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Scaling up and implementing the digital Survivorship Passport tool in routine clinical care – The European multidisciplinary PanCareSurPass project

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Abbreviations: **AT,**, Austria; **BE**, Belgium; **CCI**, Childhood Cancer International; **CCS**, Childhood Cancer Survivor; **DE,**, Germany; **EMR**, Electronic Medical Record; **EHR**, Electronic Health Record, Electronic Health Platform (EHP); **ELISE**, Ethical, Legal, Information technologies, Social, Economic; **ES**, Spain; **EU**, European Union; **FHIR**, Fast Healthcare Interoperability Resources; **GDPR**, General Data Protection Regulation; **HCP**, Health care provider; **HL7**, Health Level Seven International; **IGHG**, International Guideline Harmonization Group; **IT**, Italy; **ITT**, intention-to-treat; **LT**, Lithuania; **MCDA**, Multi-Criteria Decision Analysis; **MD**, Medical Device; **MDR**, Medical Device Regulation; **PanCare**, Pan-European Network for Care of Survivors after Childhood and Adolescent Cancer; **SC**, Survivorship Care; **SCP**, Survivorship Care Plan; **SIOP**, International Society of Paediatric Oncology; **SurPass**, Survivorship Passport; **TS**, Treatment Summary; **WP**, Work package.

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ABSTRACT

Background: Childhood cancer survivors (CCS), of whom there are about 500,000 living in Europe, are at an increased risk of developing health problems [1–6] and require lifelong Survivorship Care. There are information and knowledge gaps among CCS and healthcare providers (HCPs) about requirements for Survivorship Care [7–9] that can be addressed by the Survivorship Passport (SurPass), a digital tool providing CCS and HCPs with a comprehensive summary of past treatment and tailored recommendations for Survivorship Care. The potential of the SurPass to improve person-centred Survivorship Care has been demonstrated previously [10,11].
Methods: The EU-funded PanCareSurPass project will develop an updated version (v2.0) of the SurPass allowing for semi-automated data entry and implement it in six European countries (Austria, Belgium, Germany, Italy, Lithuania and Spain), representative of three infrastructure healthcare scenarios typically found in Europe. The implementation study will investigate the impact on person-centred care, as well as costs and processes of scaling up the SurPass. Interoperability between electronic health record systems and SurPass v2.0 will be addressed using the Health Level Seven (HL7) International interoperability standards.
Results: PanCareSurPass will deliver an interoperable digital SurPass with comprehensive evidence on person-centred outcomes, technical feasibility and health economics impacts. An Implementation Toolkit will be developed and freely shared to promote and support the future implementation of SurPass across Europe.
Conclusions: PanCareSurPass is a novel European collaboration that will improve person-centred Survivorship Care for CCS across Europe through a robust assessment of the implementation of SurPass v2.0 in different healthcare settings.

1. Introduction

As a result of improved childhood cancer treatments, more children and adolescents successfully survive cancer into adulthood. Almost 500,000 childhood cancer survivors (CCS) are now living in Europe, with around 8,000 new CCS each year [12,13]. Compared to the general population, CCS represent a vulnerable group at increased risk of developing health problems (known as late effects), resulting in lower quality of life, excess morbidity, and mortality [1–6].

Many CCS are unaware of their personal risk for late effects, which reduces their ability to self-manage their own survivorship care and wellbeing [14]. In addition, survivorship care may be received in a different care setting than the initial cancer treatment, or records may be archived or unavailable. As a result, information about cancer treatments given many years before may no longer be (easily) available to healthcare providers (HCPs) or CCS. Also, HCPs may lack information about the epidemiology, pathophysiology and origin of late effects, which may result in incorrect or delayed diagnoses and treatments [7–9]. For these reasons, the Pan-European Network for Care of Survivors after Childhood and Adolescent Cancer (PanCare) was created in 2008 as a multidisciplinary network of professionals, survivors, and their families, which aims to increase awareness, and reduce the impact, of late effects for CCS [15].

The Survivorship Passport (SurPass) is an innovative, digital tool developed through several EU-funded projects: ENCCA (which led to SurPass v1.0), ExPO-r-Net (v1.0.1), PanCareSurFup (v1.1) and PanCareFollowUp (v1.2) [10,16–20]. The SurPass is personalised and provides each CCS and their treating HCP with a Treatment Summary (TS) containing all relevant health data related to previous cancer treatment(s) (e.g., cancer diagnosis, chemotherapy, radiotherapy) and a Survivorship Care Plan (SCP) based on internationally approved evidence-based guidelines [10,11,20]. Guidelines implemented in SurPass (v1.2 and 2.0) are relevant for survivors who have reached the time-point of 5 years since diagnosis and were developed by the International Guideline Harmonization Group (IGHG) for late effects of childhood cancer (www.ighg.org) and, in parallel, by the PanCareFollowUp project (www.pancarefollowup.eu) in collaboration with the PanCare Guidelines Group [11,20]. Algorithms built into the SurPass platform link treatment exposures of each survivor to risk factors identified by the guidelines for possible undesired health outcomes, thereby allowing HCPs to efficiently develop an evidence-based SCP tailored to the survivor [19,20].

While the digital SurPass is currently being used in Italy in academic research settings, little is known about the barriers and facilitators, costs and processes of successfully implementing it in routine clinical care across Europe. To address this implementation knowledge gap, PanCare formed a consortium to secure funding for the 'PanCare studies of the scale-up and implementation of the digital Survivorship Passport to improve people-centred care for childhood cancer survivors' (PanCareSurPass) project under the EU's Horizon 2020 programme. PanCareSurPass will advance the SurPass (from v1.2 to v2.0), focusing in particular on interoperability between different Electronic Medical Records (EMR) and the SurPass platform, to replace manual data entry (v1.2) for SurPass TS generation with semi-automatic data extraction from EMRs to reduce the workload for SurPass TS generation. A multi-country implementation study will also generate a robust evidence base on how to successfully implement SurPass in six European countries (Austria, Belgium, Germany, Italy, Lithuania and Spain). Moreover, PanCareSurPass will fill a gap in the guidelines for survivors less than 5 years after diagnosis by developing recommendations for follow-up care during this time frame.

1.1. Aims

The overall aim of PanCareSurPass is to leverage the digital transformation of healthcare to improve person-centred Survivorship Care for CCS by scaling up and implementing an interoperable SurPass (v2.0) across Europe. To achieve this, PanCareSurPass will: (i) develop and test the next version of the SurPass (v2.0) that will allow semi-automated, General Data Protection Regulation (GDPR) compliant, bilateral data input from and to EMR by using interoperable Health Level Seven (HL7) International technology standards [21]; (ii) evaluate country-specific barriers and/or facilitators for the SurPass implementation into medical systems; (iii) conduct a multi-country implementation study of the SurPass implementation, and (iv) develop a prediction model to enable healthcare decision-makers to assess the suitability and costs of implementing SurPass v2.0 in their health systems.

The SurPass will be implemented in six European clinics ((Austria (AT), Belgium (BE), Germany (DE), Italy (IT), Lithuania (LT) and Spain (ES)), reflecting three representative health system scenarios, in which the required electronic health records come from: (i) national Electronic Health Record (EHR) (AT, LT); (ii) institutional/regional EHR (IT, ES); or (iii) national cancer registries and hospital-based Electronic Medical Record (EMR) (DE, BE).

2. Methods

2.1. The consortium and organisational structure

The PanCareSurPass consortium consists of 17 partners from eight European countries and spans disciplines, including experts in: interoperability, including HL7 Fast Healthcare Interoperability Resources (HL7 FHIR) (www.hl7.org) and International Patient Summary (https://international-patient-summary.net/hl7-fhir-ig/), implementation science and prediction models development, economic modelling, database and systems integration, epidemiology, and medical sciences. In addition, key stakeholders are actively involved, represented by their main associations: Childhood Cancer International (CCI) Europe, PanCare and the International Society of Paediatric Oncology (SIOP) Europe.

The project is organised in eight Work Packages (WPs, Figure 1), where WPs 1–3 are dedicated to the pre-implementation phase, WP 4 to the multi-country implementation study, WPs 5 and 6 to future European implementation and dissemination, and WPs 7 and 8 to project and ethics management.

2.2. Work Package 1: pre-implementation study

The pre-implementation study will be conducted via an online survey and innovative "Open Space" meetings. It will identify barriers and facilitators for SurPass v2.0 implementation in each country, taking into account a wide range of contextual factors, such as Care Process, Ethical, Legal, Information Technologies, Social, Economic (ELISE) aspects and Information & IT infrastructures. Both the online survey and the "Open Space" meetings will be distributed to long-term follow-up care providers, long-term follow-up care program managers, CCSs and IT-specialists between 20 and 75 per country. The distribution across stakeholders per country will be individual. WP1 will also advance the state-of-the-art in survivorship sare by developing recommendations for screening recommended during the first 5 years after diagnosis. This will enable a continuum of survivorship care starting from the end of cancer treatment [11,20].

2.3. Work Package 2: implementation strategy development

Informed by the findings of the pre-implementation study, WP2 will develop practical SurPass implementation strategies for the six countries. In addition, a literature review referring to political, social and economic factors, as well the previously mentioned factors (Care, ELISE), will also be conducted to inform a pragmatic strategy for implementation, ideally overcoming identified barriers and capitalising on facilitators. This work will yield recommendations for SurPass v2.0 implementation, as well as IT technical specifications for the SurPass v2.0 to ensure interoperability and cybersecurity.

2.4. Work Package 3: SurPass v2.0 – addressing technological challenges & solutions in six European countries

WP3 will upgrade, test, install, configure, and validate the SurPass v2.0 platform. The current SurPass (v1.2) will be extended to v2.0 to allow bilateral interoperability with local EMRs and regional/national EHRs. Integration components will be based on the HL7 FHIR standard hiding differences among implementations and to some degree simplifying implementation. Preliminary testing of semi-automated data extraction (to reduce the workload of current manual data entry for TS generation of SurPass (v1.2)) will be performed using extensive mock/simulated data sets, and then completed by the use of realistic data derived from fully anonymized data from institutional EMR. Any possible emerging issues will be identified and addressed. An Implementation Guide will be developed and made publicly available. In addition, SurPass v2.0 will include additional languages (Dutch, German, Lithuanian and Spanish) as v1.2 is available only in English and Italian. Translations will include TS variables and SCP recommendations. Finally, to allow the use of the SurPass v2.0 in routine clinical practice as an instrument to help HCPs efficiently generate personalised SurPass for individual CCS, the SurPass will be certified as a medical device (MD) under the new Medical Devices Regulation 2017/745

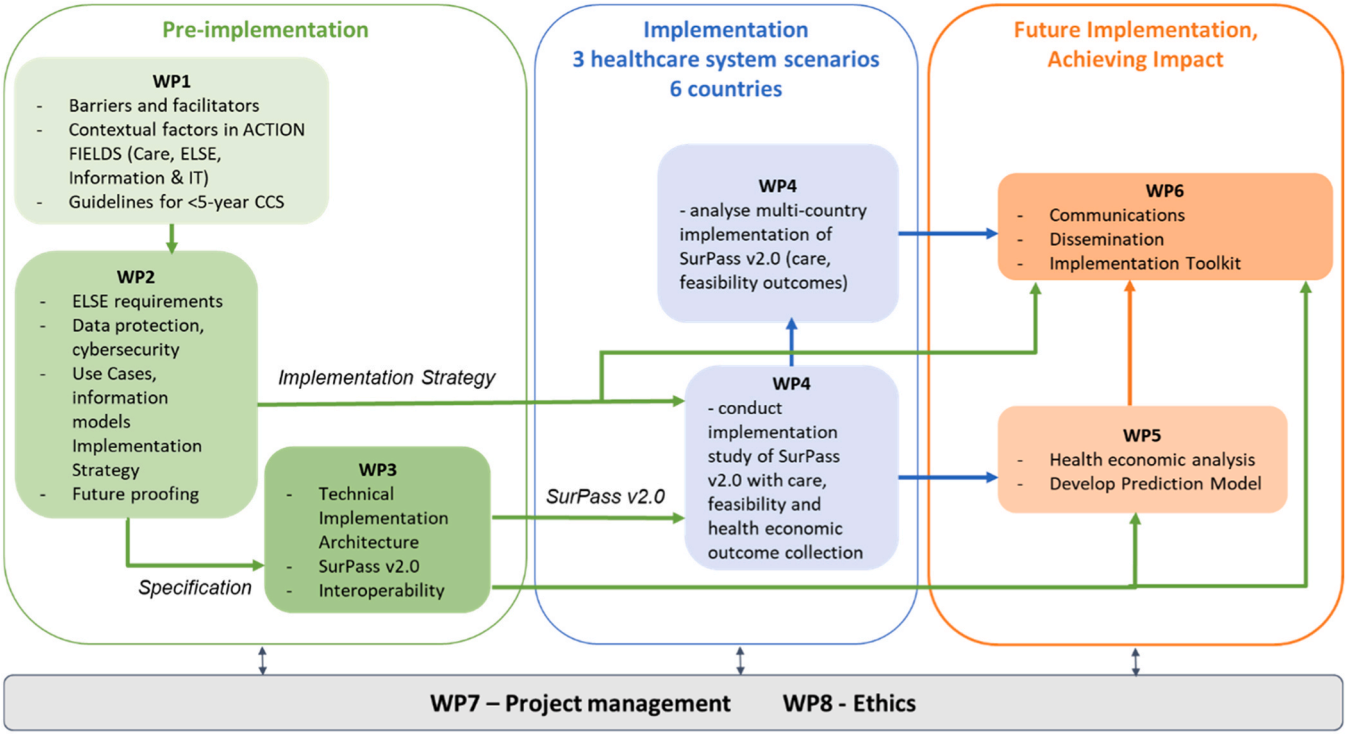

Fig. 1. Pert Chart PanCareSurPass Project.

(MDR).

2.5. Work Package 4: multi-country implementation study of the SurPass v2.0

In WP4, the finalised SurPass v2.0 will be rolled out in six target countries in a multi-country implementation study, which will include a main cohort and an observational cohort.

In the main cohort, personalised SurPass v2.0 will be delivered to consenting CCS (n = 360, 60/country) with details on how to retrieve their documentation from the local EMR. CCS included will be diagnosed with cancer before the age of 18 years, have completed the planned treatment protocol, being still in continuous remission, ≥ 5 years survivorship and being in follow-up care at one of the participating clinics. It is relevant that eligible CCS were treated with/after the introduction of the EHR at the respective clinic, so that complete treatment data should be available (electronically). CCS will be excluded in case of current treatment for secondary malignancy and if they have already received a previous version of the SurPass. The study outcomes will include patient activation as primary outcome (Patient Activation Measure, PAM, [22]), empowerment (Health Education Impact Questionnaire, heiQ, [23]), quality of life (5-level EQ-5D, [24–26]) and satisfaction (Technology Acceptance Model, TAM, [27,28]) with the digital SurPass tool. Data on cost-effectiveness (for CCS and HCPs) will also be collected for development of the Prediction Model in WP5 and health economic analyses. The main cohort will be asked to complete the different questionnaires at three timepoints: before receiving the SurPass (CCS: PAM, heiQ, EQ-5D), immediately after SurPass handover (HCPs: TAM, Operational Costs) and two to three months after receiving the SurPass (CCS: PAM, heiQ, EQ-5D, TAM, Costs).

In the (qualitative) observational cohort, conducted in Austria and Italy, the study outcome will be to test the feasibility to generate a SurPass with an intention-to-treat (ITT) approach. This ITT based SurPass is mainly intended to facilitate the care of CCS treated in eras when EMR were not available, for which it is thus usually difficult to retrieve complete treatment data (i.e. paper records have been lost or destroyed). With this approach, TS and the corresponding SCP are generated based on the cumulative doses of chemo and/or radiotherapy expected from the treatment protocol (most likely) used to treat the survivor. For this purpose, data from the protocols in use since 1974 at the two institutions will be collected and implemented in the SurPass platform. The study will also include semi-structured interviews to test the confidence of HCPs in delivering ITT-based SurPass.

2.6. Work Package 5: development of prediction model

In WP5, a Multi-Criteria Decision Analysis (MCDA) using data from the pre-implementation activities (WPs 1 - 3) and the multi-country implementation study (WP4) will be conducted considering decision contexts and stakeholder preferences. The results of the MCDA and cost analysis will be combined with elements of strategic foresight (forecasting, scenario work) to create a policy-oriented Prediction Model to enable healthcare decision-makers to assess the feasibility, suitability and costs of implementing SurPass v2.0 in their health system and predict the potential impact of SurPass v2.0 on their health system performance, HCP access to information, and survivors' satisfaction. Furthermore, decision criteria from the model and associated country-specific weights will rank priorities, helping decision makers to tailor SurPass v2.0 implementation. The model will be presented as interactive tool that guides users along a decision path.

2.7. Work Package 6: communication, dissemination, and future implementation

The objective of WP6 is to communicate and disseminate the PanCareSurPass project widely across its work packages, in particular the transformative potential of SurPass v2.0 to support survivorship sare. As such, WP6 is not pursuing a scientific research question of its own. In addition to traditional communication channels, such as press releases or conferences, a website (https://www.pancaresurpass.eu/) has been established, along with social media accounts targeting relevant end-users, which have already proven useful in other PanCare projects. The results of PanCareSurPass itself will be widely shared with key stakeholders and brought together in a freely available Implementation Toolkit to promote future implementation of the SurPass v2.0 in various healthcare settings across Europe.

2.8. Work Package 7: project management

PanCareSurPass will be overseen by a Management Team, which includes the Project Coordinator (University Medical Centre Mainz), Research Manager (Istituto Giannina Gaslini), and Administrator (Pintail Limited). The Management Team will be supported by a Project Board comprised of one representative from each partner institution, chaired by the Project Coordinator. WPs will be led by a partner institution, responsible for coordinating all activities and liaising with the Management Team to ensure effective integration of activities across WPs. In addition, there will be five external advisors (Melissa Hudson from the St. Jude Children's Hospital of Memphis in the US, Julia Inthorn from the Centre for Health Care Ethics in Hannover, Germany, Nikolaus Forgo from the Department of Innovation and Digitalization in Law of the University of Wien, Austria, Michael Rigby from the Keele University, UK, and Stefan Sabutsch from ELGA GmbH and the Austrian Interoperability Forum) who will provide feedback on the project results and/or guidance and advice on areas relevant to their expertise upon request by the Project Coordinator.

2.9. Work Package 8: ethics requirements

WP8 defines the ethics requirements of the project, including protection of personal data according to GDPR and privacy, and ensures that they will be met. The installation of an independent ethics advisor, who will provide advice on ethics issues that may arise during the project. Ethics requirements relate primarily to the pre-implementation study, the implementation study as well as the Advisory Board's view on how the SurPass system may impact clinical decision-making in the different countries. For the pre-implementation and the implementation study, it is necessary to agree on data governance structures and controllership procedures, create consent procedures and templates, study documents and seek for ethics approvals. It is also about creating an organisational framework to ensure GDPR compliance, such as the specification of a privacy policy and a Data Protection Impact Assessment (DPIA), the legal bases for data processing, the technical and organisational measures and the anonymisation/pseudonymisation techniques that will be used.

3. Results and discussion

One of the biggest challenges for IT in healthcare is interoperability, which is essential for fruitful (electronic) collaboration between different healthcare institutions, and in particular, for scaling-up and implementing the digital SurPass in routine clinical care across Europe. A key benefit of interoperability is the automatic completion of the TS with data from EMRs, which avoids double-entry of potentially large volumes of data already digitally available when generating TS. This represents a significant advantage for the implementation of survivorship care across Europe, as the TS is an essential component of care. At the same time, Interoperability is equally essential for supporting information and communication technologies to promote continuity of care, which is particularly important for survivors whose care spans multiple care settings over the course of their lives. The additional ITT approach allows for greater flexibility in creating a SurPass by not

relying on primary data.

PanCareSurPass will achieve a new state-of-the-art in person-centred survivorship care in a single, interoperable, easy-to-use digital tool for CCS and HCPs by providing comprehensive, personalised SurPass encompassing all relevant treatment data and evidence-based care tailored on individual risk factors. To achieve this, the SurPass platform will use a common template and internationally confirmed coding systems (e.g. ICD-O-3, ATC codes) for the TS and EU-wide and international recommendations for the SCP. This will improve life-long survivorship, including the critical moment of transition from paediatric to adult care, better health promotion, improved late effects care, secondary cancer prevention and reduction of inequity by increasing access to information.

Until now, the time-point of 5-years from diagnosis is the baseline used by the IGHG and PanCareFollowUp recommendations. The PanCareSurPass project will develop recommendations for surveillance from the end of treatment until 5 years after diagnosis based on adaptation of existing IGHG and PanCareFollowUp recommendations. These guidelines are not intended to substitute any other recommendation proposed by the clinical trial treatment protocol used to treat the patient, if any. They are proposed as guidance where no other organ-specific surveillance recommendation is proposed by the original treatment protocol.

In addition, positive impacts are expected to include methods/strategies for implementing innovative, ethical and legal solutions for better person-centred care, as well as a better understanding of organisational, systemic, social and behavioural changes to successfully embed evidence-based, innovative digital solutions into daily practice and ensure sustainability.

To drive the increased scale-up and use of the innovative SurPass digital tool to improve person-centred survivorship care across the EU, the results of the project will be made applicable in a range of settings and robust evidence will be disseminated.

In summary, PanCareSurPass brings together a multidisciplinary team of survivorship care experts to implement and extend the SurPass into routine clinical care with the goal of improving person-centred survivorship care across Europe. Wider use of the SurPass will allow for better responsiveness to the needs of survivors and HCPs and helps to reduce inequities by allowing CCS to arrange their own care when none is officially available in their health system. Thus, the effectiveness of health systems using the SurPass will increase over time.

Disclaimer

The material presented and views expressed here are the responsibility of the author(s) only. The EU Commission takes no responsibility for any use made of the information set out.

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Author contributions

DG and RH assembled a consortium for the EU Horizon 2020 topic 'Better Health and care, economic growth and sustainable health systems' (H2020-SC1-BHC-2018–2020) and developed the overall structure of the PanCareSurPass project, in collaboration with work package (WP) leaders LK, RL, CCh, AD, HvdP, KOB. Other co-authors contributed to the development of the project structure and activities planned in WPs where they co-lead and participate. ALF drafted the text of the manuscript. MM, RH and DG advised the drafting of the text. All other co-authors critically reviewed the manuscript for important intellectual content, and revised the manuscript. All authors approved the final manuscript as submitted and agreed to be accountable for all aspects of the work. The corresponding author confirms that all listed authors meet authorship criteria and that no others meeting the criteria have been omitted.

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Antonio Orduña Galan: Writing – review & editing, Methodology, Conceptualization. **Samira Essiaf:** Writing – review & editing, Methodology, Conceptualization. **Stefan Beyer:** Writing – review & editing, Methodology, Conceptualization. **Francesca Bagnasco:** Writing – review & editing, Methodology, Conceptualization. **Adela Cañete Nieto:** Writing – review & editing, Methodology, Investigation, Conceptualization. **Monica Muraca:** Writing – review & editing, Writing – original draft, Project administration, Methodology, Investigation, Funding acquisition, Conceptualization. **Thorsten Langer:** Writing – review & editing, Methodology, Investigation, Conceptualization. **Anne Uyttebroeck:** Writing – review & editing, Methodology, Investigation, Conceptualization. **Jelena Rascon:** Writing – review & editing, Methodology, Investigation, Conceptualization. **Edit Bardi:** Writing – review & editing, Methodology, Investigation, Conceptualization. **Riccardo Haupt:** Writing – review & editing, Writing – original draft, Supervision, Project administration, Methodology, Funding acquisition, Conceptualization. **Heleen van der Pal:** Writing – review & editing, Supervision, Methodology, Conceptualization. **Jeroen te Dorsthorst:** Writing – review & editing, Methodology, Conceptualization. **Desiree Grabow:** Writing – review & editing, Writing – original draft, Supervision, Project administration, Methodology, Funding acquisition, Conceptualization. **Alexander Degelsegger-Márquez:** Writing – review & editing, Supervision, Methodology, Conceptualization. **Igor Zamberlan:** Writing – review & editing, Methodology, Conceptualization. **Justas Trinkunas:** Writing – review & editing, Methodology, Conceptualization. **Günter Schreier:** Writing – review & editing, Methodology, Conceptualization. **Leontien Kremer:** Writing – review & editing, Supervision, Methodology, Conceptualization. **Carina Schneider:** Writing – review & editing, Methodology, Conceptualization. **Anna-Liesa Filbert:** Writing – review & editing, Writing – original draft, Project administration. **Davide Saraceno:** Writing – review & editing, Software, Methodology, Conceptualization. **Sonia di Profio:** Writing – review & editing, Methodology, Conceptualization. **Saskia M. F. Plujim:** Writing – review & editing, Methodology, Conceptualization. **Marisa Correcher Palau:** Writing – review & editing, Methodology, Conceptualization. **Kylie O'Brien:** Writing – review & editing, Writing – original draft, Project administration, Methodology, Funding acquisition, Conceptualization. **Anita Kienesberger:** Writing – review & editing, Methodology, Conceptualization. **Catherine Chronaki:** Writing – review & editing, Supervision, Methodology, Conceptualization. **Ruth Ladenstein:** Writing – review & editing, Supervision, Methodology, Investigation, Conceptualization.

Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

Appendix A. Supporting information

Supplementary data associated with this article can be found in the online version at doi:10.1016/j.ejca.2024.114029.

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