensuring continuity in cancer treatment [88, 249]. Other structural challenges, including high overhead costs, complicate maintaining expertise in outpatient settings. A potential solution could be shifting towards medical centres where specialists collaborate to provide continuous care [66].

… ASV

→ allerdings auch mit Herausforderungen verbunden

There is a growing trend towards integrating centralised and network-based care approaches across all analysed countries. This **network-based or integrated care model** ensures systematic cross-sectoral care while improving patient access. Sweden and Denmark have implemented regionalised cancer networks, while Belgium and the Netherlands have created multi-tier oncology networks that ensure smooth transitions within and between care settings [176, 179, 214, 227]. In Germany, the recently passed KHVVG aims to enhance cross-sectoral care by promoting outpatient models, especially in regions with structural challenges. This shift is expected to reduce short inpatient stays, thus improving efficiency without compromising care quality [87, 119].

Trend hin zu zentralisierter & netzwerkbasierter Versorgung

Emerging Trends: Home-Based Cancer Treatment and Nurse-Led Care

Network-based or integrated care models, including home-based cancer treatment and nurse-led care, are expanding across several European countries, with variations in how these services are implemented. Sweden and Belgium provide the most home-based services, including survivorship and palliative care, while the Netherlands and Denmark also offer several treatments at home. Austria provides selected home-based services, and Germany currently does not offer any. Some countries have introduced home-based chemotherapy in response to rising cancer cases and the need for cost-effective care. However, home-based chemotherapy remains limited, with a focus on selected drugs, and faces logistical challenges such as ensuring patient compliance and the availability of nurses [145, 146, 170].

zudem werden auch vermehrt Behandlungen, Nach- & Palliativversorgungen im häuslichen Umfeld durchgeführt

In Belgium, a pilot project shifted breast cancer treatments to home settings, reducing hospital visits and improving patient experiences, but nursing shortages have hindered the expansion of home chemotherapy. Similarly, the Netherlands has explored home-based chemotherapy but continues to deliver most treatments in hospital outpatient clinics due to efficiency concerns [215, 216]. In Sweden, follow-up and supportive care are often managed by advanced cancer nurses and nurse-led clinics, which account for a significant

Potential von optionalen Versorgungsmodellen → abhängig von strukturellen & prozessualen Faktoren

portion of outpatient care, including curative and palliative treatments [179, 210, 211]. The Swedish ASIH system provides home chemotherapy, particularly for palliative care, although these services are limited in scope.

Versorgung im häuslichen Umfeld könnte die pat.-zentrierte Pflege verbessern

Germany's lack of home-based cancer care may be attributed to its well-established **decentralised care model**, reducing the need for home-based medical services. In contrast, countries with **centralised specialist models** are exploring home-based care to decentralise services and improve patient convenience. As home-based care models evolve, they have the potential to enhance patient-centred care, but they require sufficient staffing and resources. Specialist nurse shortages across Europe present a challenge to expanding these services and must be addressed for successful implementation [210, 211, 250].

Standardised Cancer Care Pathways across Sectors

standardisierte CCPs wie in SE & DK zur Optimierung des Pat.-Managements & Reduzierung von Wartezeiten …

In cancer care, the priority is timely access to appropriate structures and effective navigation through services, regardless of whether they are outpatient or inpatient [66, 81]. **Centralised specialist** and **network-based cancer care models** are foundational for coherent cross-sectoral care in Sweden, Denmark, and Belgium, where CCPs aim to optimise patient management and reduce waiting times [132].

… aber auch mit Herausforderungen verbunden: unterschiedliche Auffassungen über die Zuständigkeiten

CCPs in Denmark were introduced to address patient concerns about treatment coordination and unclear responsibility among care providers, especially in cases with comorbidities [159, 160]. Sweden's CCP programme, with over 30 pathways, provides clear guidelines for symptom investigation and referral [150-152]. Oncological societies highlight the need for interdisciplinary collaboration to improve cancer care quality and efficiency [121]. However, implementing CCPs poses challenges, including differing views on responsibilities among health care professionals [132]. In Denmark, general practitioners play a crucial role in the breast cancer CCP by conducting assessments and ordering diagnostic tests, streamlining care [152].

Monitoring & (evidenzbasierte) Anpassungen sind Grundvoraussetzungen für effiziente CCPs

Evaluating the quality and success of CCPs requires ongoing adaptation and data-driven assessments. In Sweden, for instance, the goal is to include at least 70% of cancer patients in CCPs, with a target of 80% for timely treatment initiation [176]. Monitoring regional disparities in cancer care outcomes is crucial to ensuring equitable access to high-quality services, particularly in rural areas [132]. Effective cross-sectoral care coordination depends on a robust data infrastructure to address centralisation, outpatient care challenges, and network-based models. This approach ensures a coherent healthcare process incorporating standardised diagnostic strategies while considering patient satisfaction, accessibility, and regional inequalities [176, 182, 183].

6.3.3 Cross-Sectoral Health Care Data Integration

sektorübergreifende Datenverfügbarkeit essenziell

kein Land mit einem vollständig integriertem ePA-System …

Timely access to accurate health information is crucial for enhancing safety, effectiveness, and efficiency in care. Fragmented systems lead to data transfer disruptions between inpatient and outpatient services, causing information loss and inefficiencies. Integrating health data across sectors can optimise clinical care and improve public health efforts. Yet, no country among the analysed (Austria, Belgium, Denmark, Germany, the Netherlands, and Sweden) has a fully integrated EHR system accessible across all healthcare settings [251, 252].

Austria's EHR system, ELGA, facilitates data sharing in public healthcare but excludes private sector patients, resulting in limited access. Germany's decentralised data management is improving with the implementation of the German HER system ("elektronische Patientenakte") [66, 81, 119]. Denmark has advanced digital infrastructure, but its separate systems prevent comprehensive data access. Similarly, Sweden's progress in health data systems does not fully integrate data from private providers [146, 147]. Belgium and the Netherlands face challenges due to fragmented regional systems and limited integration across healthcare infrastructures [215, 216, 230, 235, 236].

… aber verstärkte Bemühungen & Entwicklungen in allen identifizierten Ländern bestehende Systeme auszubauen

In conclusion, while EHR systems exist in these countries, none provide seamless nationwide access to patient data across all sectors. There is a pressing need for greater interoperability and integration to support cross-sectoral care and ensure the continuity of patient data. The future role of the European Health Data Space (EHDS) in implementing integrated EHR systems remains uncertain, but establishing a registry strategy is essential for sustainable data management across regions [253, 254].

Rolle des European Health Data Space (EHDS) für ePA ungewiss → Registerdatenstrategie aber essenziell

6.4 Limitations

This report presents a comprehensive analysis of breast cancer care and cross-sectoral models in several European countries; however, several limitations must be considered when interpreting the findings. The selection of breast cancer as a case study, particularly for Austria, may not fully capture the broader landscape of cancer care in the country. Austria is recognised for its high standards of breast cancer care, supported by extensive data acquisition and certification of breast cancer centres, which may obscure challenges faced in other, less-certified areas of cancer care. This also holds true for other examined countries, as breast cancer, being a high-volume entity, is subject to different regulations and oversight compared to less common malignancies, which may lack the same level of coordination and certification.

Limitationen:

Brustkrebsversorgung als Fallbeispiel für gesamte Krebsversorgung nicht repräsentativ

A further limitation lies in the disparity of available literature between the countries. Germany, in particular, benefits from a vast body of literature and a well-established certification system, leading to a potentially disproportionate focus in the analysis. In contrast, the availability of comparable data and publications in other countries was more limited, which may have contributed to an uneven depiction of cancer care across the regions examined. Additionally, language barriers may have prevented the inclusion of certain relevant documents, particularly those not available in English or German, potentially excluding critical information from the analysis.

unterschiedliche Verfügbarkeit von Infos aus identifizierten Ländern

sprachliche Barrieren bei Nicht-deutsch & englischsprachigen Informationen & Publikationen

It is also important to note that this report does not serve as a guideline synthesis. Clinical guidelines were only used to contextualise the interview data gathered and not as the primary basis for the analysis. This approach may limit the breadth of standardised recommendations included in the report. Furthermore, the current report does not examine quality indicators, which would be highly interesting for future scientific analysis. These indicators could provide valuable insights into the effectiveness, efficiency, quality, and outcomes of breast cancer care across the countries studied, allowing for more robust evaluations of healthcare systems.

keine systematische Leitliniensynthese

keine Qualitätsindikatoren erhoben → künftige wissenschaftliche Analysen

The expert consultations, which played a crucial role in shaping the report, also present some limitations. Ensuring a balanced representation of perspectives was challenging, with only two experts consulted per country. This challenge becomes particularly evident in Germany, where outpatient haematologists and oncologists are central to cross-sectoral cancer care. Unfortunately, no representatives from this key group participated in the consultations, limiting the depth of insights into the outpatient care landscape. Moreover, most of the professionals interviewed came from academic or larger hospitals, which tend to have more resources and a centralised approach to care. As a result, perspectives from smaller, peripheral hospitals, which may face different challenges, could be underrepresented.

ausgewogene & repräsentative Auswahl der Expert*innen-Perspektiven war eine Herausforderung

7 Conclusion

Krebsversorgung muss spezifische system- & länderspezifische Charakteristika berücksichtigen

In conclusion, the analysis underscores the importance of tailoring care and hospitalisation practices to the unique needs of each healthcare system. Countries with **centralised specialist models**, such as Austria, may benefit from gradually integrating outpatient and home-based care where feasible. Given Austria's reliance on hospital-centred cancer care, particularly for complex treatments like breast cancer surgeries, a shift towards a more **decentralised** or **network-based model** could help reduce the pressure on hospital resources while improving patient autonomy and care quality. However, such a shift requires careful planning to ensure that the necessary infrastructure (e.g.: data infrastructure) and workforce are in place to support safe, high-quality care outside of hospitals.

strukturelle & prozessuale Voraussetzungen müssen sichergestellt werden

As in many countries, one critical challenge for Austria is the ongoing shortage of health care professionals, particularly nurses, who are essential for delivering safe and effective home treatments [48, 233]. In Austria, addressing this shortage is particularly important if the country aims to expand home-based care. The success of **integrated or network-based models** depends on having a sufficient number of trained cancer care nurses to monitor patients in outpatient settings, including home treatment – especially in rural or underserved regions, where access to healthcare is already more limited.

Trend hin zur spezialisierten Versorgung inklusive Zertifizierungen

In response to these challenges, several countries are moving towards **centralised specialist models** to improve quality and safety. For Austria, this could mean further centralising cancer care in dedicated cancer centres to ensure patients receive the highest quality treatment. Certification of cancer centres is crucial for maintaining high standards of care by providing the necessary expertise, facilities, and resources to treat complex cases. It promotes adherence to best practices and fosters continuous quality improvement, which is essential for delivering consistent and safe cancer care [121-123].

gleichzeitig gilt es aber "Brüche" in der Versorgung zu vermeiden

→ sektorübergreifende Koordination wichtig

However, lessons from countries such as Denmark (**centralised specialist model**), where increasing specialisation and centralisation, combined with more outpatient contacts and shorter hospitalisations, have sometimes disrupted coherent care pathways, highlight the importance of careful coordination. Many cancer patients have comorbidities, which complicate the treatment process and require seamless coordination across specialities and professionals [160]. Therefore, these factors must be carefully considered when making shifts to outpatient services, as such changes could disrupt patient care pathways. Ensuring smooth transitions and coordination between sectors is essential for maintaining continuity of care.

Gleichgewicht zwischen hochwertiger Krebsversorgung & gerechtem Zugang

zusätzlicher Benefit: Reduktion von Ineffizienzen

Nevertheless, **integrated or network-based models and centralised specialist models** offer considerable advantages by improving cooperation and coordination between specialised centres, outpatient services, and hospitals. This collaboration reduces inefficiencies such as information loss and test duplication, helping maintain care quality and effectiveness. Expanding cross-sectoral care networks can also positively impact coverage, particularly in underserved regions, by ensuring more comprehensive and equitable access to cancer care [4]. However, centralisation can present challenges, including longer patient travel distances, especially in remote areas [255, 256]. Austria will need to balance the benefits of centralisation with the need to ensure equitable access to cancer care for all patients, regardless of their location.

Addressing these challenges highlights the complexity of fully capturing cross-sectoral cancer care across diverse healthcare systems. Future research would benefit from a more inclusive approach, particularly for Austria, by focusing on a broader range of cancer types, health care settings, and the integration of quality indicators to assess the impact of outpatient and home-based models on patient outcomes.

zukünftige Forschung notwendig

In this evolving landscape, Austria will need to carefully consider balancing its **centralised specialist model** with the growing demand for outpatient and home-based care while addressing critical workforce shortages and ensuring high standards of care through specialised and certified centres. The path forward for Austria may include a more integrated approach that fosters cross-sector collaboration and ensures that patients can access timely, effective cancer care, whether in a hospital, outpatient clinic, or home.

Umsetzung von Maßnahmen & Empfehlungen erfordert Kenntnis des Status quo & Definition zukünftiger Ziele

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