ECHoS
Cancer Mission Hubs

## Highlights

June 16-17, Utrecht

# ECHoS KEP
# The Netherlands

Nederlands
Kanker
Collectief

# Looking back

We look back on a wonderful and meaningful Knowledge Exchange. Over two days, we spoke openly, listened closely, and recognised ourselves in each other's stories.

Despite our different health systems and national structures, we often face the same hurdles. A fragmented field, limited resources, the challenge of stakeholder alignment. And the question of how to turn plans and ambition into impactful action.

In those shared questions lies enormous potential to learn, reflect and grow together.

But not through copy-paste. Instead: **copy – adapt – paste**. Because every country has its own its own starting point, stories and customs. And that's exactly why sharing works. Not to replicate, but to translate.

This exchange also showed the value of connection. Between countries, of course, but also between national and European perspectives. Between patients and professionals. Between policy and practice. And beautifully, during our visit to the Prinses Máxima Center: between research and care, and between cancer treatment and long-term quality of life.

We hope these days were as inspiring and enjoyable for you as they were for us. That you leave feeling connected, strengthened and ready to accelerate what matters.

If you ever want to revisit what we shared, we hope this booklet will serve as a useful reference. Sometimes, the best way to move forward is22 to reread what moved you first.

Let's keep building this network. Let's keep meeting.

**Carla van Laer, on behalf of the NKC hub**
**and supporting organisations IKNL, KWF and NFK**

# Contents

IKNL
Netherlands
comprehensive
cancer organisation

KWF

nfk
Nederlandse
Federatie van
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# Lookbook - International delegation

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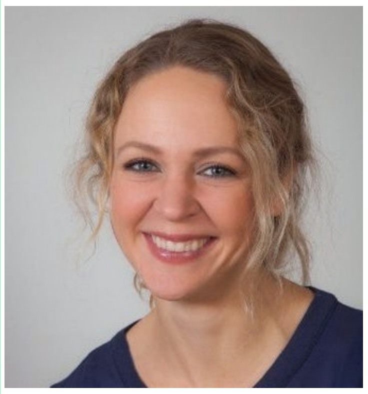

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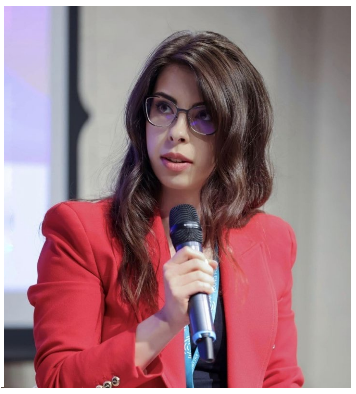

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# Tour de Table (1/4)

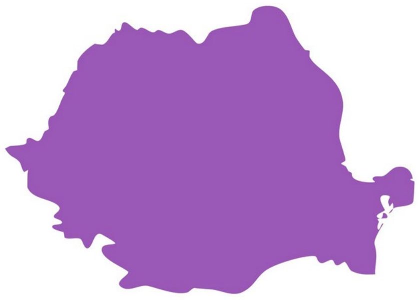
## Romania, Bianca Cucos

**What's different?**

Romania shows that political endorsement doesn't automatically lead to implementation. Although it was the first EU country to align its National Cancer Plan with the EU Cancer Mission (2022), momentum was lost soon after. Romania distinguishes three phases in its journey: optimism (during planning), pessimism (after adoption), and now a pragmatic phase focused on doing what's possible. NGOs and citizen groups play a noteworthy strong role, and tools from the social sciences (like NetMap) are used to map and engage stakeholders.

**Main challenges**

- Lack of structural funding
- No national coordination or follow-up
- Fragmentation between national and regional efforts
- Political instability and limited interest in cancer policy
- Public distrust and stigma around cancer and prevention



**What works well**

- Community engagement through "citizens' juries" and outreach (e.g. football events)
- Strong role of NGOs and civic networks
- Active involvement in EU-funded initiatives (4P-CAN, EU-CIP)
- Realistic approach: focus on what can be done
- Fast-paced piloting via "Living Labs" (three iterations in one year)

*See SWOT and the full presentation for initiatives and partnerships.*

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## Portugal, Ana Domingos

**What's different?**

Portugal is building a Mission Hub-like structure without formal recognition, but with strong institutional ties. The power lies in a broad stakeholder network (>460 people), including government, science, patients and industry. Despite lacking a formal mandate, a great deal is achieved through policy dialogues, position papers and strategic alignment with EU projects. The Hub is entirely run by collaborative effort and voluntary time.

**Main challenges**

- No formal structure or official mandate to represent Portugal
- Unstable funding, dependent on annual policy priorities
- No central communication strategy
- Sustaining engagement with volunteers
- Blurred lines between research and care mandate

**What works well**

- Strong interministerial support and close ties with public health institutions
- Clear governance structure (weekly/monthly/quarterly rhythms)
- Active participation in EU policy fora
- A position paper triggered national change in clinical research legislation
- Stakeholder engagement organized by themes: prevention, survivorship, pediatric oncology

*See SWOT for additional detail and the full presentation for outlines structure and examples.*

# Tour de Table (2/4)

## Sweden, Martin Jansson

**What's different?**

Sweden operates within a highly decentralized health system, with 21 autonomous regions responsible for healthcare. Instead of a formal NCMH, Sweden has established a national platform for cross-sectoral collaboration. This platform links EU-level priorities to local, regional and national initiatives and emphasizes mission-oriented ways of working through permanent multi-sectoral working groups. The approach relies heavily on coordination rather than central authority.

**Main challenges**

- Fragmentation and lack of shared ownership
- Complex governance: different actors with different agendas
- No formal structure or mandate for the NCMH
- Short timeline of the Cancer Mission creates uncertainty about sustainability
- Weak tradition of collaboration with industry

**What works well**

- Strong national cancer strategy (since 2009, updated 2025)
- Robust infrastructure: Regional Cancer Centers, university hospitals, national agencies
- Transparent dialogue and urgency within national reference group
- Multi-level working groups with wide stakeholder involvement
- Opportunities for “top-down” prioritization via national and EU calls

*See SWOT and the full presentation for working group structure and alignment efforts.*

## Norway, Sofia Anderholm Strand

**What's different?**

Norway has developed a well-structured, multi-tiered hub, involving actors from policy, research, healthcare and civil society. It combines a formal governance system with a high degree of bottom-up ownership and has strong ministry endorsement. The hub is used as a strategic platform for aligning national and European cancer priorities and for mobilizing participation in EU calls.

**Main challenges**

- No long-term funding (hub runs on in-kind contributions)
- Participation and commitment are person-dependent
- Gaps in local-level engagement (e.g. municipalities)
- No formal agreements → limited accountability
- Limited visibility among patients and the public

**What works well**

- Agile and fast-moving structure
- Strong coordination between hub levels: secretariat, strategy, high-level forum
- Regular meetings and communication (weekly to annual)
- Stakeholder mapping and integration across sectors
- Use of hub to align national priorities and boost EU impact

*See SWOT and the full presentation for structural details and activity examples*

# Tour de Table (3/4)

## Netherlands, Carla van Laer

**What's different?**

The Netherlands stands out for its coordinated bottom-up approach. The Netherlands Cancer Agenda (NKA) was co-created by 140+ stakeholders and is primarily implemented through acceleration teams: multi-stakeholder groups that turn goals into action. The NKC hub supports these teams and ensures progress and cohesion. Uniquely, the hub operates independently of any institution, with dedicated funding and a process-oriented team.

**Main challenges**

- Fragmentation due to the sheer number of initiatives and stakeholders
- Maintaining balance between process and content roles in the hub
- No formal ownership of the agenda → risk of weak accountability
- Research and care sectors not always aligned with citizen needs
- Prioritization is difficult due to broad ambition

**What works well**

- Strong branding, transparency, and shared language
- Government endorsement despite political independence
- Measurable KPIs and continuous reflection
- Clear division of roles: hub = process, teams = content
- Structural funding and visible outputs (e.g. Cancer Impact Barometer)

*See SWOT and the full presentation for hub setup and examples from the Dutch context.*

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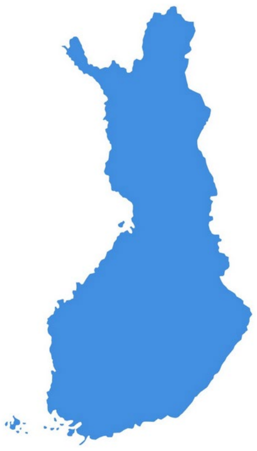
## Finland, Mirjami Tran Min and Kirsi Talala

**What's different?**

Finland is preparing to launch its National Cancer Mission Hub in 2025, coordinated by the Finnish Cancer Center (FICAN). The Hub is closely connected to the development of the first National Cancer Strategy, a highly inclusive process involving over 200 experts and broad stakeholder input. This strategy doubles as the foundation for the future hub. Finland's approach is strongly research-based, with a legal mandate to align activities in prevention, care and rehabilitation.

**Main challenges**

- No permanent or secured funding yet
- Limited time and personnel capacity
- Need for clear, sustainable governance structure
- Communication is a point of attention
- Difficulties engaging the public and civil society meaningfully



**What works well**

- Legally mandated coordination role for FICAN
- Strong partnership with government and health institutes
- Transparent planning process with broad stakeholder involvement
- Synergy between cancer strategy and hub development
- Use of pentahelix model to structure collaboration

*See SWOT and the full presentation for outlines strategy development and preparatory steps..*

# Tour de Table (4/4)

## Belgium, Marie Delnord

**What's different?**

Belgium has an NCMH-like structure known as the EBCP Mirror Group, coordinated by Sciensano's Cancer Centre and officially mandated by the Federal Health Minister. It is embedded in the federal health ecosystem and has structural funding, clear governance (TWGs with ~400 stakeholders), and well-developed communication tools. Belgium's strength lies in policy alignment and high levels of monitoring of EU participation, despite not having an up-to-date national cancer plan.

**Main challenges:**

- Participation is often voluntary → limited capacity of small/patient organisations
- Overlaps and redundancies in EU-funded projects
- Some stakeholder confusion around roles in thematic working groups
- No up-to-date national cancer plan (though some elements continue under broader health strategies
- Difficulty identifying tangible KPIs beyond EBCP framework

**What works well:**

- Strong governmental support and structural funding
- Dedicated team and governance (2 FTEs)
- Thematic Working Groups (TWGs) on key domains
- Systematic stakeholder mapping and alignment with EU priorities
- Robust outreach: newsletters, policy briefs, social media, citizen engagement
- Close ties to national focal/contact points (e.g. BELSPO, NFPs, NCPs)

*See SWOT and the full presentation for structure, KPIs, and outreach methods.*

## Austria, Barbara Fröschl

**What's different?**

Austria currently does not have a formal NCMH but works with a Mission Action Group (MAG) Mirror Group that serves a hub-like role. It brings together stakeholders from across government, research, public health and patient organisations. Governance is co-chaired by two ministries (Health and Research), with support from GÖG (public health institute) and FFG (research funding agency). Austria's strategy places emphasis on policy alignment and the integration of research and care.

**Main challenges**

- No formal agreements or binding commitments
- No fixed or structural funding
- Limited involvement of financing bodies in strategic discussions
- National political instability
- Low perceived interest in EU-level coordination

**What works well**

- Broad involvement across sectors ("pentahelix" model)
- Mission-oriented focus within the MAG
- Activities include stakeholder coordination, awareness, joint actions
- Integration with National Cancer Framework and Mission Cancer action plan
- Formal government support, though still evolving toward a full hub

*See SWOT and the full presentation for structural overview and key coordination tasks.*

# Learnings

## Of the Dutch approach to make a national cancer plan

**Carla van Laer, NKC**

**What's special about the Dutch approach?**
In just one year, the Netherlands produced a shared national cancer agenda – bottom-up, a-political and with over 140 organisations involved. The result: the Netherlands Cancer Agenda (NKA), a clear set of 20 goals covering life before, with and after cancer. This is not a traditional policy document, but a shared compass for joint action. Its strength lies not in ownership, but in alignment and in how it's being brought to life. At the heart of the implementation are the acceleration teams: small, multidisciplinary groups that take on a featured goal. They bring together experts, patients, and stakeholders to define what progress looks like and how to get there. These teams are agile, focused, and action-oriented and perhaps the clearest expression of how the Dutch turned strategy into movement.

**How did we get here? A two-phase approach**
*Phase 1: Making the Agenda*
- Started with a public call to action, open to all who wanted to contribute
- Used Theory of Change workshops to define 20 shared goals
- No closed writing group or political authorship – content was shaped collectively
- Drafts were published openly to invite critique and build legitimacy

*Phase 2: From paper to practice*
- Implementation structured around acceleration teams, each with a defined mission, clear timeline, and lightweight coordination
- Supported by a neutral hub that facilitates, connects and leads the process, but doesn't steer content
- Regular reflection moments help recalibrate and keep momentum
- The agenda evolves in practice: not carved in stone, but growing with what works

**Key lessons from the Dutch model**
- Move fast by slowing down first: take time to define the real problem before acting
- Go where the energy is: start with those who are ready
- Theory of Change is powerful, but requires patience, trust and strategic thinking
- Trust beats structure: no formal mandate, yet collective ownership works
- Acceleration teams are the engine: small, focused groups move faster than large consensus tables
- A neutral hub makes action possible: by being outside the content, it can support all sides
- Clarity over control: define roles early, communicate what you're not doing

**In short**
A cancer plan built in one year, powered by shared urgency, small expert teams and a neutral hub — the Dutch approach shows how clarity, trust and focus can accelerate impact.

**Learn more**
- Full presentation
- Netherlands Cancer Agenda

# From data to impact

## How Data-Driven Insights Support National Cancer Mission Hubs

**Jolanda Sinha (IKNL), Tilja van den Berg (NKC), Guy Muller (KWF)**

### Wat problem are we addressing?

National Cancer Mission Hubs face the complex task of translating Europe's Cancer Mission into national and regional action. This means setting priorities, organising care pathways, engaging stakeholders, reducing inequalities – all with limited resources. Without robust, timely and population-based data, hubs risk blind spots. Making it harder to design effective interventions, monitor progress, and adjust strategies over time.

### What is our solution?

This presentation demonstrated how a data-driven approach can directly support the core functions of National Cancer Mission Hubs. It showed how data were used to develop the Netherlands Cancer Agenda and to structure national priorities. The Netherlands Cancer Atlas was used to identify geographic variations in cancer incidence, diagnosis and outcomes, guiding regional and network-based planning. Finally, the presentation illustrated how data can be translated into local action, helping municipalities and regions tailor prevention and care to the specific needs of their population.

### What have we learned?

- Cancer Mission Hubs need data to guide prioritization, organisation and implementation
- Data allows hubs to identify where inequalities emerge and which populations to target
- Scenario models strengthen the policy case for early prevention and resource allocation
- National monitoring combined with regional analyses supports both strategic and operational planning
- Data enables hubs to demonstrate progress to policy makers, funders, and the public
- European collaboration can help learning from each other (make visible where others do better) develop shared data standards and synergies across national hubs

**Key learning**
Combining national data, regional variation and local needs helps hubs drive effective cancer control at every level.

**Learn more**

- Full presentation
- NKR: About NCR data
- Kanker Impact Barometer
- Kanker Atlas

Policy makers & Public: Cancer Atlas

Diagnoses (2011-2020)

Statistics

Average number of diagnoses per year: 110.570

Average number of diagnoses per 100.000 persons: 651,2

Cancer diagnosis rate compared to the Dutch average

Average diagnosis rate in this area is lower than the Dutch average

Average diagnosis rate in this area is equal to the Dutch average

Average diagnosis rate in this area is higher than the Dutch average

# Donate Your Experience

## The patient-driven research panel by and for people with cancer

**Vivian Engelen and Dagna Lek, NFK**

Donate Your Experience (Doneer Je Ervaring) is the voice of people living with or after cancer in the Netherlands. NFK (Dutch Federation of Cancer Patient Organisations) makes sure it is heard where it matters. Donate Your Experience is not a goal in itself, but a tool to strengthen patient advocacy. It creates public visibility, sharpens the case for change and opens institutional doors.

**What problem are we addressing?**
What do people living with or after cancer experience or need? By collecting these insights, NFK and patient organsations can better advocate for their interests and influence policies, care and public awareness.

**Why does this matter?**
By listening directly to the voices of people affected by cancer, we can work towards better quality of life and better quality of care.

**What is our solution?**

- Donate Your Experience is a patient-driven panel coordinated by NFK
- Panel members receive up to five survey invitations per year
- Recruitement of respondents is also done by patient organisations and partners of NFK
- Surveys are co-created with patients, researchers and advocates – sometimes with input from professionals
- In order to create awareness and drive action, results are shared via media, hospitals, medical associations and policymakers
- Every survey produces a report, factsheet and press release. Some lead to scientific publications
- DJE data is actively used to shape the Netherlands Cancer Agenda

**In short**
Donate your Experience:
data are key to open doors

Het panel van en voor kankerpatiënten
doneer je ervaring.nl
Een initiatief van nfk

**Learn more**

- Full presentation
- OBS PACE article: Transforming patient perspectives into policy
- NFK: Doneer je ervaring
- Doneer je Ervaring website

# 1. About the Princess Máxima Center

## The unique model of the Princess Máxima Center for pediatric oncology

**René Medema, chief scientic officer**

The Princess Máxima Centrum was built from scratch with a bold vision: to fully concentrate care, research, and education for pediatric oncology in one national center. This integrated model combines all childhood cancer expertise under one roof – something few countries have done. The mission came from the field itself, driven by parents and professionals, not by government planning.

**What works well**

- National centralization of pediatric oncology improves survival, care experience, and innovation
- Seamless collaboration between researchers and clinicians boosts translational research
- Shared infrastructure (labs, data, patient facilities) allows faster progress
- Clear focus: one disease area, one age group, one dedicated national effort
- Strong international collaboration and open data exchange (e.g. via CMOP and SIOPEN)

**Why is this relevant for other countries?**

- Shows what’s possible when you design around the needs of patients, not systems
- Demonstrates that focus, integration and trust can overcome resistance
- Offers a model for how mission-driven ecosystems can be built from vision to reality
- Suggests that structural change is feasible — even in a complex care environment

UMC Utrecht
Wilhelmina Kinderziekenhuis

- Pediatric Intensive Care
- Operating rooms
- Emergency Care
- Diagnostics
- Consultents

prinses
máxima
centrum

- Tumor specific wards
- Quality of Life
- Radiology
- Pharmacy, lab, trial & data center
- Academy
- 44 research groups

**In short**
The Princess Máxima Center shows how integration, focus and trust can turn a bold vision into a world-leading cancer ecosystem for children.

**Learn more**

- Full presentation
- Website Princess Maxima Center

# Diagnostics

## Building integrated diagnostics from the ground up – connecting care and research in real time

Bas Tops, head of laboratory

At the Princess Máxima Center, diagnostics are fully integrated into the care and research ecosystem. Instead of working in separate silos, different diagnostic disciplines – such as pathology, flow cytometry, molecular diagnostics, and cytology – have been brought together into one unified lab for childhood cancer diagnostics. This creates volume, uniformity, and access to broad expertise. More importantly, the lab was built from scratch with the explicit goal to serve both clinical care and research. The result is a setup that enables synergy: 1 + 1 = 3.

**Key take-aways**

- All diagnostic disciplines are co-located and coordinated in a single lab
- Diagnostic workflows are adapted to support research goals
- Tests are designed to benefit both care and research
- A dedicated biobank and core facilities facilitate innovation and sample sharing
- Cutting-edge techniques like whole transcriptome sequencing and nanopore sequencing are used to improve diagnosis speed and accuracy
- Agnostic testing allows for broader insights and unexpected findings
- Structured data capture and pseudonymization make re-use possible and safe

**Why is this relevant for other countries?**

Many countries struggle with fragmented diagnostic systems and a gap between research and clinical care. The Princess Máxima Center shows what's possible when you start from a shared vision and build an integrated system from the ground up. It demonstrates how diagnostic labs can be structured to simultaneously meet the needs of patients, clinicians, and researchers.

**In short**
An integrated diagnostic lab, built from scratch, that seamlessly connects clinical care and research to accelerate innovation in childhood cancer

**Learn more**

- Full presentation
- Biobank at PMC

3.

Princess Máxima Center

# Organoids

## How the Princess Máxima Center uses organoids to advance personalized treatment in pediatric oncology

Marc van de Wetering, researcher

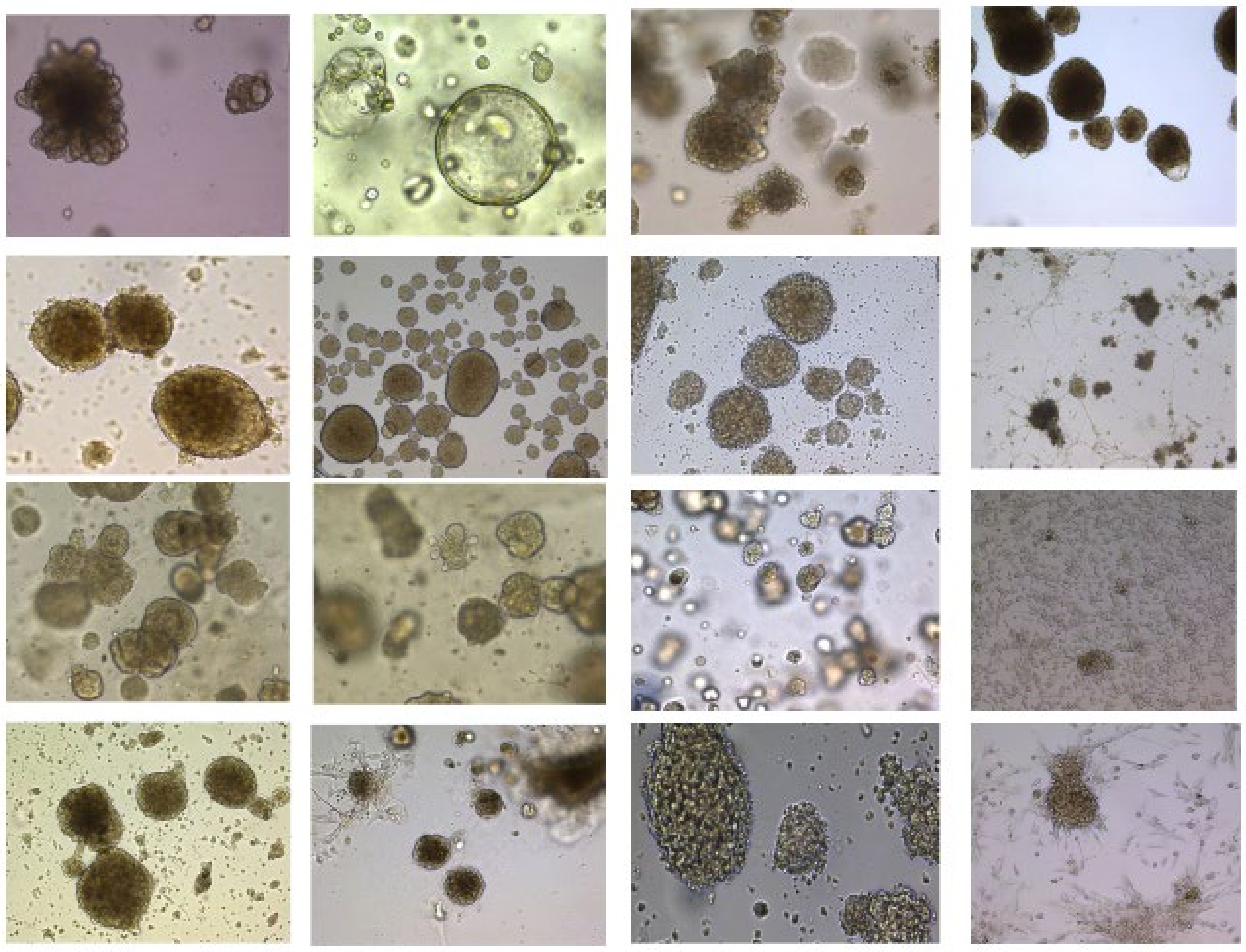
Organoids — patient-derived tumor miniatures grown in the lab — allow researchers to test how a specific child's cancer responds to different drugs. The Center has developed one of the world's largest pediatric organoid biobanks, directly linked to clinical practice. This enables faster, safer, and more targeted treatment options for children with rare and difficult-to-treat cancers.

**What works well**

- Organoids reflect the individual biology of a patient's tumor
- Real-time drug screening can inform treatment choices for high-risk patients
- Large-scale biobanking across diagnoses supports research and discovery
- Close integration of lab and clinic accelerates translation to care
- Strong international collaborations strengthen the scientific foundation and shared learning

**Why is this relevant for other countries?**

- Demonstrates how pediatric precision oncology can be realized in practice
- Offers a model for integrating research infrastructure into standard care
- Shows how biobanking and patient-derived models can be scaled across a national center
- Sparks potential for cross-border research cooperation and shared testing platforms



**In short**
With organoids, the Princess Máxima Centrum brings precision oncology to life – tailoring treatments to each child's biology while building global knowledge.

**Learn more**

- Full presentation
- Central Máxima Organoids Bank (CMOB)

## 4.

# Late effects

## Quality of life after childhood cancer – from vision to infrastructure

Wouter Kollen, Cherine Mathot and Raphaële van Litsenburg

The Princess Máxima Center has developed one of the most comprehensive programmes for childhood cancer survivorship in Europe. Their late effects strategy is deeply embedded in how care, research and education are structured. It covers not just medical follow-up, but also psychosocial support, child development, family care, lifestyle, and life after treatment. What's striking is how everything is aligned: from clinical pathways to advisory boards, from building design to European collaboration.

**What works well**

Late effects care at the Princess Máxima Center is not an add-on – it is integrated across care, research, education and infrastructure. Their survivorship programme stands out for its coherence and depth. Examples include:. Examples include:

- Personalized follow-up plans
- Psychosocial support embedded in care
- Early attention for development, learning and transition to adulthood
- Involvement of children and parents in design and governance
- Research that feeds directly into practice

**Why is this relevant for other countries?**

- Survivorship starts on day one — design it into the system, not around it
- Multidisciplinary, family-centred teams improve quality and outcomes
- Building dedicated expertise and networks helps keep care close to home
- Long-term quality of life deserves as much structure as short-term treatment
- Join forces in European networks to co-develop tools, guidelines and standards

**In short**

The Princess Máxima Center shows how survivorship care can become a structural, integrated part of pediatric oncology – built for the long term, and with children and families at its core.

**Learn more**

- Full presentation
- Late effects at PMC (in Dutch)

# Copy
# Adapt
# Paste

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# Repeat

Thank you for joining this ECHoS knowledge exchange.
Hope to see you again at a next meet-up.