



# European PanCareFollowUp Recommendations for surveillance of late effects of childhood, adolescent, and young adult cancer

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## Background

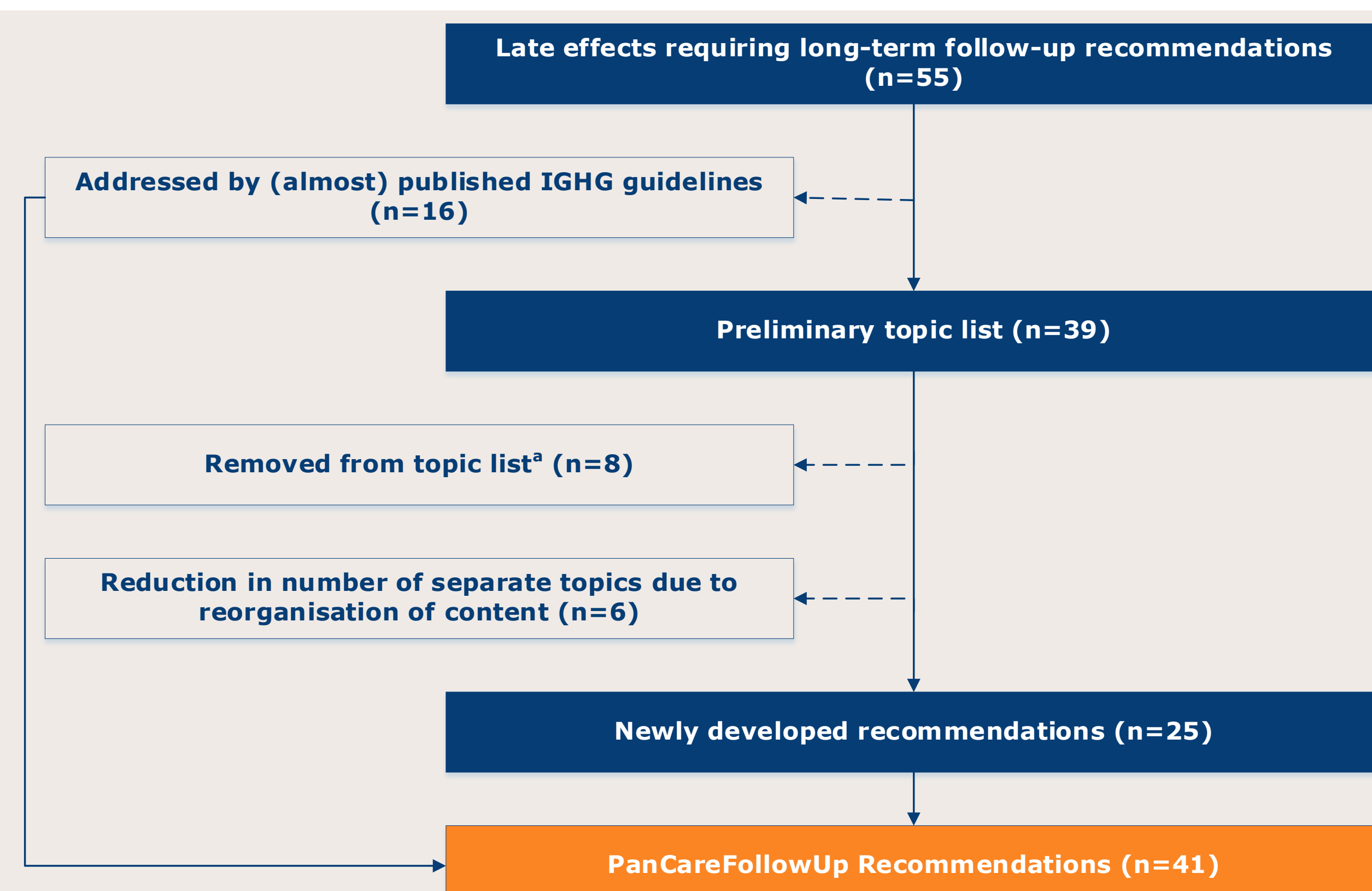
- Guidelines are needed to inform optimal surveillance strategies for childhood, adolescent and young adult cancer survivors
- The International Late Effects of Childhood Cancer Guideline Harmonization Group (IGHG) has already developed various evidence-based guidelines, but not all relevant topics are covered yet
- Therefore, the PanCareFollowUp Recommendations Working Group developed European harmonised recommendations
- The objective was to describe the surveillance requirements for high-quality care, while balancing the different infrastructures and resources across European health care systems

## Methods

- A PanCareFollowUp Recommendations Working Group was initiated, consisting of 23 late effects specialists, researchers and survivor representatives from nine European countries
- Late effects were identified that require long-term follow-up strategies
- Existing evidence-based guidelines by the IGHG were adopted if available
- For topics where no evidence-based recommendations existed yet, the following approach was used:
  - Review of four existing long-term follow-up guidelines (COG, DCOG, SIGN and UKCCLG\*)
  - Extraction of information on surveillance population, surveillance method, timing, frequency, discontinuation and recommended actions in case of abnormalities
- The PanCareFollowUp Recommendations were finalised after a consultation round involving 18 experts from 14 countries

\* North American Children's Oncology Group, Dutch Childhood Oncology Group, Scottish Intercollegiate Guidelines Network, UK Children's Cancer and Leukaemia Group

## Results



**Flowchart.** Overview of recommendation topic selection. <sup>a</sup> Included as part of another IGHG guideline, not addressed in existing guidelines, or existing guidelines similar to general population recommendations.

## Results (continued)

- 25 harmonised recommendations for LTFU care were developed collaboratively addressing topics requiring awareness only (n=6), awareness, history and/or physical examination (n=9), or additional surveillance tests (n=10)
- Including the (nearly) published IGHG guidelines, the PanCareFollowUp Recommendations consist of 41 recommendations (see Table)

Awareness only		
Alopecia	Cerebrovascular problems	Dental and oral problems
Gastro-intestinal problems	Peripheral neuropathy	
Awareness, history and/or physical exam without surveillance test		
Health promotion	Subsequent neoplasms	Subsequent skin cancer
Cancer-related fatigue*	Psychosocial problems*	Mental health problems*
Chronic pain	Neurocognitive problems	Eye problems
Craniofacial growth problems	Spine scoliosis and kyphosis	Lower urinary tract problems
Obstetric problems*		
Awareness, history and/or physical exam with potential surveillance test		
Subsequent thyroid cancer*	Subsequent CNS neoplasm*	
Awareness, history and/or physical exam with surveillance test		
Subsequent breast cancer*	Subsequent colorectal cancer	Diabetes mellitus
Dyslipidaemia	Overweight and obesity	Hypertension
Bone problems	Male fertility	Central precocious puberty*
Ear problems*	Thyroid function problems	Cardiac problems*
Asymptomatic CAD*	Pulmonary problems	Renal problems
Late liver injury*	Iron overload*	Spleen problems
Male fertility problems and sexual dysfunction*	Premature ovarian insufficiency*	Hypothalamic-pituitary dysfunction*

**Table.** Overview of the 41 PanCareFollowUp Recommendations including 25 newly developed harmonised recommendations, and 16 recommendations from (nearly) published IGHG guidelines (indicated by \*). CAD = coronary artery disease.

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## Conclusions

- The PanCareFollowUp Recommendations emphasise awareness among survivors and health care providers in addition to tailored clinical evaluation and/or surveillance tests
- Included are 16 existing IGHG guidelines and 25 additional recommendations developed by a pragmatic methodology
- The PanCareFollowUp Recommendations are currently being used in the Horizon 2020-funded PanCareFollowUp project to improve health and quality of life of childhood, adolescent and young adult cancer survivors (see separate poster)