Bridging Care: From Research to Clinical Practice

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Sustainable Models of Care

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Disclosure



AI tools (*ChatGPT*and *NotebookLM*) supported **language editing and the creation of visual materials.**

All scientific content, interpretation, and conclusions are the presenter's responsibility and were reviewed in accordance with scientific integrity and responsible AI principles.

Agenda

1. Sustainability concept in Pediatric Palliative Care
2. What we know
3. A bridge to the future



Sustainability concept in Pediatric Palliative Care



Two Children & One question

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CHILD A

- A trained family, reliable electricity, financial resources and continuous professional support.

CHILD B

- A single caregiver, financial insecurity, unstable services and limited professional support.

Is home-based care equally sustainable for both?

What matters?

We often describe sustainable pediatric palliative care as care that is

- closer to home,
- less dependent on hospitals,
- more efficient in its use of resources.

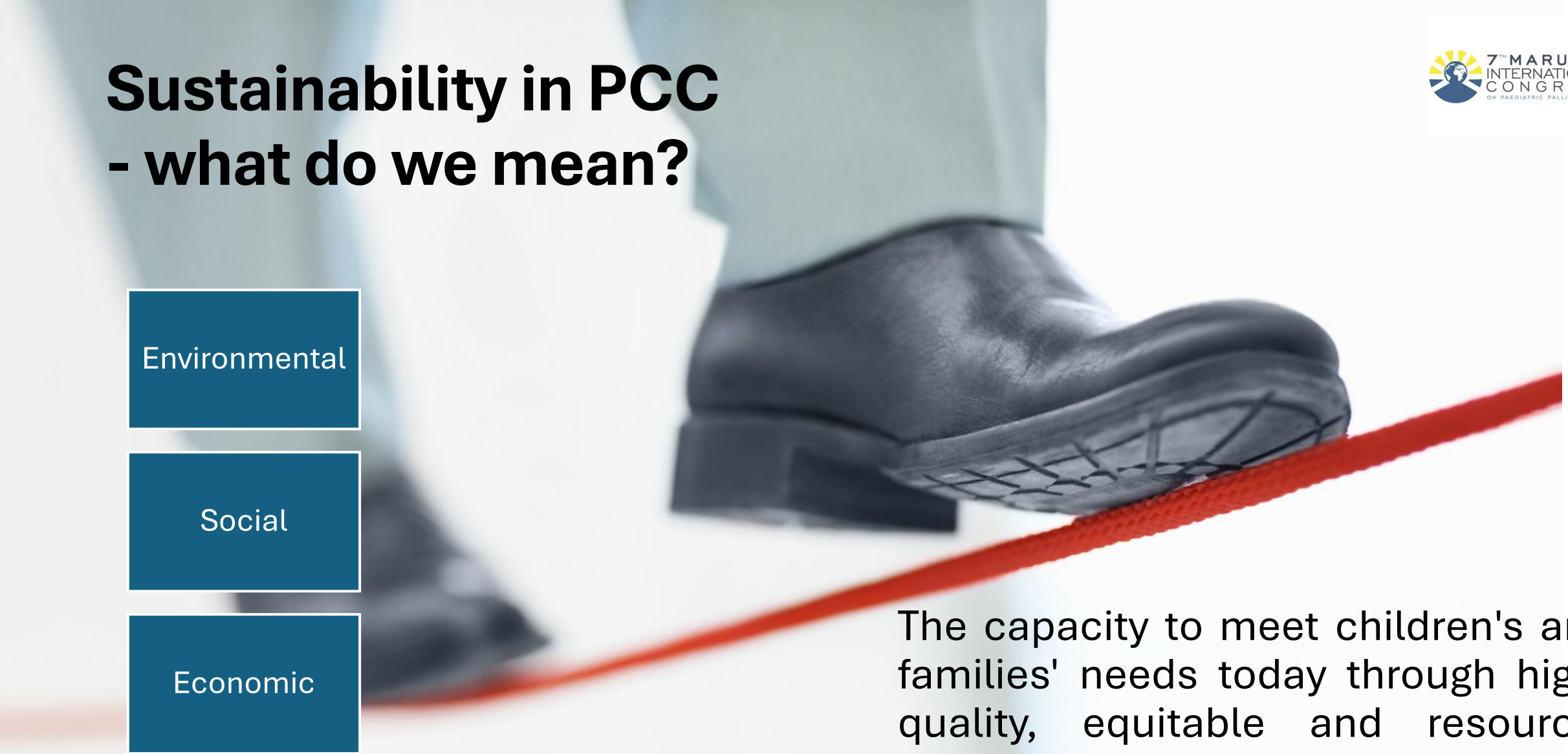
- But is that enough?



SUSTAINABLE DEVELOPMENT GOALS



Sustainability in PCC - what do we mean?



- Environmental
- Social
- Economic

The capacity to meet children's and families' needs today through high-quality, equitable and resource-responsible care, while preserving our collective ability to provide such care tomorrow (next generations).

Adapted from; World Commission on Environment and Development, 1987 & Singh et al. (2026) — The Lancet Commission on Sustainable Health Care measurement framework for advancing sustainable health care transformation.

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Global Atlas of Palliative Care

Key messages for paediatric palliative care

1



10.6 million

children (0–19) need palliative care worldwide

2



96.2%

live in LMICs

3



of need is linked to **non-malignant conditions**

4



<10%

receive palliative care

5





6%

of countries have full integration

42%

have no known PPC activity

Source: Global Atlas of Palliative Care (WHPCA/WHO); Downing et al., 2026

What current evidence suggests



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Impact of home-based programs

What current evidence suggests

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Place of death & goal alignment

RR 4.64

Higher likelihood of dying at home.

Symptom control & quality of life



Better pain control and family routines.

Healthcare resource utilisation

12 → 0
PICU days

Reduced admissions and emergency visits in some studies.

Economic efficiency

Up to 87%

Lower medical costs in some programmes.

Environmental sustainability



Home care may lower emissions than acute hospital care.

Illustrative summary based on home-based PPC literature (e.g., Chong et al., 2018; Smith et al., 2024; home-based PPC reviews).

eHealth and Telemedicine in Paediatric Home Care

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OPPORTUNITIES

1

USER-CENTERED CO-DESIGN

Active participation of children, parents and clinicians using frameworks such as UTAUT and Design Thinking.



2

DEVELOPMENTAL ADAPTATION

Age-tailored interfaces, gamification (avatars/badges) and child-friendly electronic PROMs (ePROs).



3

HYBRID MODEL

Positioning technology as a supplement to — never a replacement for — in-person compassionate care.

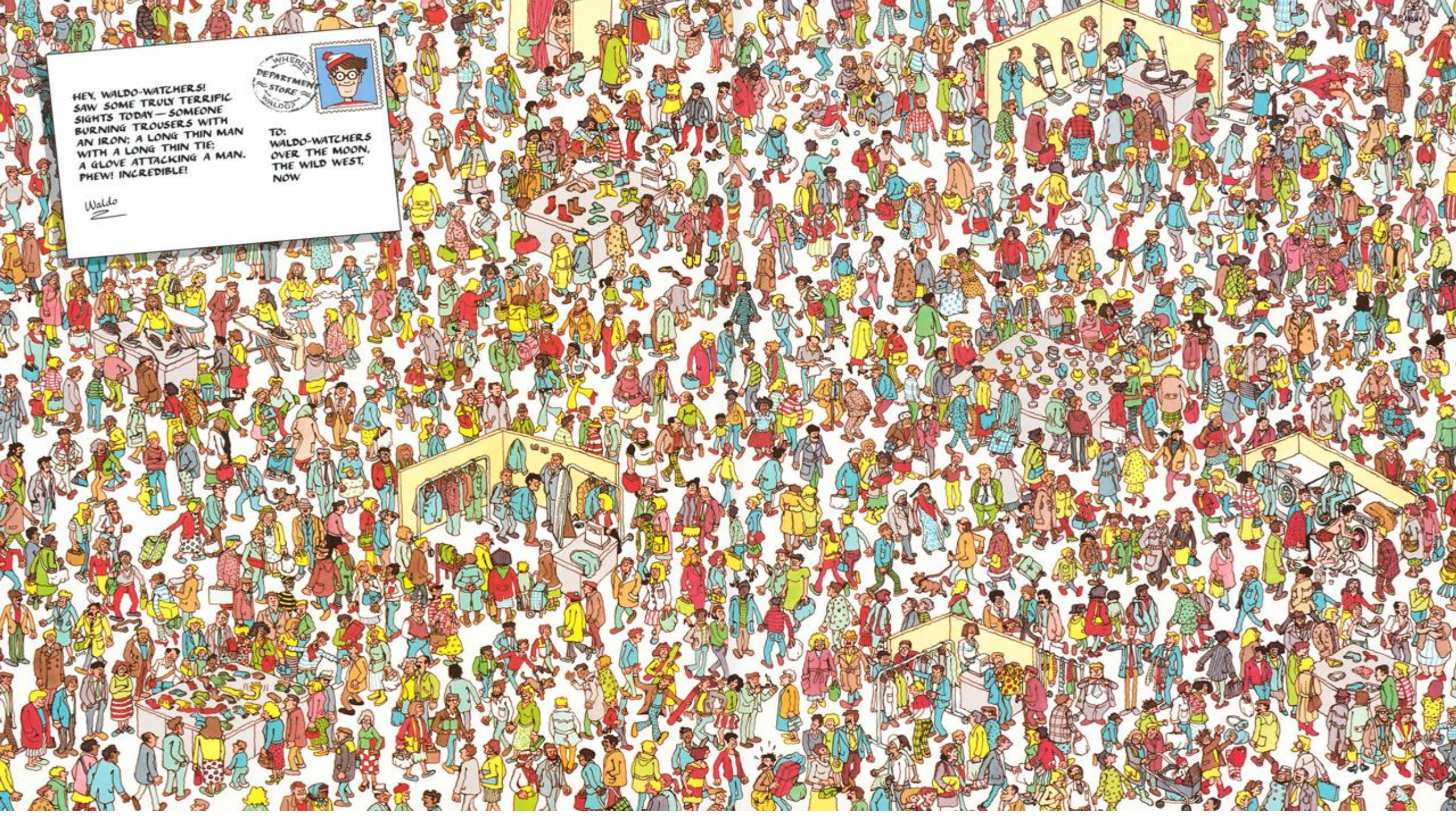


4

EQUITY & RESILIENCE

Institutional lending of devices/data plans, transparent data governance, and offline functionality with automatic syncing.




HEY, WALDO-WATCHERS! SAW SOME TRULY TERRIFIC SIGHTS TODAY — SOMEONE BURNING TROUSERS WITH AN IRON; A LONG THIN MAN WITH A LONG THIN TIE; A GLOVE ATTACKING A MAN. PHEW! INCREDIBLE!
Waldo
WHERE'S DEPARTMENT STORE WALDO?
TO: WALDO-WATCHERS OVER THE MOON, THE WILD WEST, NOW


HEY, WALDO-WATCHERS! SAW SOME TRULY TERRIFIC SIGHTS TODAY — SOMEONE BURNING TROUSERS WITH AN IRON; A LONG THIN MAN WITH A LONG THIN TIE; A GLOVE ATTACKING A MAN. PHEW! INCREDIBLE!
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Home care: limitations, risks and blind spots

What current evidence still fails to capture

1 Methodological limitations

- Few RCTs
- Small, heterogeneous samples
- Evidence mostly from high-income countries
- Limited direct child voice

2 Identified risks in home care

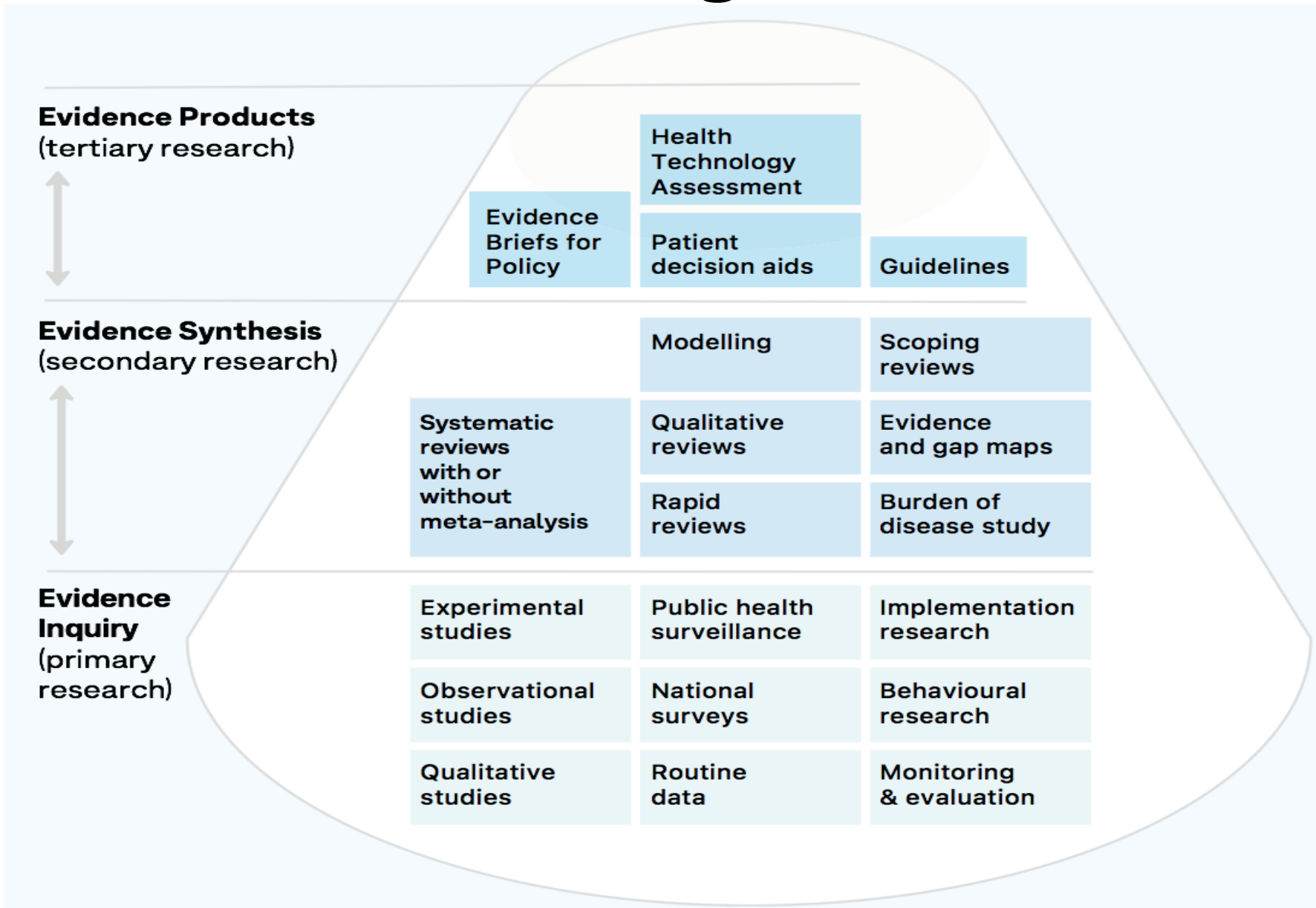
- Caregiver burden
- Financial burden
- Professional isolation
- eHealth risks
- Climate vulnerability

3 Unmeasured gaps

- Child-reported outcomes
- Preferred vs actual place of death
- Holistic economic evaluation
- Longitudinal bereavement follow-up
- Carbon footprint data

Promising models — but important risks and blind spots remain.

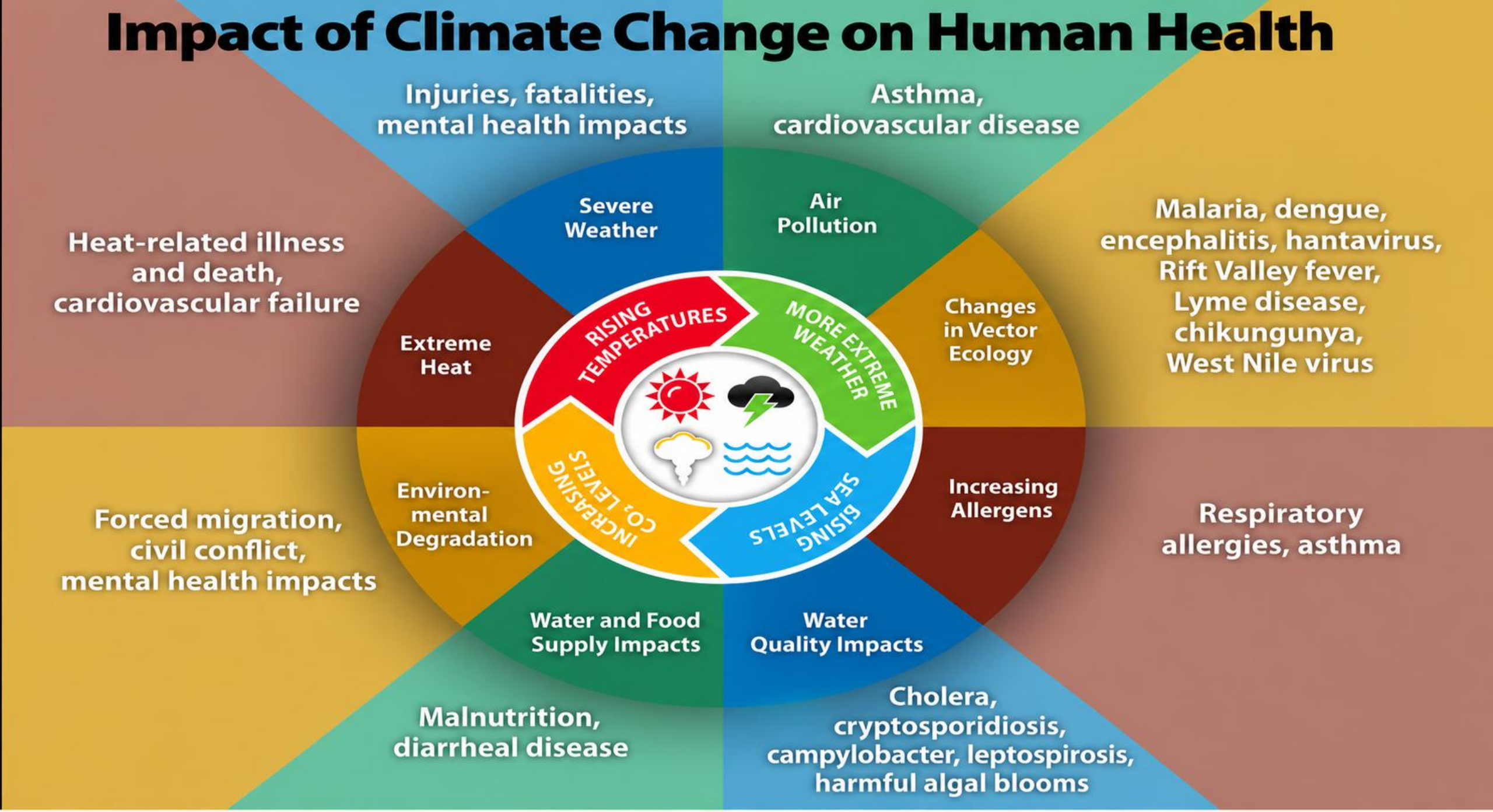
Funnel of knowledge





WHO, 2022, **Evidence, policy, impact. WHO guide for evidence-informed decision-making . WHO.** disponível em https://www.who.int/publications/b/59070

Impact of Climate Change on Human Health



Source: Centers for Disease Control and Prevention (CDC). Climate Effects on Health. https://www.cdc.gov/climateandhealth/effects/default.htm

Environmental sustainability & children's health

Why climate resilience matters for paediatric home care

CHILDREN IN GENERAL

Greater sensitivity throughout development

Pregnancy & early life

Risk of preterm birth and low birthweight

Heat & air pollution

Dehydration and respiratory illness

Disasters & disruption

Distress, trauma and interrupted education

CHILDREN WITH PALLIATIVE CARE NEEDS

Additional risks when continuous care is essential

Electricity dependence

Ventilation, oxygen and feeding devices

Disrupted care pathways

Medicines, equipment and transport

Clinical vulnerability

Heat stress and respiratory compromise

UNICEF, 2024; World Health Organization, & UNICEF, 2026; Ministério da Saúde do Brasil; 2025
Harris, D., Chekuri, B., Schroll, A., Shah, N., Swende, L., Uzuegbu, C., & Young, P. (2024

Sustainable home care must also be climate-resilient.

Sources: UNICEF & Karolinska Institutet (2024); WHO (2023); WHO (2026).

A bridge to the future



This Congress is already showing us valuable work on efficiency, integration, quality, equity and service design



5 Tip Questions to Take Home

Appropriate & effective	• The right care. • Are we improving what matters to the child?
Equitable & accessible	• For every child and family • Can the most vulnerable access the same level of care?
Resource-responsible	• Without transferring unfair burdens Are we supporting families without overburdening them?
Resilient	• Capable of adapting Can quality and continuity be maintained under pressure?
Planet-conscious	• Respecting future generations Can we preserve the workforce and resources needed tomorrow?

Core recommendations for sustainable models

Six priorities for action across paediatric palliative care

01

Sustainable financing

Include PPC in national budgets and universal health coverage.

02

Integrated pathways

Enable early referral and links between specialist and primary care.

03

Workforce protection

Invest in training, supervision and emotional support.

04

Climate resilience

Prepare emergency backup plans and promote appropriate prescribing.

05

Human-centred eHealth

Co-design, ensure digital equity and retain hybrid care.

06

Public health approach

Strengthen compassionate communities and measure long-term outcomes.

From isolated initiatives to a shared, sustainable system of care.

Proposed synthesis informed by WHO (2023), Benini et al. (2022) and current home-based PPC evidence.



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