Integrating Patient Safety into Informal Caregiving

Draft agenda (Helsinki, 14–15 April 2026)

On 14–15 April 2026, BetterCare (COST Action CA22152, https://cost-bettercare.eu) meets in Helsinki (funding by COST | Cooperación Europea en Ciencia y Tecnología and with the support of LAB University of Applied Sciences) to bring patient safety into informal caregiving. The meeting connects countries and key stakeholders to agree shared priorities: prevent caregiver errors at home, strengthen safer transitions, and build practical support for caregivers and care recipients.

Home care is becoming more complex and intense as populations age and chronic conditions rise. When care shifts to families, safety risks can go unnoticed—affecting both care recipients and caregivers' wellbeing. BetterCare's Helsinki meeting will turn this reality into a joint, cross-country agenda for safer care at home.

Helsinki 2026 is designed to deliver concrete outputs: a shared definition of patient safety in informal caregiving, a rapid map of national policies/initiatives to spot gaps and overlaps, and a strengthened transnational collaboration network to scale research and innovation on safe care at home.

Objectives

- Share BetterCare definition of patient safety in informal caregiving contexts.
- Identify patient safety risks in informal caregiving and their implications for institutional responsibility and accountability.
- Explore the double-victim concept to better understand the emotional and psychological burden of home caregiving.
- Highlight the role of healthcare and social care institutions in supporting caregivers and promoting safety beyond clinical settings.
- Identify common challenges faced by informal caregivers across the countries (e.g., lack of training, fragmented support systems).
- Map national policies and existing initiatives to build a cross-country collaborative network dedicated to improving patient safety in informal caregiving through shared research, development, and innovation.

April 14th, 2026

9:30 – 9:40 | Welcome and Opening Remarks (Practical information and group allocation)

9:45 - 10:40 | Setting the Stage: Informal Care in a Changing Demographic Landscape (15 mn)

- Population ageing and the growing prevalence of chronic multimorbidity.

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- Workforce shortages and resource constraints driving a shift of care responsibilities to families.
- Informal care at home as an expanded care system operating without formal safety structures.

Session 1 - Breakout groups (4–5 participants each):

A. System drivers: What is the single most important system-level shift (ageing, multimorbidity, workforce constraints) likely to increase home-care risk over the next five years, and why?

B. Invisible workload: Where does the formal system implicitly rely on families (tasks, decisions, monitoring) without explicitly naming it? List three "silent transfers of responsibility."

C. Equity and vulnerability: Which populations are most exposed to harm in informal care (e.g., frailty, dementia, low health literacy, rural/low-resource settings), and what mechanisms drive this vulnerability?

D. Measurement starting point: If only two indicators could be used to detect rising safety risk in informal care, what should they be and which realistic data sources could provide them?

Wrap-up & next steps (15 minutes)

10:45 – 11:10 | Break

11:15- 12:35 | Informal Care as a Blind Spot in Risk Management (15 mn)

- Common safety risks: medication errors, unsafe mobility assistance, delayed responses to deterioration.
- Fragmentation between formal and informal care: lack of communication, and follow-up.
- Systematic underestimation of home-based risks and the absence of explicit safety protocols when care is provided by informal caregivers.

Questions for debate: What types of adverse events have you observed, or suspect, may originate in informal care settings? Are these risks routinely identified, assessed, or monitored within your quality and safety systems?

Session 2 - Breakout groups (4–5 participants each):

A. Events and scenarios: Identify five concrete adverse events that can originate at home (rather than in hospital) and link each to a plausible trigger during transitions of care.

B. Detection and monitoring: Where could these risks be detected early (touchpoints), and what is the minimal viable monitoring approach (data, frequency, ownership)?

C. Communication gaps: Map the communication failures that enable harm: who does not communicate with whom, when, and what critical information is lost? Propose two practical "handover rules."

D. Accountability boundary: When harm originates in informal care, where should institutional responsibility begin and end? Define what should be accountable (system design) and what should not (blaming caregivers).

Wrap-up & next steps (15 minutes)

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12:40-13:25 | Lunch

13:30 – 15:55 | The Emotional Fallout of Errors: The Double Victim Experience in Informal Caregivers (15 mn)

- The double-victim concept: emotional distress, guilt, and loss of confidence following an error or adverse event.
- System-level consequences: increased reattendances, disruption of care plans, caregiver withdrawal or burnout.

Questions for debate: How should an institution respond when an informal caregiver reports emotional distress following a preventable incident at home?

Session 3 - Breakout groups (4–5 participants each):

A. Signals and thresholds: What are early warning signs of double-victimisation in informal caregivers (behavioural, emotional, functional), and what thresholds should trigger support?

B. Institutional response pathway: Design a simple response pathway after a preventable incident at home: entry points, triage, support actions, follow-up, and closure.

C. Just Culture at home: How can Just Culture principles be applied when the person involved is a family caregiver rather than staff? What does "learning not blaming" mean in practice?

D. System outcomes: How does caregiver distress translate into system outcomes (reattendances, care-plan disruption, medication changes, avoidance of services)? Select two outcomes and propose mitigation actions.

Wrap-up & next steps (15 minutes)

April 15th, 2026

9:30 – 11:45 | Building Safer Systems: Risk Management and Resilience in Informal Care (15 mn)

- Empowering caregivers through knowledge, practical tools, and clear points of contact
Integrating home-based risk management into existing patient safety and continuity-of-care frameworks.
Case for discussion: An older adult with dementia and mobility limitations is discharged from hospital into the care of a family member.
Which risks are most common during transition and home care?
What mechanisms could be implemented to monitor safety risks at home and prevent caregiver burnout or emotional harm?
Session 4 case and breakout prompts - Case for discussion: An older adult with dementia and mobility limitations is discharged from hospital into the care of a family member - Breakout groups (4–5 participants each):

A. Safe transitions and discharge design: Redesign the discharge process: what information, training, and verification should occur before discharge to prevent the three most likely home risks?

B. Monitoring and escalation: Propose a feasible home-safety monitoring model (low-tech and digital option): who monitors, what is monitored, and what happens when a risk signal appears?

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C. Caregiver capability and tools: Define a minimum caregiver toolkit (five elements) that increases safety and confidence (e.g., checklists, contacts, practical training, respite, peer support). Prioritise for feasibility.
D. Preventing emotional harm: Define prevention of caregiver emotional harm as a safety goal: which preventive measures reduce guilt and distress after incidents, and how can they be embedded in routine services?
12:00-12:45 | Wrap-up & next steps. Key Take-Home Messages

BetterCare (COST Action CA22152) meets in Helsinki, 14–15 Apr 2026, to push patient safety beyond hospitals: safer informal caregiving, safer transitions, and better support for caregivers. #PatientSafety #HomeCare #Caregivers #IntegratedCare #COST.

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