

Contact Nurse & My Care Plan

An Excellent Practice in Personalised Cancer Care

Berit Sunde | Nurse Director Cancer Theme | OECl Oncology Days 2026

Context & The Challenge

Fragmented care

Patients navigating complex pathways across multiple departments and providers, with unclear handovers and duplication.

Information gaps

Lack of clear timelines, roles and next steps created anxiety and uncertainty throughout the cancer journey.

Coordination burden

Multidisciplinary teams needed a structured, shared framework to align, communicate and plan care holistically.

Swedish National Framework

National Cancer Strategy

Provides the overarching direction for person-centred, equitable cancer care

Regional Cancer Centres (RCC)

Translate national strategy into regional guidelines and structured pathways

Standardised Care Pathways

Define the clinical steps, timelines and responsibilities for each cancer type

Digital Health Integration

Enables shared care plans across providers and patient access via digital platforms

Contact Nurse

Drawing on Harold Freeman's Harlem program, Sweden established the Contact Nurse role nationally in 2012.

The Contact Nurse

Primary point of contact throughout the entire cancer journey

Clinical coordinator · Patient advocate · Continuity anchor

- Updates and coordinates My Care Plan with the patient
- Monitors waiting times and flags delays in the pathway
- Bridges communication across the multidisciplinary team
- Provides psychosocial, practical and emotional support
- Ensures continuity across all care transitions



1,500–1,800 contact nurses across Sweden · New national job description established 2025

My Care Plan



"A personal overview of the cancer journey — for every patient."

Personal & structured

Tailored to the individual. Covers diagnosis, treatment, timelines, patient rights, self-care and support.

Digital + paper access

Available via 1177 e-services and in print — no patient is excluded.

Shared decision-making

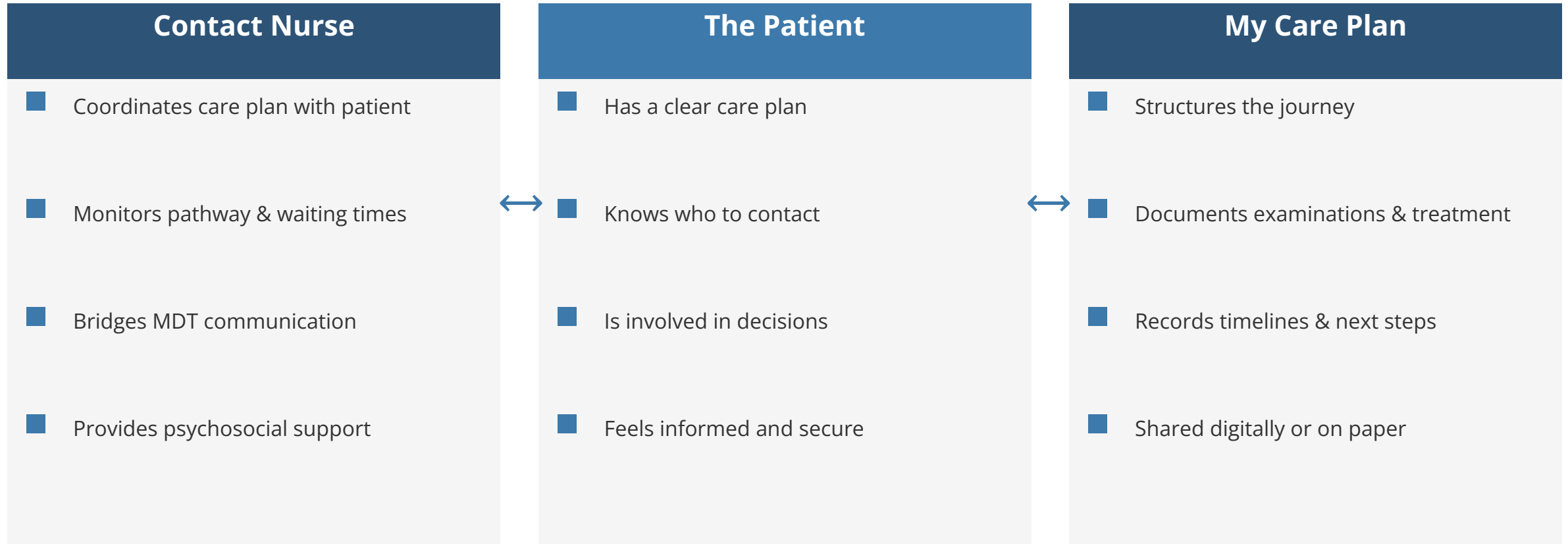
Developed together with the patient and the contact nurse.

Continuity

Updated throughout the pathway — one document that follows the patient.

100,000+ care plans started nationally in Sweden since digital launch in 2020

How They Work Together



Together these practices deliver: Transparency · Shared Decision-Making · Continuity of Care · Person-Centred Support

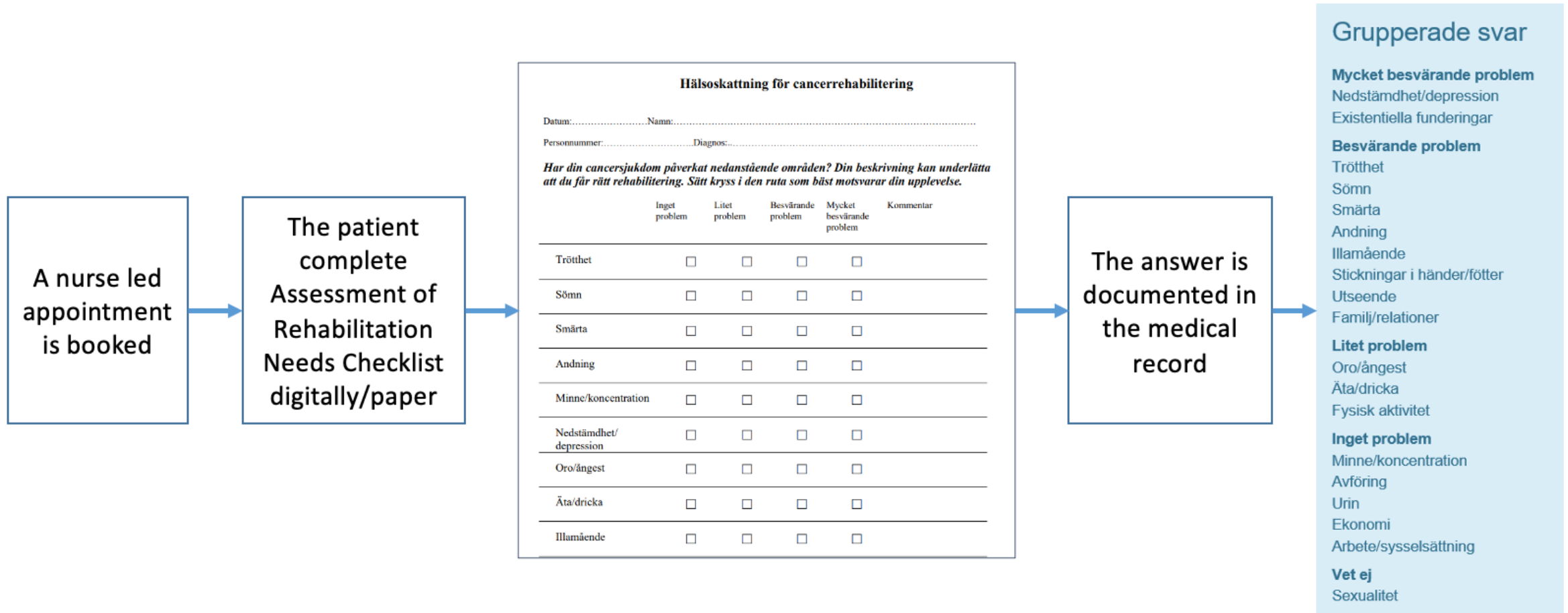


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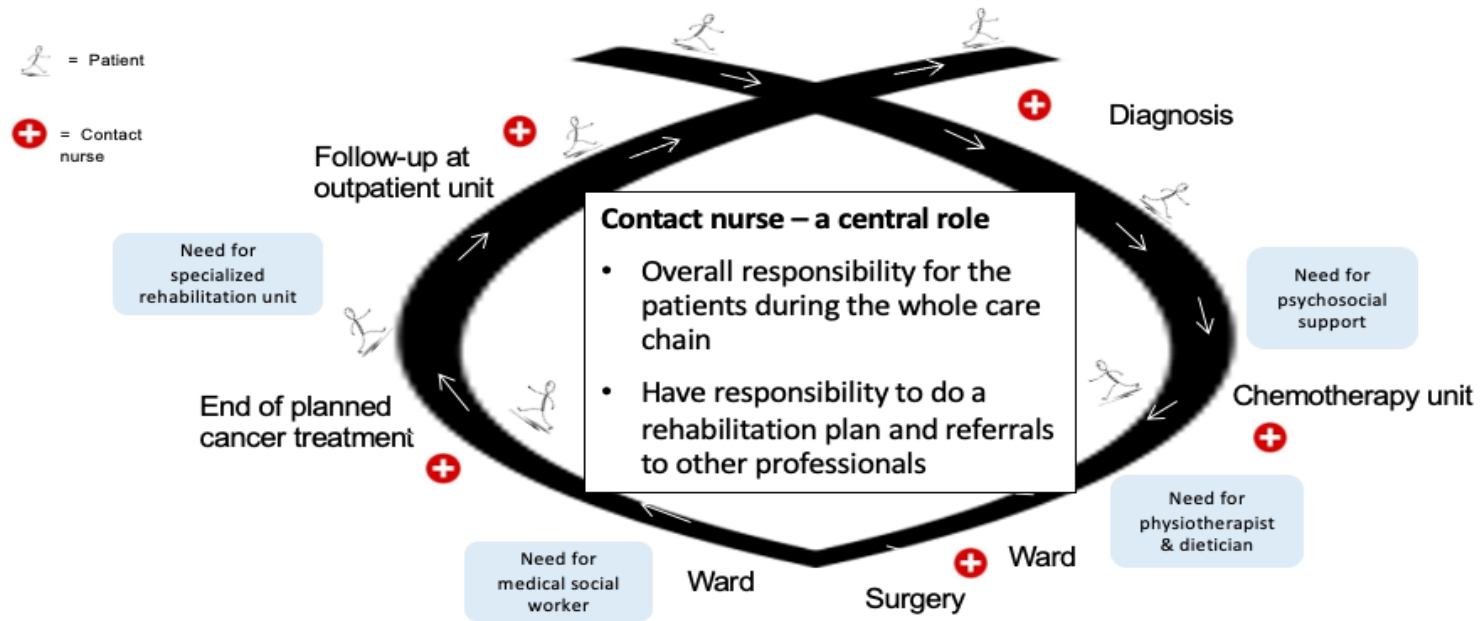
Assessment of Rehabilitations Needs (ARNC)/ Hälsokattningen



ARNC identifies who needs what —

Equity in Cancer Care — The Right Support for Each Patient

Not every patient needs the same — but every patient deserves what they need.



ARNC identifies who needs what —

The contact nurse ensures in the team that the right patient gets the right support at the right time.

Filter

Formulär
Hälsokattning

År för Svarsdatum
Flera värden

Organisation, svarsmottagare
Den vårdenhet som är mottagare av patientens svar

Verksamhet
Alla

Vårdenhet
Alla

Organisation, ekonomisk organisation
Från den vårdhändelse som befinner sig närmast patientens svarstidpunkt

Tema/Funktion/Stab, vårdhändelse
N52 Tema Cancer

Verksamhet, vårdhändelse
Alla

Sektion, vårdhändelse
Alla

Kostnadsställe, vårdhändelse
Alla

Kombika, vårdhändelse
Alla

Totalt antal svar

Totalt

11 658

14%

Antal unika patienter

Antal besvarade för...

Andel svar med inget/litet...

2021	527	570	85%
2022	1 843	2 122	86%
2023	2 832	3 259	87%
2024	3 487	4 085	87%
2025	4 027	4 801	86%
Slutsumma	11 658	14 837	

Kön

Kvinna

4%

Man

2%

Åldersfördelning

Saknas

<20

20-24 år

25-29 år

30-34 år

35-39 år

40-44 år

45-49 år

50-54 år

55-59 år

60-64 år

65-69 år

70-74 år

75-79 år

80-84 år

85-89 år

90-94 år

95-99 år

7%

1%

20%

7%

8%

21%

19%

18%

16%

16%

15%

11%

11%

12%

12%

3%

5%

7%

Patientens svar över tid

	Fysiska problem	Psykosociala problem	Slutsumma
Patienter som besvarat formuläret ..	2 432	2 433	2 433
Andel positiva svar, första svarstillfälle	87,8%	87,4%	87,6%
Andel positiva svar, senaste svarstillfälle	85,9%	86,5%	86,2%
Förändring index	-1,9%enh	-0,9%enh	-1,4%enh

Växla organisation
Sektion, matchad org

Svar per Sektion, matchad org | uppdaterad 2026-06-09 04:41:51

5267 Sekt Lungonkologi	4 331	13%
5295 Sekt Bröstkirurgi	986	9%
5305 Sekt Bröst endokrin sarkom	963	17%
5304 Sekt Gyn onk	915	18%
5296 Sekt Endokrin sarkomkirurgi	690	14%
5272 Sekt Urologi S	654	7%
5277 Sekt Gyn cancerkir	569	11%
5288 Sekt Lever pankreaskir	462	15%
5257 Sekt Lymfom	383	18%
5268 Sekt Huvud hals hud onk	364	15%
5245 Sekt CAST	354	10%
5286 Sekt Matstrups magsäckskir	318	16%
5279 Sekt Urologi H	296	11%
5299 Sekt Gastrointestinal onk	292	18%
5265 Sekt Huvud halscancerkir	248	12%
5278 Sekt Kolorektal cancerkir	101	14%

Växla diagnos/åtgärd/DRG
Diagnoskategori, vårdhändelse

Middle column – departments

Right column- symptoms/function

Left column- Collected data per year, gender and age

Per fråga

Slutsumma

14%

Fysiska problem

Totalsumma

14%

Fysisk aktivitet

25%

Sömn

25%

Smärta

21%

Avföring

13%

Andning

13%

Minne/koncentration

12%

Äta/dricka

12%

Balans

10%

Stickningar i händer/fötter

10%

Urin

7%

Illamående

6%

Psykosociala problem

Totalsumma

13%

Trötthet

32%

Oro/ångest

19%

Sexualitet

17%

Nedstämdhet/depression

15%

Arbete/sysselsättning

12%

Existentiella funderingar

12%

Ekonomi

7%

Utseende

7%

Familj/relationer

5%

Beroende

2%

%fördelning av svar för svarsalternativ 2-3 (önskat värde: lågt)

		Svarsdatum																			
		2021				2022				2023				2024				2025			
2 Besvärande problem	% av total Antal svar	10,4%				9,4%				9,2%				9,2%				9,7%			
3 Mycket besvärande problem	% av total Antal svar	3,7%				3,7%				3,4%				3,5%				4,0%			

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Impact & Evidence

Assessment of Rehabilitation Needs in Cancer (ARNC) — Hälsoenkätningen

Scale & reach

11,658 unique patients assessed (2021–2025)

527 → 4,027 patients per year — consistent growth

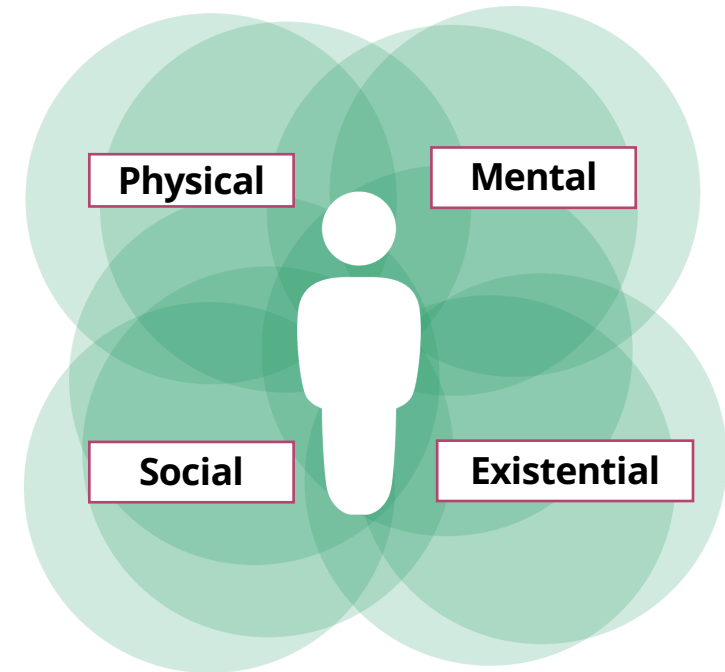
14,837 total assessments completed

What the data shows

14% of patients flag significant needs — enabling targeted follow-up

32% report fatigue as a distressing problem

19% report anxiety or worry



Patients complete the assessment digitally — responses transfer automatically to the medical record.

Patient experience (PREM) — Theme Cancer, last 12 months:

Information 95.2% · Involvement in decisions 88.1% · Overall experience 96.5% (hospital average 93.8%)



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Critical Success Factors

National & Regional Framework

The Swedish Cancer Strategy and RCC guidelines provides a shared direction, common goals and accountability across all centres.

Digital + Paper Access

Dual format ensures accessibility for all patients regardless of digital literacy or access, leaving no one behind.

Nurse Ownership

Contact nurses takes genuine responsibility for using, updating and following up the care plan together with the patient — not a task delegated from management.

Patient Involvement

Co-developing the care plan with the patient strengthens trust, engagement and a genuine sense of partnership in care.

Flexible Design

My Care Plan is structured yet adaptable to individual patient needs — making it practical without becoming rigid or bureaucratic.

Outcome Measurement

Capturing patient reported outcomes and experiences keeps care person-centred and gives teams the evidence to keep improving.

Next Steps & Future Development

Standardise the Contact Nurse Role

Align role descriptions, training and responsibilities across all Cancer Theme departments — ensuring equal, high-quality and person-centred care throughout the cancer pathway.

NOW

Integrate Hälsoenkätning

Embed ARNC as a structured, mandatory element of cancer rehabilitation — enabling systematic screening of physical, mental, social and existential needs at every stage.

NEXT

Evaluate & Improve

Systematic evaluation of patient-reported outcomes, continuity of care metrics, and how well rehabilitation needs are identified and addressed over time.

FUTURE

Strengthen the Contact Nurse profession

Clearer role descriptions and continued training — aligned with 2025 national RCC guidelines.

Use PREM/PROM to drive improvement

Patient-reported data as a systematic feedback loop for quality improvement across teams.

Share learnings through networks

Engage with to exchange experiences and build on each other's practice.



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Voices from healthcare and patients

"My Care Plan helps me explain complex things in a clear and accessible way"

"Switching to My Care Plan required less adjustment than expected – it was worth it. It raises the quality of our information."



"Whenever I have questions about my cancer, I can find the answer or send a message. I got a reply the very next day. That made me feel safe."

"No more waiting on hold. I can read my information digitally, whenever I want – and that's great."



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Lessons learnt

From our experience — perhaps useful for yours

1

Start simple — it does not have to be digital

Paper-based care plans work and deliver value. Digital integration can come later.

2

Give nurses real ownership

The Contact Nurse role works when nurses genuinely own it — not when it is imposed top-down. Clinical champions make it stick.

3

National mandates help — but local culture decides

A formal framework accelerates adoption, but local clinical champions and clinics culture determine whether the practice is truly embedded.

4

Holistic assessment transforms care quality

PROM tools like ARNC (Hälsoskattningen) move care from transactional to genuinely person-centred — addressing needs beyond the tumour.

5

Involve the patient from day one

Care plans only work when developed with the patient, not for the patient. Co-development builds trust and makes the tool meaningful.



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Thank You

Contact Nurse & My Care Plan at Karolinska CCC

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Questions welcome!



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