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Dissertation Title: A Qualitative Systematic Review exploring the literature on Teenage and Young Adult and Adolescent and Young Adult cancer patients' experiences of survivorship and Late-Effects clinics.

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Declaration

I hereby declare that this thesis is my own work and effort and that it is has not been submitted elsewhere for any award. Where other sources of information have been used, they have been acknowledged.

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Acronyms and Abbreviations

ACA- Affordable Care Act

ACCESS AYA- After Cancer Care Ends Survivorship Starts for Adolescents and Young Adults

AYA- Adolescent and Young Adult

CAG- Cancer Advisory Group

CASP- Critical Appraisal Skills Programme

CBT- Cognitive behavioural therapy

CINAHL- The Cumulative Index of Nursing and Allied Health Literature

CNS- Clinical Nurse Specialist

COG- Children's Oncology Group

CRUK Cancer Research UK

ESMO- European Society for Medical Oncology

GP- General Practitioner

HCPs- Health Care Professionals

MeSH- Medical Subject Headings

NCI-National Cancer Institute

NHS- National Health Service

NICE- National Institute of Clinical Excellence

PCP- Primary Care Physician

PICo- Population, Interest, Context

PRISMA- Preferred Reporting Items for Systematic reviews and Meta-Analyses

SCP- Survivorship care plan

SERP- University School of Health Ethics Review Panel

SIOPE- The European Society for Paediatric Oncology

SR- Systematic Review

TYA- Teenage and Young Adult

UK- United Kingdom

UKRI- UK Research and Innovation

USA- United States of America

Abstract

Background AYA and TYA cancer survivors represent a distinct population with complex care needs. They face unique challenges compared to adults and paediatric populations due to their developmental stage, longer life expectancy and increased risks of late effects post-treatment. Despite improved survival rates, many experience ongoing physical, psychological and social consequences post-treatment. Survivorship care aims to address these needs however, evidence suggests that experiences with follow-up care, including survivorship and late effects services are variable. Engagement remains inconsistent and there is limited evidence about the experiences of survivorship and late effects services for this patient population.

Project Design A qualitative systematic review was conducted exploring TYA/AYA cancer survivors' experiences of survivorship and late effects clinics. Four electronic databases were searched: CINAHL, Medline, Scopus, Web of Science. Study quality was appraised using CASP.

Findings Four themes were identified: Lack of knowledge understanding and being prepared for late effects; Barriers to accessing and engaging with survivorship care services; Holistic care needs in survivorship; Communication, coordination and transition of care. Survivors reported a lack of understanding of late effects and uncertainty regarding long-term health risks. Emotional factors including fear of recurrence and avoidance, alongside practical barriers including financial and competing responsibilities influenced engagement with follow-up services. Survivors emphasised the importance of age-appropriate, multidisciplinary, holistic support addressing psychosocial, physical and practical needs. Fragmented care pathways, poorly managed transitions and a lack of coordinated care further contributed to disengagement.

Conclusion AYA and TYA cancer survivors describe limited information regarding survivorship services and potential late effects risks. SCPs were identified as a way of providing information on late effects risks and follow-up schedules, however these were inconsistent or absent. Survivors described limited availability and inconsistent or fragmented services. AYAs valued early information in relation to survivorship and late effects, continuity of care, holistic survivorship focusing on psychosocial wellbeing, peer support and the use of digital tools or programmes.

Chapter 1: Introduction and Background

1.1 Introduction

This dissertation is a systematic review (SR) of qualitative evidence exploring adolescents and young adults (AYA) and teenage and young adult (TYA) cancer survivor's experiences with survivorship and late effects clinics. This chapter provides context to the research problem, defines key terms and outlines the differences between survivorship and late effects clinics. Epidemiology, significance and rationale for conducting the study are discussed highlighting gaps in current care, inconsistencies in experiences and justification for a qualitative SR. This chapter presents the aims, objectives and research question culminating with the overall structure of this dissertation.

1.2 Background

AYA and TYA represent a distinct patient population across the cancer continuum with unique biological, psychosocial, and developmental needs that influence their care and outcomes (Carpenter *et al*., 2025). A cancer diagnosis during this key developmental period can be disruptive, not only affecting physical health, but also psychosocial wellbeing and the ability to achieve key milestones including education, career progression, and forming relationships (May *et al*., 2018; Crowder *et al*., 2023).

Advances in cancer treatment have improved survival rates for this population, making cancer survivorship an increasingly important area of focus (Brauer *et al*., 2019). However, young adult cancer survivors face complex challenges post-treatment, highlighting the need to better understand their long-term health, psychosocial wellbeing, and experiences with follow-up care (Aagesen *et al,* 2024). Young adults describe the transition from active treatment to post-treatment survivorship as a period characterised by anxiety, isolation, and reduced support from healthcare providers (Camp *et al*., 2023). This transition often coincides with transferring from oncology-based care to primary care, which may require additional flexibility and support within survivorship care (Szalda *et al*., 2018).

Although there is a growing focus on effective survivorship for young adults with cancer, evidence suggests that their experiences with follow-up care, including survivorship and late effects clinics, are variable. Many report unmet needs, fragmented services, or inadequate access to these services (May *et al*., 2018; Ke *et al*., 2020; Carpenter *et al*., 2025). These challenges highlight the importance of exploring the experiences of AYA and TYA cancer survivors to inform service development, clinical practice and policy.

1.2.1 Defining AYA and TYA

The terms AYA and TYA are used interchangeably to describe young people diagnosed with cancer, although the age ranges vary internationally (Lea *et al*., 2020; Janssen *et al.*, 2021; Smith *et al*., 2022a). In the United Kingdom

(UK), TYA refers to individuals aged 13–24 years or 15-24 (Fern *et al*., 2021; Cancer Research UK [CRUK], 2023), while other countries define AYA more broadly, ranging from 15–25 years in Australia to 15–39 years in the United States of America (USA) (Janssen *et al*., 2021a). Using both terms within this review allows for inclusion of studies reflecting these international differences and supports a comprehensive understanding of young cancer survivors' experiences.

1.2.2 Epidemiology and Significance of the study

Internationally, approximately 1.2 million AYAs are diagnosed with cancer annually (Janssen *et al*., 2021a). Consequently, AYAs represent a growing cancer survivor population, with five-year survival rates now exceeding 80% (May *et al*., 2018). Despite these improvements, survival advances in AYAs are compromised compared to those seen in paediatric and older adult populations (Fidler *et al*., 2019).

Treatment for cancer places AYAs at an increased risk of late effects and early morbidity compared with the general population, highlighting the need for structured long-term follow-up care (Gianinazzi *et al*., 2022). Survivors experience prolonged health and quality of life concerns following treatment, including physical, psychological, and social challenges that can persist well into survivorship (Collaço *et al*., 2025).

Due to the combination of more aggressive treatment regimens and longer life expectancy, AYA cancer survivors are particularly vulnerable to serious long-term late effects. Compared with healthy siblings, AYAs have up to eight times the risk of developing a serious chronic health condition. The incidence of disabling or life-threatening condition or death, thirty years post treatment was reported to be 42.4% (May *et al*., 2018). Common late effects reported by young adults include cognitive difficulties, fatigue, reduced physical capacity, body deformity and psychological or sexual distress, which can interfere with education, employment, relationships, and social participation (Aagesen *et al.,* 2024).

Survivorship is recognised as a research priority in AYA oncology, focusing on managing late effects, addressing psychosocial challenges, and improving quality of life (Brauer *et al*., 2019). However, evidence indicates that follow-up care remains inconsistent, underutilised and poorly tailored to age-specific needs (Carpenter *et al*., 2025). Current national and international policies and service specifications emphasise the importance of survivorship and long-term follow-up care for TYA/AYA cancer survivors yet, evidence suggests that implementation is variable across services (National Health Service [NHS] England, 2023; National Cancer Institute [NCI], 2024a).

1.2.3 Survivorship and Late Effects Clinics

Cancer survivorship is a complex and multidimensional aspect of post-treatment support, incorporating long term health monitoring, psychological care and health promotion (Viola *et al*., 2017). Currently, there lacks a

national standardisation that defines survivorship clinics for AYA/TYA cancer survivors (Janssen *et al*., 2023b). Ramsay *et al*. (2018) and Szalda *et al*. (2018) highlight the importance of structured coordinated care to support young adults in transitioning from active treatment to long-term survivorship. However, Ke *et al*. (2020) reports that coordinated care remains variable. Survivorship clinics aim to deliver holistic ongoing support by combining preventative strategies, education and tailored follow-up to enhance long-term outcomes (Viola *et al.,* 2017). Viola *et al*. (2017) and Collaço *et al*. (2025) recognise that these clinics are delivered through multidisciplinary or nurse-led services. These include oncology input, primary care collaboration, psychosocial support, fertility counselling, nutritional guidance, and advice on returning to education or employment. Survivorship care plans (SCPs) are a crucial component to the provision of survivorship care. This document provides young adult survivors with information on treatment received, potential risks and recommended follow-up to support young adults navigate medical, personal and social transitions (Szalda *et al.,* 2018). Conversely, Baird *et al*. (2019) identifies AYAs were unaware of SCPs or had never received one. Survivorship clinics are therefore broad in scope, aiming not only to monitor health but also to promote wellbeing, independence, and quality of life.

In contrast, late effects clinics focus specifically on the identification, surveillance and management of treatment-related late effects (Smith *et al*., 2025b). These services aim to detect treatment-related toxicities early and reduce preventable long-term morbidity (Stamer *et al*., 2024). Late effects clinics are typically medically oriented and may involve multidisciplinary input, including oncology, cardiology and endocrinology. This is dependent

on the patient's treatment history and risk profile (Stamer *et al*., 2024; Collaço *et al*., 2025). These services are essential due to the elevated risk AYA cancer survivor's face of developing cardiotoxicity, endocrine disorders, fertility issues, and secondary malignancies (Smith *et al*., 2025b). However, AYAs report feeling unprepared for these risks or only becoming aware of late effects several years post-treatment (Szalda *et al*., 2018; Beauchemin *et al*., 2025; Smith *et al*., 2025b). Gianinazzi *et al*. (2022) reports a persistent lack of information received by AYAs regarding late effects with survivors expressing a clear need for specific and actionable information.

Long-term follow-up is often cited in the literature as an umbrella term that combines both survivorship and late effects care (Psihogios *et al*., 2019; Walsh *et al*., 2019). Long-term follow-up incorporates disease-stratified surveillance and risk-based management of late effects, alongside interventions to promote healthy lifestyle behaviours (Kagramanov *et al*., 2021). Evidence from AYA and childhood cancer survivors demonstrates that engagement in long-term follow-up is associated with better long-term health and psychological outcomes (Collaço *et al*., 2025). However, the lack of evidence-based guidelines impedes access, utilisation and the implementation of these clinics are inconsistent (Psihogios *et al*., 2019; Egger-Heidrich *et al*., 2025).

Both survivorship and late effects services are essential for optimising long-term outcomes for AYA/TYA cancer survivors. Therefore, understanding survivors' experiences is key to improving care delivery and ensuring services effectively meet their specific needs.

1.2.4 Rationale for the Study

A SR exploring TYA and AYAs experiences of survivorship and late effects clinics was undertaken in response to the limited availability of specialist follow-up services for TYAs within the local healthcare setting. A survivorship clinic has been developed locally however, it is targeted at 18 years and above and involves only a single post-treatment visit (Government of Jersey, 2022). The Clinical Nurse Specialist (CNS) conducting this SR works independently caring for TYAs. The post-treatment challenges TYA survivors face is observed frequently, including navigating ongoing medical issues, psychological struggles and developmental milestones. These first-hand observations highlight the need to review the wider body of qualitative research to understand the experiences of TYA and AYA cancer survivors in survivorship and late effects services.

Despite survivorship being recognised as a key research priority in AYA oncology, multiple studies highlight that many young adult survivors have limited knowledge of potential late effects. They received insufficient risk-based follow-up, and reported unmet informational, emotional, and practical needs during survivorship (Szalda *et al*., 2018; Brauer *et al*., 2019; Psihogios *et al.,* 2019). These gaps are compounded by inconsistencies in access to survivorship and late effects clinics both nationally and internationally.

AYAs and TYAs with cancer represent a distinct and under-researched population (Viola *et al*., 2017; Crowder *et al*., 2023). Research on long-term outcomes has been derived mainly from paediatric cancer survivor studies, which underrepresent patients at the older end of the AYA age range (Fidler *et al*., 2019). Engagement of AYA survivors in research has also been historically low, particularly in clinical trials, further limiting the evidence base on their specific needs and experiences (Smith *et al*., 2022a).

Given the challenges in engaging and recruiting TYAs and AYAs in research, and maintaining anonymity within a small local population, a primary research project was not suitable for this study. Crane and Broome (2017) identified these challenges within their SR highlighting that adolescents expressed concern as to how their information would be used and shared. A SR was therefore selected as the most appropriate research design to explore diverse populations across a range of settings and countries. This approach allows for a wider exploration of current practices and patient experiences, which can contribute to future policy and practice and identify areas where further research is required.

1.3 Formulating the research question

The research question was formulated using the PICo framework (Population, Interest, Context) (Table 1.1). This is a crucial first step in the research process, facilitating the identification of gaps in existing evidence and ensures the inquiry aligns with the aims of the study (Ratan *et al.*, 2019). The PICo framework was selected as it suits qualitative evidence synthesis and does not require a comparison component. The emphasis

being on understanding experiences and perceptions rather than evaluating interventions (Moola *et al*., 2020). In contrast, PICO (Population, Intervention, Comparison, Outcome) framework is designed for quantitative studies and was therefore deemed less appropriate for reviews exploring phenomena of interest without an intervention or comparator (Hosseini *et al*., 2024).

Table 1.1: PICo

Population (P)	Teenage and young adults/ Adolescents and young adults cancer survivors
Interest (I)	Experiences of survivorship/late effects clinic
Context (Co)	Post-treatment follow-up care

Research question:

What is known about teenage and young adult/adolescent and young adult cancer survivors' experiences with late effects or survivorship clinics after treatment?

Aim

To systematically identify, appraise, and synthesise existing qualitative, research exploring TYA/AYA cancer survivors' experiences, of late effects and survivorship clinics post-treatment.

Objectives

1. To examine through qualitative studies the impact of survivorship and late effects clinics upon TYA/AYA cancer survivors.

2. To critically appraise the research and synthesise the findings on how TYAs/AYAs perceive the role of survivorship and late effects clinics in addressing their physical and psychological wellbeing.

3. Identify reported benefits and areas for improvement reported by TYAs in relation to their experience of survivorship and late effects clinics.

1.4 Summary and Structure of Dissertation

AYA and TYA cancer survivors experience significant challenges post treatment, highlighting the need for specific survivorship and late effects clinics. Evidence suggests that these services are often inconsistent, and do not entirely meet the needs of this cohort. This qualitative SR aims to identify aspects of follow-up care that are effective and areas where these services do not meet the needs of this population. The findings will inform clinical practice, guide future service development, and support policy improvements both locally and internationally.

The dissertation is structured into five chapters. Chapter 2 will provide details of the project design, including the philosophical underpinning, search strategy, inclusion and exclusion criteria and approach to synthesis. Chapter 3 presents the findings of the SR using a narrative synthesis approach and

identifies four themes which will be explored within this study. Chapter 4 provides a discussion of the findings in relation to the wider literature base including relevant policy and frameworks. It reflects upon the role of the advanced practitioner and highlights the strengths and limitations. Chapter 5 concludes the dissertation with key insights and recommendations for future practice and research.

Chapter 2: Project Design

2.1 Introduction

This chapter provides a comprehensive account of the methodology and methods employed in conducting this SR. It outlines the processes involved, explains the rationale for methods chosen and follows the Preferred Reporting Items for Systematic reviews and Meta-Analyses (PRISMA) framework for rigorous evidence synthesis (Page *et al*., 2021). It will cover the philosophical paradigm underpinning the study, the search strategy, inclusion and exclusion criteria, data reduction, analysis methods, data synthesis and ethical considerations.

2.2 Theoretical Basis.

Research is guided by a philosophical paradigm, which is a set of ideas and beliefs that provides a framework for conducting and interpreting studies (Nickerson, 2024). Cresswell and Cresswell (2018) identify the most commonly discussed research paradigms in the literature as positivism, pragmatism, transformative and constructivism or interpretivism. This qualitative SR explores the experiences and meanings reported by TYA and AYA cancer survivors regarding survivorship and late effects clinics. The research question positions the project within the interpretivist paradigm, as it seeks to understand and gain insight into subjective experiences. This paradigm involves interpreting participant's perspectives and the ways in which they construct meaning from their experiences (Cresswell and Cresswell 2018).

In contrast, positivism would not align with this review, as it focuses on gaining knowledge through objective measurement and observation, which is consistent with a quantitative approach that pursues to analyse numerical data (Jansen, 2025). Interpretivism views reality as shaped by individual perspectives, determining that people may experience and understand the world in diverse ways (Alharahsheh and Pius, 2020). Situating this project within an interpretivist paradigm ensures that the studies identified for inclusion focus upon subjective experiences and meanings reported by TYA and AYA cancer survivors. Thus, this approach ensures that the review captures the depth and context of participants' perspectives, which is vital in addressing the research question.

2.3 Methodology

A qualitative SR was selected over mixed-methods or quantitative approaches due to the nature of the phenomena of interest and the focus on exploring TYA/AYA cancer survivors' experiences with late effects and survivorship clinics, which is best captured through qualitative research (Cresswell and Cresswell, 2018). A SR is defined as secondary research focused on answering a focused question and following a structured methodology (Sgarbossa *et al*., 2022).

SRs are considered as one of the most rigorous research methodologies for identifying, appraising, and synthesising high-quality evidence related to a specific research question (Munn *et al.,* 2018; Randels and Finnegan, 2023). The SR is considered the gold standard for evidence synthesis, positioned at the top of the hierarchy of evidence, particularly when meta-analysis is achieved (Vatkar *et al.,* 2025). However, meta-analysis is typically used in a quantitative SR and is not appropriate for this study (Paul, 2022). The process of a SR involves searching databases, screening of articles to assess eligibility, appraisal of included studies and synthesis of the results (Shaheen *et al.,* 2023). A SR provides a structured and transparent method for summarising existing literature, identifying gaps in research and generating insights that can inform clinical practice, policy and future research (Page *et al*., 2021).

Ranganathan and Aggarwal (2020) highlights that the use of a pre-defined protocol, which documents systematic methods in advance, aims to minimise bias. Shaheen *et al*. (2023) concur that it is essential for the researcher to document any limitations of included studies. They state that if methodological flaws or biases are present within a SR incorrect conclusions may be drawn, potentially leading to misguided decision making in practice.

2.3.1 Qualitative research

Qualitative research within healthcare seeks to gather and interpret individual experiences and social interaction to explain the phenomena of interest (Lockwood, Munn and Porritt, 2015; Lim, 2024). Qualitative

research employs an array of methods to explore the phenomena of interest such as focus groups, participant observation and interviews (Lim, 2024). An advantage of qualitative research is its ability to understand the complex human behaviours and processes that are challenging to capture through quantitative research (Tenny, Brannan and Brannan, 2022). However, Lim (2024) highlights several limitations to qualitative research including limited generalisability resulting from smaller sample sizes, the time and resources required, the complexity of analysing large amounts of data and its susceptibility to researcher bias. Despite these limitations, qualitative research is valuable and can support healthcare professionals (HCPs) in developing a deeper understanding of the patients' experiences, which may improve interactions with patients (Munn *et al*., 2018).

The review will follow PRISMA 2020 guidelines, ensuring methodological rigour, transparency and reproducibility (Page *et al*., 2021). All stages including search strategies, inclusion criteria, data extraction, and appraisal are documented to allow external scrutiny and replication. A qualitative SR was chosen to capture TYA/AYA survivors' experiences and the personal meanings they assign to survivorship and late effects care. The connection between the methodology and philosophical stance ensures consistency throughout the review (Mesel, 2012).

2.4 Search Strategy

An initial extensive search was conducted to gain an overview of the existing literature and to identify previous research that has been undertaken in this

specific area, which revealed no existing SR. According to Aromataris *et al*. (2024), an exploratory search is an essential first step in developing a SR. This helps the researcher familiarise themselves with the available evidence and refine the focus of the review. The search strategy within a SR is a vital component in identifying all relevant sources of evidence for the review (Munn *et al.,* 2018). Developing an effective search strategy requires careful planning and tailoring to the specific aims of the study to ensure that both published and unpublished literature are captured comprehensively (Aveyard, Payne and Preston, 2021). The breadth and relevance of the studies identified directly influence the reliability of the findings and the strength of the conclusions drawn (Harari *et al*., 2020). It is essential that search processes are explicit, transparent, and reproducible clearly outlining the databases searched, keywords used, and any limiters or filters applied (Ross-White, 2021).

2.4.1 Inclusion/Exclusion Criteria

The review applied specific inclusion and exclusion criteria. These criteria ensured a systematic, reliable, and unbiased approach to the review (Randles and Finnegan, 2023). Butler, Hall and Copnell (2016) concur, adding that a pre-defined inclusion and exclusion criteria helps to mitigate personal bias. Inclusion criteria clearly define the study population to ensure a consistent and systematic approach to study selection (Garg, 2016). Exclusion criteria identify studies that fall outside the scope of the review which may compromise its clarity and focus (Patino and Ferreira, 2018). The development of a clear inclusion and exclusion criteria are determined by the research question and the resources available, helping to specify and set

boundaries for the SR (Parahoo, 2024). Holly, Salmond and Saimbert (2021) highlight that literature searches guided by an explicit pre-defined inclusion and exclusion criteria provides stronger evidence for the field of research. Inclusion and exclusion criteria are listed in Table 2.1.

Table 2.1: Inclusion and Exclusion Criteria

Inclusion	**Exclusion**
TYA/AYA cancer survivors aged 13-39	Paediatric-only populations (<13 years)
Studies published within the last 10 years	Studies published more than 10 years ago
Focus on patient experiences, perceptions of survivorship or late effects clinics post-treatment	Studies focusing exclusively on adult (>39 years) survivors
Qualitative study designs	Articles not available in English
	Grey literature, conference abstracts, systematic reviews, mixed-methods studies

The criteria were carefully chosen to capture the most relevant, reliable, and focused evidence on TYA and AYA cancer survivors' subjective experiences of late effects and survivorship clinics. The age range 13-39 was chosen to align with commonly accepted worldwide definitions of TYAs and AYAs in oncology research (Stein *et al*., 2025). However, it is acknowledged that including such a wide age range may introduce variability in experiences due to developmental stages and cancer types (Ferrari *et al.,* 2021). This has been considered when interpreting and synthesising the findings.

Quantitative studies were purposefully excluded in this review to focus on rich narrative data that explore experiences rather than measure outcomes numerically (Cresswell and Cresswell, 2018; Gonella *et al.,* 2020). Atkins *et al*. (2012) report the inclusion of mixed-methods studies in a qualitative SR can result in less credible findings and are less likely to provide rich in-depth data compared to purely qualitative studies. Similarly, Hong (2023) states that mixed-methods studies often integrate both qualitative and quantitative findings, making it difficult to extract and interpret only the qualitative data. This approach recognises that findings may exclude data across larger populations or healthcare settings. This limitation reflects the interpretivist approach underpinning the study and its research question.

The review restricted the inclusion to articles published in English-language due to practical constraints including lack of translation resources (James Cook University Library, 2024). Although, Brassey, Spencer and Heneghan (2017) recommend the inclusion of studies in all languages to minimise bias and support equity and diversity. Restricting the inclusion to English language studies was more realistic for this review. The 10-year limit balances the need for up-to-date contemporary research with a broad enough timeframe to capture relevant trends and findings, while maintaining a manageable scope (James Cook University Library, 2024). Though, limiting studies to the last 10 years may exclude earlier research, which may be relevant given that TYA/AYA cancer care commenced around 1990 (Taylor *et al*., 2021). Paez (2017) argues that including grey literature may provide valuable data not available in published sources. Although, an initial exploratory search of thesis papers was conducted, no studies were considered relevant to the research question.

2.4.2 Database searching

In conducting this SR, an extensive literature search was carried out. The electronic databases searched to identify high-quality evidence included CINAHL, Medline, Web of Science and Scopus. These databases were selected for their relevance to healthcare and extensive coverage of peer-reviewed literature. Ewald *et al.* (2022) suggests that searching at least two databases improves the depth of the review and reduces the likelihood of drawing inaccurate conclusions. Mathew (2024) concurs, noting the use of one or two databases increases the risk of bias by potentially overlooking relevant studies.

A comprehensive search begins with identifying the relevant search terms, including both controlled vocabulary (e.g., Medical Subject Headings [MeSH]) and free-text terms to capture all relevant literature (Aveyard, Payne and Preston, 2021). Following the identification of databases, keywords were selected using the PICo framework to ensure alignment with the research question and objectives (Aveyard, Payne and Preston, 2021), (Table 2.2 Search terms). Keywords and synonyms were combined using Boolean operators (AND, OR) to improve the sensitivity of database searches (Lefebvre *et al.,* 2025). Truncation was applied to capture alternative word endings (e.g., "adolescen*" to include "adolescents," and "adolescence") (Table 2.3 Search terms, Boolean operators and Truncation). Utilising Boolean operators and truncation broadens the search and ensures all key concepts are included (Macmillan *et al*., 2019).

Table 2.2: Search terms

Population	teen*, adolescen*, young adult*, youth, AYA*, teenage*, emerging adult*, TYA* cancer survivor*, oncology survivor*, teen* cancer survivor* adolescen* survivor* of cancer, post-treatment cancer patient*
Interest	experience*, perception*, perspective*, attitude*, view*, opinion*, satisfaction, preference*, lived experience*, qualitative
Context	follow-up clinic*, aftercare clinic*, survivorship clinic*, late effect* clinic*, transition clinic*, follow-up care, aftercare, survivorship care, long-term follow-up, late effect*, long-term effect*, late complication*

Table 2.3: Search terms, Boolean operators and Truncation

("teen*" OR "adolescen*" OR "young adult*" OR "youth" OR "AYA*" OR "teenage*" OR "emerging adult*" OR "TYA*")
AND
("cancer survivor*" OR "oncology survivor*" OR "teen* cancer survivor*" OR "adolescen* survivor* of cancer" OR "post-treatment cancer patient*")
AND
("late effect*" OR "long-term effect*" OR "late complication*" OR "survivorship")
AND
("follow-up clinic*" OR "aftercare clinic*" OR "survivorship clinic*" OR "late effect* clinic*" OR "transition clinic*" OR "follow-up care" OR "aftercare" OR "survivorship care" OR "long-term follow-up")
AND
("experience*" OR "perception*" OR "perspective*" OR "attitude*" OR "view*" OR "opinion*" OR "satisfaction" OR "preference*" OR "lived experience*" OR "qualitative")

Search limiters were applied to narrow the search to meet specific predefined criteria (Creswell and Creswell, 2018).

The search process was recorded in a word document to support organisation and transparency, logging the databases searched and results at each stage. Searches were saved, and email alerts were set up for newly published articles. This aligns with Bramer *et al*. (2018) who highlights that a well-documented search process enhances accountability and reproducibility. Titles and abstract were screened against the pre-defined inclusion and exclusion criteria. Duplicate records were removed manually. Potentially relevant studies were retrieved in full and assessed for eligibility.

2.5 Data Reduction and Analysis Methods

Initially (n=14) studies were retrieved for review. Backward citation searching was undertaken to ensure no relevant studies were missed during the initial database searches (Phillips, 2024). This process involves manually examining the reference lists of all included studies to identify additional papers that met the inclusion criteria but had not appeared in the database search results (Butler, Hall and Copnell, 2016). Backward citation searching resulted in the inclusion of an additional (n=5) studies to be reviewed via the Critical Appraisal Skills Programme (CASP, 2018).

The (n= 19) studies identified as relevant were critically appraised using the CASP qualitative checklist (CASP, 2018). Following appraisal (n=3) mixed

methods and (n=1) study focusing on paediatric patients were excluded. Resulting in (n=15) for inclusion within the SR. The CASP tool was selected due to its structured and transparent checklist to assessing credibility, relevance and rigour across a range of qualitative methodologies (CASP, 2018). It does this through a rigorous evaluation of the study aims, design, recruitment strategy, data collection methods, ethical considerations and analysis (Long *et al*., 2020) (Appendix I). During the decision to consider the most appropriate appraisal tool the JBI qualitative checklist was reviewed. Lockwood, Munn and Porritt (2015) highlight that the JBI qualitative checklist provides a detailed appraisal, with particular emphasis on consistency between research methodology, data collection, analysis and reported findings. However, Long *et al*. (2020) identifies that the CASP is one of the most widely used tools for assessing the quality of qualitative studies within health-related evidence syntheses. Given that this project is within the confines of healthcare, it was felt that the CASP appraisal tool would be the most appropriate design.

Appraisal tools used in quantitative research focus on measurement validity and reliability (Tang *et al*., 2025). In contrast, the CASP tool for qualitative analysis aligns with Lincoln and Guba's (1985) criteria for trustworthiness, which include credibility, transferability, dependability and confirmability. This enables a structured and robust critical evaluation of study quality and determine how applicable each study is to practice. This approach ensures that study findings are assessed based on their methodological strengths and limitations rather than through numerical measurement.

This appraisal process informed the synthesis of evidence by highlighting methodological quality of included studies. The studies methodological rigour was graded yes, no or can't tell (Appendix II). High-quality studies guided the interpretation of findings, while lower-quality studies were considered with caution (CASP, 2018). Following CASP critical appraisal (n=15) articles remained.

2.5 Data Synthesis

Following the appraisal of individual studies, a narrative synthesis was employed to analyse findings across studies. Lisa and Porritt (2016) identify that this method extends beyond describing or summarising the main features of the studies. They highlight that it supports comparison across studies, identification of relationships within the data and assessment of the overall strength of the evidence.

The process for narrative synthesis involves organising study characteristics and findings into tables and identifying patterns across studies to inform the findings of the SR (Aromataris *et al*., 2024). Narrative synthesis was chosen over meta-aggregation as the study aims to understand individual experiences, whereas meta-aggregation focuses on producing a new interpretation, model or theory of the qualitative findings (France *et al*., 2019). Narrative synthesis aligns with the interpretivist paradigm underpinning this review, supporting the synthesis of qualitative findings and facilitating an understanding of the subjective experiences reported by TYA and AYA cancer survivors. Yet a limitation acknowledged is that narrative

synthesis relies on the subjective interpretation of the reviewer, which may introduce bias and limit reproducibility (Holly, Salmond and Saimbert, 2021).

2.6 Ethical considerations

A SR does not involve direct participant contact. However, ethical responsibilities still need to be rigorous (Suri, 2020). Ethical issues are considered in relation to the core principles of ethics, including beneficence, non-maleficence, autonomy and justice (Varkey, 2020). In a SR, ethical considerations include accurate representation of studies, recognising their limitations, and avoiding bias (Prime, 2024). Integrity also requires verification of ethical approval and informed consent within included studies (Higgins *et al.,* 2022). Thus, avoiding the inclusion of research that could compromise participant wellbeing. Studies lacking clear approval were identified and treated with caution during synthesis.

This proposal was submitted for scientific review to the University School of Health Ethics Review Panel (SERP). The proposal was approved, and as this study is a SR, formal ethical approval was not required (Appendix III). In line with the NHS HRA Decision Tool (HRA, no date), this study does not require formal ethical approval from the Jersey Health Research Ethics Committee.

2.6.1 Reflexivity

Reflexivity is an important ethical consideration within qualitative research, requiring the researcher to recognise how their own background, beliefs and professional experience may influence the research process and interpretation of findings (Gerrish and Lathlean, 2015). Porritt *et al*. (2025) affirm that reflexivity involves consideration of personal, interpersonal, methodological and contextual factors. It requires a continuous critique of one's own subjectivity and background as a researcher and how this may influence the study (Olmos-Vega *et al.*, 2022). As a CNS working with TYA cancer survivors, it is acknowledged that there is potential for preconceptions that could influence the analysis of this review. To minimise personal bias and ensure transparency, key findings were extracted multiple times into Excel, and each study was appraised using CASP. Lincoln and Guba's (1985) framework supported my judgements to ensure credible and transparent interpretation.

2.7 Summary of chapter

This chapter has presented the project design and methods employed in conducting a robust systematic review following the PRISMA framework. The next chapter will present the literature search results, data extraction and the methodological rigour of included papers are critically explored. The findings are presented narratively into four themes that emerged.

Chapter 3: Findings

3.1 Introduction

This chapter presents the findings of this SR. The search process was guided and structured using the PRISMA framework as it provides a standardised approach enhancing the quality, reproducibility, and credibility of SR (Page *et al.*, 2021). The overall search process is illustrated through a PRISMA flow (Figure 3.1). Tabulated data extracted from the (n=15) included studies are presented. Additionally, the methodological rigour of these studies is critically discussed followed by a table representing the four identified themes and the narrative synthesis of the themes.

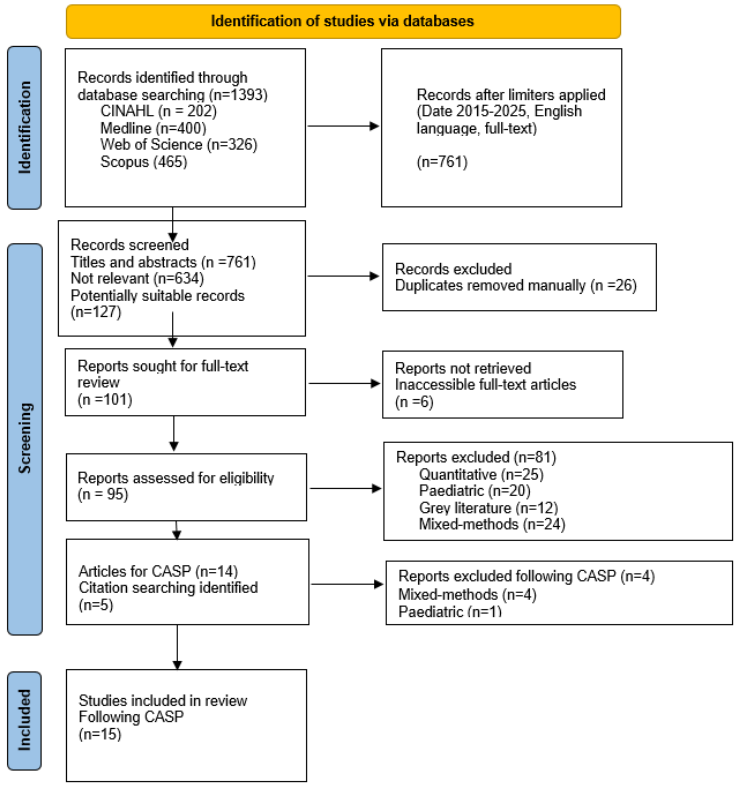

Figure 3.1 PRISMA Flow (Page *et al.*, 2021)

3.2 Data Extraction

As part of the meta-synthesis stage of this review, a data extraction table (Table 3.2) was utilised to organise and manage information from included studies. This table assisted in comparing study characteristics, identifying recurrent patterns and differences and highlighting gaps in the literature (Aromataris *et al*., 2024).

The following standardised data were extracted from each study:

- Author(s), year, country
- Study aim, design, sample size, ethical approval, consent
- Participant characteristics
- Setting
- Findings

The data extraction table supports transparency within the review and facilitates the narrative synthesis of findings across the included studies. Transparency and detailed record keeping are essential components of a rigorous SR ensuring that each stage is traceable and reproducible (Page *et al*., 2021). Although data extraction is typically carried out by two researchers to minimise errors and bias, this review was conducted by a single researcher. To mitigate potential bias the extraction process was structured and systematic with careful crosschecking of details to ensure accuracy (Centre for Reviews and Dissemination, 2008). Maintaining thorough documentation and transparency throughout the review process strengthens the credibility and dependability of the findings (Brackett and Batten, 2020). The CASP appraisal of included studies are presented in

appendix II, together with an example of a study appraised by CASP is included in appendix IV.

Table 3.2: Data extraction

Study (Author, title, year, country)	Aim/Research question	Methodology	Design	Participant selection	Ethical approval	Data analysis	Findings
Psihogios *et al*. (2019) Preferences for cancer survivorship care among adolescents and young adults who experienced healthcare transitions and their parents. USA single centre	To interpret experiences and preferences for survivorship care delivery among AYA childhood cancer survivors who experienced healthcare transitions	Qualitative	Cross-sectional, Focus groups	Purposive Hospital setting 14 AYA aged 15-29	Ethical approval Consent gained	Audio-taped Focus groups Professionally transcribed Direct content analysis	Challenges with care transitions Requirement for age-appropriate information and resources Improved communication between patients and HCPs
Brauer *et al*. (2019) Improving to where?": treatment-related health risks and perceptions of the future among adolescents and young adults after hematopoietic cell transplantation. USA Single centre	The impact of the cancer experience on sense of life potential and perception of the future from the perspectives of adolescents and young adults after hematopoietic cell transplantation	Qualitative Constructivist grounded theory	Telephone interviews and in-person	Purposive Hospital setting 18 AYA aged 15-29	Ethical approval Consent gained	Recorded interviews Transcribed verbatim	AYA oncology research is growing, however practice is still heavily informed by paediatric cancer data AYAs continue to experience long-term physical and psychosocial health issues

							Ongoing anxiety regarding future and late effects risks Need for SCP Requirement for coordinated holistic care
Ramsay *et al*. (2018) Follow-Up Care Provider Preferences of Adolescent and Young Adult Cancer Survivors. USA two sites	To explore the experiences and perspectives of AYA cancer survivors regarding patient–provider relationships and their preferences surrounding type of healthcare provider for follow-up care	Qualitative	Focus groups	Purposive Utah cancer registry 28 AYA aged 15-39	Ethical approval Consent gained	Recorded and transcribed discussions NVivo content analysis	AYA survivors value strong positive patient-provider relationships Strengthening relationships may improve adherence to follow-up care Improved relationships may contribute to improved long-term health outcomes Coordinated, holistic follow-up care models are recommended to support AYAs more effectively Structured transitions: use of

							SCP supports providers with clearer guidance and recommendations
Figueroa Gray *et al*. (2024) A Patient-Centered Conceptual Model of AYA Cancer Survivorship Care Informed by a Qualitative Interview Study USA one site with broad reach	Determine the holistic needs of AYA cancer survivors and develop a patient-centered conceptual model of AYA survivorship care.	Qualitative	Semi-structured telephone interviews	Purposive Recruitment through charity and via social media channels. 25 young adults Aged 15-39	Ethical approval Consent gained	Audio recorded and transcribed Thematic analysis Iterative code development	AYAs have distinct care needs compared to those of children and adults Patient-centered conceptual model of care essential Need for continuous coordinated holistic care Ongoing mental health support essential Peer support required Informational needs (fertility, finance, side-effects and late effects) to support own quality of life.
May *et al*. (2018) Adolescent and Young Adult Cancer Survivors' Experiences	Examine the experiences of diagnosis and treatment, and	Qualitative	Semi-structured	Purposive	Ethical approval	Nvivo coded interviews	Lack of information and unprepared to

of the Healthcare System: A Qualitative Study. Australia Multi-site	attitudes toward ongoing healthcare of AYA survivors of AYA cancer, to determine barriers to healthcare engagement in the early survivorship period		telephone interviews	Hospital setting 43 AYA Aged 15-25	Consent gained		navigate survivorship. More information required on late effects and long-term follow-up. AYAs generally report positive experiences with healthcare teams. Increasing awareness among AYA providers to improve long-term engagement.
Aagesen *et al*. (2024) Development of a rehabilitation programme for young adult cancer survivors using co-production. Denmark Multi-site	Aimed to co-produce and develop an age-specific, municipality-based cancer rehabilitation intervention programme to improve young adults' self-efficacy and health-related quality of life.	Qualitative	Co-production intervention development through workshops using Hawkins *et al*.'s framework.	Purposive Social media and rehabilitation programme recruitment. 26 young adults Aged 18-39	Ethical approval Consent gained	Iterative, interpretive analysis TIDieR checklist applied	Importance of peer support Tailored age-specific support Support with late effects Need for flexible individualised support addressing physical, psychosocial and social aspects of survivorship.

Smith *et al*. (2022) Perspectives of adolescent and young adult cancer survivors: review of community-based discussion boards USA	To assess AYA cancer survivors' concerns using postings from the American Cancer Society Cancer Survivors Network, an online, publicly available forum	Qualitative	Discussion forum postings using a previously published cancer survivorship framework	Purposive Secondary recruitment via online discussion board postings. 145 AYAs Aged 15-39 181 posts	No ethical approval or consent required	Data coded independently 10% double coded Reviewed by two researchers	Psychological concerns; coping difficulties, depression, emotional adjustment after cancer Community support and friendships, partners, peers Communication with HCP, care coordination
Vollmer Dahlke *et al*. (2017) Adolescent and Young Adult Cancer Survivorship Educational Programming: A Qualitative Evaluation. USA single site	To evaluate the outcomes of the After Cancer Care Ends, Survivorship Starts for Adolescent and Young Adults (ACCESS AYA) programming	Qualitative Constructivist	Survey Semi-structured telephone interviews	Purposive Access AYA programme and social media recruitment. 4 AYA Aged 15-39	Ethical approval Consent gained	Recorded interviews External contractor transcribed interviews Coding approach guided by Miles, Huberman and Saldana	The need for resources for AYAs and professionals Holistic care needs addressing psychosocial and physical needs. Tailored age-appropriate support for fertility, body image, cognitive effects, and late effects. Policy and programme

							improvements to support transitions from active treatment to community-based survivorship. SCP, age-appropriate information and tailored support. Recruitment challenges in AYA population.
Dorfman *et al*. (2022) Symptom Communication Preferences and Communication Barriers for Young Adult Cancer Survivors and Their Health Care Providers. USA Single centre	To understand young adult cancer survivors' and health care providers' preferences and barriers related to symptom communication after treatment.	Qualitative	Semi-structured telephone interviews	Purposive Hospital setting 21 young adults Aged 18-39	Ethical approval Consent gained	Audio-recorded interviews Transcribed verbatim Preliminary codebook Thematic analysis NVivo	Effective communication between young adults and providers is crucial for managing post-treatment concerns. Communication preferences varied between survivors and providers, which may hinder effective symptom discussions. Survivor barriers (discomfort, uncertainty,

							developmental factors). Communication interventions must reflect both survivor and provider preferences (developmentally appropriate).
Walsh *et al*. (2019) Shifting Needs and Preferences: Supporting Young Adult Cancer Patients During the Transition from Active Treatment to Survivorship Care. USA Single centre	To identify and explore the social support needs and preferences of young adult cancer patients during the transition process from active treatment to survivorship care.	Qualitative	Semi-structured interviews, in-person and telephone Longitudinal	Purposive Hospital setting 13 young adults Aged 17-25	Ethical approval Consent gained	Interviews transcribed Inductive coding Thematic analysis	HCPs to build trust early with patients Conversations relating to social interests, stressors and potential barriers to accessing supportive care services Provide clear age-appropriate supportive care resources to help manage medical and psychosocial challenges. Support care needs can change over time, timely, individualised and tailored supportive

							care to each young adult.
Murnane *et al*. (2025) Optimizing Support for Adolescent and Young Adult Cancer Survivors: Recommendations on Exercise, Nutrition, and Post-Treatment Care Needs from a Qualitative Study. Australia Multi-site	To understand how AYA cancer survivors interact with exercise and nutrition information and programs after treatment, to explore their experiences in accessing these supports, and to identify where they perceive gaps to be in their care	Qualitative	Semi-structured interviews via zoom	Purposive Recruited through youth cancer advisory board members, newsletters and social media 11 AYAs Aged 15-25	Ethical approval Consent gained	Inductive thematic analysis	Challenges faced by AYAs post treatment (physical and psychological). Access to resources/ limited services HCPs need more education to support AYAs. Need for personalised exercise and dietary support, these services unavailable. Financial barriers create a major obstacle to engaging in recommended supportive care or lifestyle programmes. To address these gaps; enhanced screening to identify needs, incorporation of support systems within healthcare teams and policy

							reforms to reduce financial burden
Collaço *et al*. (2025) Article SUPPORT MY WAY: Supporting Young People After Treatment for Cancer: What Is Needed, When This Is Needed and How This Can Be Best Delivered. UK Single Centre	To identify the support needs of teenagers and young adults aged 16–25 who had completed cancer treatment 1–6 years earlier, and secondly to create recommendations for future practice	Qualitative	Semi-structured interviews, co-design workshops, via telephone or teams	Purposive Hospital setting 24 TYAs Aged 16- 25	Ethical approval Consent gained	Thematic analysis Double coding	TYAs have diverse and complex support needs post-treatment that require flexible, personalised survivorship care approaches Support should be re-offered proactively at key life stages, needs change over time and readiness to access support Accessible communication Offer a range of support options allowing TYAs to choose what is right for them Fragmented care pathways and practical delivery challenges effects implementation for this support model

							Need for coordinated survivorship care Peer support Accessible support through community programmes, digital platforms and direct contact with HCPs
Hydeman *et al*. (2019) Survivorship Needs of Adolescent and Young Adult Cancer Survivors: A Concept Mapping Analysis. USA Single centre	Identify and understand the key challenges that AYA cancer survivors face after completing treatment	Qualitative	Focus groups using concept mapping design 27 AYA Aged 18-39	Purposive Identified through cancer registry and Hospital setting.	Ethical approval Consent gained	Concept global Max for analysis	AYAs have complex long lasting medical and psychosocial needs No AYA survivorship guidelines exist AYAs reported persistent late effects, psychosocial challenges and difficulties navigating follow-up care Younger AYAs- struggled with dependence, identity formation, disrupted life milestones

							Middle-age- financial concerns, insurance, employment. Older-financial and family planning. Psychosocial and relationship issues least addressed. Physical and cognitive late effects poorly addressed, unprepared to manage them. Gaps in communication Need for SCP Need for developmentally tailored survivorship
Ke *et al*. (2020) Optimizing Survivorship Care Services for Asian Adolescent and Young Adult Cancer Survivors:	Explore the perceptions of current and prospective survivorship services from both groups in Singapore to propose service	Qualitative	Focus groups	Convenience National cancer centre and Singapore cancer society, in-person and	Ethical approval Consent gained	Discussions audio-recorded Transcribed verbatim Deductive thematic	AYA survivors need personalised age-appropriate follow-up care Autonomy focusing on survivors'

A Qualitative Study. Singapore Single centre	design and delivery strategies			mail recruitment 23 AYA Aged 16-39		analysis in NVivo	motivation to engage in services Improvements in services e.g. support groups (peer support) Lack of information regarding services available Fears around disclosure of cancer and discrimination in new employment Information preferences and use of online platforms for centralised information Need for improved AYA outreach services for emotional support. Introduce a care navigator to guide AYAs through survivorship Training for HCPs

							Consolidate services to reduce fragmentation and improve accessibility
Aase, Ingebretsen and Hauken. (2022) "There Should Have Been a More Holistic Approach"—A Qualitative Study of Young Adult Cancer Survivors' Experiences of Follow-up After Cancer Treatment. Norway Nationwide	Explore how YACSs experience follow-up from the healthcare system after finishing cancer treatment	Qualitative Interpretive descriptive design	Face to face in depth semi-structured interviews longitudinal	Purposive Hospital setting 20 young adults Aged 18-39	Ethical approval Consent gained	Systematic text condensation (4 step descriptive design).	Young adults felt poorly prepared for transition from cancer patient to survivor Required a treatment summary and more information about late effects Lack of GP experience/ knowledge with Follow-up for AYAs Hospital follow-ups narrowly focused on cancer relapse not the broader survivorship challenges. Follow-up system fragmented Need for multidisciplinary follow-up to address

							multidimensional needs. Age specific SCP Coordinated care and communication between primary and specialist care required. Psychologists, cancer nurses and cancer coordinators should play a central role in supporting young adults.

3.3 Methodological rigour of the studies

The studies methodological quality was evaluated in relation to Lincoln and Guba's (1985) criteria for trustworthiness, credibility, dependability and confirmability. All studies were considered to be of high methodological quality. Several limitations appeared which are critically explored. Evaluating the risk of bias in included studies is vital to producing a trustworthy SR (Porritt, Gomersall and Lockwood, 2014).

The narrative synthesis presents the findings from (n=15) qualitative primary research studies exploring TYA/AYA cancer survivors experiences with late effects and survivorship clinics post-treatment. The studies were conducted across a wide range of countries; USA (n=9), followed by Australia (n=2), UK (n=1), Norway (n=1), Singapore (n=1) and Denmark (n=1). Most studies included were from the USA. The USA healthcare system varies widely from the UK, Europe, Singapore and Australia. While many patients within the USA rely on private insurance to cover healthcare costs, the UK operates under the NHS, which provides healthcare free at the point of use (Jacob, 2023). These organisational differences may limit the generalisability of findings between countries. Additionally, the SR failed to identify studies from low-income countries, further limiting transferability of findings.

Focus groups were used in four studies (Ramsay *et al*., 2018; Hydeman *et al*., 2019; Psihogios *et al*., 2019; Ke *et al*., 2020), these can facilitate open discussions, sharing of ideas and debate (Office for Health Improvement and Disparities, 2020). Though, participants may feel pressure to conform to the majority of the group, limiting sharing of

differing or less popular opinions (Khan and Abedin, 2022). Furthermore, focus groups rely on participants' attendance (Office for Health Improvement and Disparities, 2020). Hydeman *et al*. (2019) reports that despite four contributors committing to partake in one of the focus groups only one AYA survivor participated, consequently preventing interpretation of one of the groups' data.

Nine of the studies conducted semi-structured interviews either in-person, via telephone or on zoom (Vollmer-Dahlke *et al*., 2017; May *et al*; 2018; Brauer *et al*., 2019; Walsh *et al*., 2019; Aase, Ingebretsen and Hauken, 2022; Dorfman *et al*., 2022; Figueroa *et al*., 2024; Collaço *et al*., 2025; Murnane *et al*., 2025). Semi-structured interviews are perceived valuable in qualitative research, they enable researchers to obtain in-depth information from participants while maintaining enough flexibility to explore emerging topics or ask additional questions (Ruslin *et al*., 2022). Conversely, semi-structured interviews can introduce researcher bias, the interviewers' reactions, probing questions and interpretations can influence the data (Stevens, 2024). Furthermore, face-to-face interviews allow the researcher to observe non-verbal cues such as body language and emotional expressions and adopt their questions or responses accordingly (Gerrish and Lathlean, 2015). Nonetheless, they state that telephone interviews are more convenient for participants requiring less travel and minimal equipment. Given the challenges of engaging AYAs in research, telephone semi-structured interviews are likely the most suitable method for this survivor group (Vollmer Dahlke *et al*., 2017).

Co-production and co-design were utilised in (n=2) studies (Aagesen *et al*., 2024; Collaço *et al*., 2025). Involving participants as partners within the research process enables them to influence decisions, shape the direction of the study and ensures outcomes are relevant to their experiences and needs (UK Research and Innovation [UKRI], 2025). Although, this process requires significant time and investment, co-production can deliver more relevant and meaningful results (Mannell *et al*., 2023).

Smith *et al*'s. (2022a) study included online-discussion forums as its data source. The authors acknowledged several limitations including the limited demographic information available within posts and the small number of posts suggests that AYAs are engaging with other social media platforms. Moreover, those who choose to post online may have a stronger online presence. This reduces how well the sample reflects the broader population of AYAs limiting credibility and transferability of results.

Sample sizes ranged from small qualitative samples (n=4) to (n=145) online qualitative responses. The smallest sample was in the study by Vollmer Dahlke *et al*. (2017) with (n=4) AYAs. This study failed to reach data saturation and has potential of bias due to participants being self-selected. While small sample sizes can provide rich qualitative data, several studies failed to document if saturation was reached. Where

response rates were reported, they were generally low. Ramsay *et al*, (2018) only achieved a 44% participation rate, Collaço *et al*. (2025) reported a rate of 30.8% and Hydeman *et al*, (2019) reported an even lower rate of 11.8%. The low engagement rates may reflect the recognised challenges of recruiting AYAs into research (Smith *et al*., 2022a).

Participants were primarily AYA/TYA cancer survivors aged 15-39 years, although some studies included HCPs, parents, or advocates. This data was excluded on synthesis but are considered in the discussion chapter. Across studies, female participants were overrepresented compared to males, which may limit diverse perspectives. The majority of studies (n=9) (Vollmer Dahlke *et al*., 2017; Brauer *et al*., 2019; Hydeman *et al*., 2019; Psihogios *et al*., 2019; Walsh *et al*., 2019; Ke *et al*., 2020; Dorfman *et al*., 2022; Figueroa Gray *et al*., 2024; Collaço *et al*., 2025) were conducted within a single-centre which can present bias and further limit the transferability of findings. Bellomo, Warrillow and Reade (2009) highlights that single centre studies limit contextual diversity to support widespread changes in practice.

In reviewing the methodological quality in relation to reflexivity, several studies failed to discuss the relationship between the researcher and participant (Vollmer Dahlke *et al*., 2017; May *et al*., 2018; Ramsay *et al*; 2018; Hydeman *et al*., 2019; Psihogios *et al*., 2019; Aase, Ingebretsen and Hauken, 2022; Dorfman *et al*., 2022; Figueroa Gray *et al*., 2024). Vollmer Dahlke *et al.* (2017) and Aase, Ingebretsen and

Hauken. (2022) acknowledged that they had reflected on their prior understanding and were receptive to participants' responses, yet this was not explicitly demonstrated. Olmos-Vega *et al*. (2022) asserts reflexivity should be a continuous process to minimise bias. Three studies identified the researcher as an internal facilitator (e.g. oncology nurse or psychologist), which may introduce bias through prior relationships or professional background (Gerrish and Lathlean, 2015; Brauer *et al*., 2019; Aase, Ingebretsen and Hauken, 2022; Aagesen *et al*., 2024). May *et al*., (2018), Brauer *et al*., (2019) and Collaço *et al*., (2025) noted that participants were self-selected for recruitment via the nurse or doctor further introducing potential bias. Selected participants may be more engaged with healthcare and follow-up, limiting diverse responses from those lost to follow-up or less engaged (Howe *et al*., 2016).

Although several studies mentioned there were no prior relationships with participants, it is difficult to interpret whether prior knowledge or experiences with AYA care shaped the results and findings (Hydeman *et al*., 2019; Walsh *et al*., 2019; Ke *et al*., 2020; Smith *et al*., 2022a; Collaço *et al*., 2025). The study by Murnane *et al*. (2025) outlined their professional roles to those involved and used reflexive memos throughout their study to mitigate potential bias, highlighting transparency and methodological rigour. Ahmed (2024) identifies the use of reflexive journaling as a strategy for ensuring quality and enhancing confirmability in qualitative research.

Given the methodological limitations of the included studies, results should be interpreted with caution. Conversely, the studies included within this review provided rich narrative data on TYA/AYA survivor's experiences with survivorship and late effects care. Cresswell and Cresswell (2018) highlight that although limitations occur within studies, they can still provide valuable results.

3.4 Themes

There were four themes identified that are presented in table 3.3. A supporting table summarising the themes and the articles contributing to each theme is provided in Appendix V.

Table 3.3: Table of themes

Theme 1	**Theme 2**	**Theme 3**	**Theme 4**
Lack of knowledge, understanding and being prepared for late effects	**Barriers to accessing and engaging with survivorship care services**	**Holistic care needs in survivorship**	**Communication, coordination and transition of care**
Identified in eleven studies.	Identified in ten studies.	Identified in eight studies.	Identified in ten studies.

Theme 1: Lack of knowledge, understanding and being prepared for late effects.

A consistent finding across (n=12) of the included studies was that TYA/AYA cancer survivors often felt unprepared for the long-term consequences of their treatment. Survivors reported limited awareness of potential late effects, including physical, psychosocial and practical concerns. Aase, Ingebretsen and Hauken (2022) and Murnane *et al*. (2025) highlighted that some participants were unaware of which late effects they were susceptible to and expected to resume normality post-treatment. Similarly, Brauer *et al*. (2019) reported that many AYAs lacked clarity about survivorship and presumed their health would fully recover post haematopoietic cell transplantation without ongoing complications. May *et al*. (2018) reports comparable findings noting that some survivors lacked sufficient information about their treatment and its long-term effects, making post-treatment health management challenging. Psihogios *et al*. (2019) further highlighted that many survivors were unaware of their specific late effects risks and did not understand the purpose of long-term follow-up. While some AYAs were committed to short-term follow-up, several had no interest in long-term follow-up as it meant their lives were defined by cancer. A participant that failed to engage in long-term follow-up expressed "*I somehow got this in my head that once I get into remission, I'll be immune from cancer forever. I don't know where I got that idea, but I never asked anyone about it"* (Psihogios *et al*., 2019).

Survivors reported gaps in education among themselves and HCPs. Many described uncertainties regarding who was responsible for monitoring late effects and lacked confidence in primary care providers

awareness of AYA specific follow-up needs. Ramsay *et al*. (2018) found that survivors often preferred oncologist-led follow-up, rather than general practitioners (GP) due to concerns about GPs' knowledge or interest in late effects and surveillance for secondary cancers. Experiences were similarly reported by Aase, Ingebretsen and Hauken. (2022) where survivors felt their late effects were dismissed or attributed to psychological causes, contributing to frustration and feelings of being a burden to their GP. The absence of structured survivorship education and planning intensified these challenges, with multiple studies reporting limited awareness or not receiving a SCP at all (Vollmer Dahlke *et al*., 2017; Hydeman *et al*., 2019; Aase, Ingebretsen and Hauken, 2022). SCPs were identified as a valuable tool for improving understanding of late effects and follow-up expectations.

Information was frequently described as insufficient or not developmentally appropriate, predominantly in relation to fertility and long-term health. Smith *et al*. (2022a) and Figueroa Gray *et al*. (2024) found that survivors felt unprepared and uninformed to manage fertility related late effects and broader survivorship issues including health promotion, disease prevention and surveillance for recurrence or secondary malignancies. Age-appropriate communication and resources were considered essential, as adult-focused services and support groups did not meet AYA needs. Digital tools and platforms including MyChart and other apps were identified as convenient ways to deliver education, track symptoms and provide reassurance, improving access to survivorship information (Vollmer Dahlke *et al*., 2017; Dorfman *et al*., 2022; Murnane *et al*., 2025). These findings highlight educational gaps

at survivor, HCP and organisational levels, directly affecting TYA/AYA's ability to understand, anticipate and manage late effects.

Theme 2: Barriers to accessing and engaging with survivorship care services

Barriers to access and engagement with survivorship services for TYA/AYA cancer survivors were frequently cited across studies. Psychosocial and emotional barriers were a common theme for disengagement with survivorship and follow-up services post-treatment. Psihogios *et al*. (2019) reported that fear and uncertainty regarding future health, fear of cancer recurrence and late effects were persistent among AYAs post-treatment. It was also noted while some survivors recognise the importance of long-term follow-up, others wanted to distance themselves from cancer, leading to disengagement with ongoing care. Others reported that their health-related anxiety was the key reason for discontinuing with follow-up. Similar findings were reported by Figueroa Gray *et al*. (2024), where all participants experienced mental health challenges including depression, anxiety, loss of control and isolation. Aase, Ingebretsen and Hauken (2022) described a lonely and unsupported transition to survivorship, with one participant stating they felt *"feeling abandoned and alone".*

Practical and operational challenges were highlighted as a barrier to accessing survivorship care. AYA cancer survivors experienced challenges related to education, employment, relocation and competing

life demands such as attending college or managing busy school and work schedules, which limited their ability to attend follow-up appointments or survivorship programmes (Psihogios *et al*., 2019; Ke *et al*., 2020). Financial burden was a recurring obstacle across studies conducted within the USA. Survivors described lack of insurance, mounting debt and the cost of attending community-based or supportive services as unaffordable, despite perceiving these services as beneficial (Vollmer Dahlke *et al*., 2017; Figueroa Gray *et al*., 2024). Figueroa Gray *et al*. (2024) found that challenges related to returning to work, taking time off for medical appointments, further limited participation in survivorship care.

Barriers related to availability of services was also frequently reported. Survivors described challenges understanding how to access follow-up care and navigating fragmented healthcare systems (Hydeman *et al*., 2019; Ke *et al*., 2020). Absence of knowledge on available late effects and survivorship services beyond the cancer centre was identified as well as inadequate information, unorganised arrangements and non-existence of promotion of these services (Ke *et al*., 2020). Limited availability of age-appropriate services restricted access. Aagesen *et al*. (2024) reported that young adult specific cancer rehabilitation services in Denmark were scarce, with only a small number of municipalities and hospital physiotherapy or occupational therapy units offering tailored provision. Conversely, a study by Vollmer Dahlke *et al*. (2017) reported that those with access to a specialised AYA programme (after cancer care ends survivorship starts [ACCESS]), survivors had an improved

understanding of survivorship care, late effects and healthy lifestyle behaviours, highlighting disparities in access to supportive services.

Lastly, personal barriers within healthcare influenced engagement with survivorship services. Ramsay *et al*. (2018) found that survivors who had a negative relationship with their healthcare provider desired to change providers or failed to attend follow-up appointments. Ramsay *et al*. (2018) and Collaço *et al*. (2025) both report the need for continuity of care in survivorship and care oversight from professionals familiar with their cancer history rather than reliance on their GP.

Theme 3: Holistic care needs in survivorship

TYA/AYA survivors conveyed the need for holistic, multi-professional care in survivorship that extended beyond disease surveillance and addressed the physical, psychosocial and practical aspects of life post-treatment. A wide range of physical late effects were reported including fatigue, pain, dermatological, musculoskeletal symptoms, body image concerns and reduced exercise tolerance (Walsh *et al*., 2019; Smith *et al*., 2022a). These effects persisted long after treatment and were closely linked to psychosocial, emotional and functional difficulties affecting survivors' daily lives and overall wellbeing.

Psychosocial needs were a focal component of holistic care. Survivors reported ongoing anxiety, depression, identity disruption and difficulties

with social reintegration, relationships and returning to education and employment (Hydeman *et al*., 2019; Walsh *et al*., 2019; Figueroa Gray *et al*., 2024). Psihogios *et al*. (2019) and Figueroa Gray *et al*. (2024) found that mental health support was described as insufficient or inaccessible despite being perceived as one of the most pressing unmet needs during survivorship. Highlighting that survivorship care focused primarily on cancer surveillance and failed to adequately address emotional wellbeing, coping and quality of life.

Peer support was emphasised as a key element of holistic survivorship care. Survivors valued opportunities to connect with others of a similar age who had a shared cancer experience. They described peer support as beneficial for reducing isolation, normalising late effects and supporting identity restoration during survivorship. Whilst general adult support groups were recognised as being developmentally inappropriate for this cohort of patients (Hydeman *et al*., 2019; Figueroa Gray *et al*., 2024). Collaço *et al*. (2025) reports that TYAs favoured peer support over counselling, though peer support was often accessed several months post-treatment dependant on life stage. Whereas Ke *et al*. (2020) found that AYAs preferred peer support early into survivorship, therefore, reinforcing the importance of age specific care and peer support integrated within survivorship models of care.

Further holistic needs challenges related to practical and lifestyle needs were frequently cited. AYA/TYA survivors stressed issues around fertility, health promotion, disease prevention and long-term self-

management of health risks, financial stressors and disruption of employment (Vollmer Dahlke *et al*., 2017; Smith *et al*., 2022a; Figueroa Gray *et al*., 2024). Vollmer Dahlke *et al*. (2017) emphasises an effective holistic care model through there ACCESS AYA programme, with one participant quoting "*it wasn't all based on the illness or the complications . . . it was based on having fun, being normal and moving on".* These findings underline the importance of having a tailored age-appropriate holistic survivorship service that supports TYA/AYAs with the physical, psychosocial and practical needs post-treatment.

Theme 4: Communication, coordination and transition of care

Survivorship care was described as fragmented, poorly coordinated and difficult to navigate. This was a prevalent theme in relation to transitions from active treatment to follow-up care and from specialist-led oncology care to primary or community-based services. AYA survivors reported uncertainty regarding who was responsible for their ongoing care, how follow-up should be organised and where to seek support for any ongoing concerns (Vollmer Dahlke *et al*., 2017; May *et al*., 2018; Aase, Ingebretsen and Hauken, 2022; Murnane *et al*., 2025). Contributing to feelings of insecurity, uncertainty and abandonment following treatment.

Another common concern identified was the breakdown in communication. Survivors reported not being spoken to directly by HCPs, inconsistent or absent SCPs, limited information and guidance

regarding late effects and follow-up schedules or lack of available services (May *et al*., 2018; Psihogios *et al*., 2019). AYAs reported a lack of continuity of care including frequent changes in hospital clinicians and a lack of handover between oncology teams and GPs. This resulted in survivors having to continually repeat their cancer history, leading to frustration, emotional distress and reluctance to disclose ongoing challenges (Ramsay *et al*., 2018; Aase, Ingebretsen and Hauken, 2022; Collaço *et al*., 2025).

Transitions in care were described as challenging, this included transition from paediatric to adult services and from oncology-led follow-up to GP or primary care physicians (PCP). Though some survivors understood that these transitions were inevitable, several felt unprepared and unsupported expressing fear about losing providers they trusted and concerns regarding PCP knowledge of late effects and cancer specific follow-up (Ramsay *et al*., 2018; Psihogios *et al*., 2019; Walsh *et al*., 2019; Aase, Ingebretsen and Hauken, 2022). Nevertheless, Ramsay *et al*. (2018) and Murnane *et al*. (2025) found that some survivors experienced positive transitions, emphasising the importance of trust, clear role definition and continued involvement of oncology teams during handover to other providers.

Young adult survivors identified digital communication and coordinated models of care as potential facilitators for improving survivorship services. Survivors expressed a preference for age-appropriate, flexible communication methods such as text messaging, WhatsApp messaging,

mobile apps, patient portals and online SCPs. They found these tools accessible and useful for supporting self-monitoring, timely information sharing, and ongoing connection with healthcare providers between appointments (Vollmer Dahlke *et al*., 2017; Psihogios *et al*., 2019; Collaço *et al*., 2025).

In the study carried out by Vollmer Dahlke *et al*. (2017), AYA survivors valued an educational programme that supported navigation of life post-treatment and increased their understanding of survivorship care. Similarly, Aagesen *et al*. (2024) described the implementation of an interdisciplinary, educational rehabilitation programme in Denmark, they found survivors had an improved their understanding of survivorship and late effects. Yet access to such coordinated and developmentally appropriate services remained inconsistent and inequitable (Ke *et al*., 2020).

A final suggestion emphasised the need for centralised platforms to provide young survivors with up-to-date, relevant and reliable information on survivorship and late effects (Ke *et al*., 2020). Additionally, they accentuated the role of a care navigator as vital to support AYAs through transitions post-treatment, ensuring access to appropriate services and facilitating communication across providers. TYAs also valued the support of the youth support coordinators, who provided practical assistance such as financial guidance and access to recreational activities (Collaço *et al*., 2025). These findings stress that improving communication, coordination, and structured transition

pathways are essential to meet the multidimensional needs of TYA/AYA cancer survivors during post-treatment survivorship.

3.5 Summary of chapter

Across the (n=15) included studies TYA/AYA cancer survivors reported various challenges related to insufficient knowledge of late effects, barriers to accessing survivorship services, unmet holistic care needs and fragmented communication and care-coordination. The experiences of TYA/AYA survivors were shaped by the physical, psychosocial and practical challenges faced accentuating the multidimensional nature of survivorship. Several needs were identified including peer support, digital communication, educational programmes and care navigators. Though, access was often inconsistent and inequitable. While no studies specifically discussed survivorship and late effects clinics, these findings provide a rich understanding of post-treatment survivorship experience. These findings will inform the subsequent discussion of implications for practice, service delivery and policy.

Chapter 4: Discussion

4.1 Introduction

This chapter will draw together key findings from the SR and explore the wider literature in relation to these findings. The results identified persistent gaps in meeting the multidimensional needs of AYA/TYA survivors, fragmented survivorship services and issues with the delivery and structure of survivorship services. Therefore, implicating engagement with late effects follow-up, survivorship care, wellbeing and long-term health. The discussion explores study strengths and limitations, reflects on the findings in relation to advanced practice and provides recommendations for future research.

4.2 Discussion of themes

The review demonstrates that lack of knowledge and preparedness for late effects remains a significant challenge for TYA/AYA cancer survivors. Survivors lacked clarity of their individual late effects risks, the purpose and expectations of long-term follow-up and assumed treatment completion marked a return to normal health (Aase, Ingebretsen and Hauken 2022; Murnane *et al*., 2025). These gaps were linked to disengagement with follow-up care and difficulties managing psychosocial and practical aspects of survivorship (Psihogios *et al*., 2019). These findings coincide with the wider literature identifying poor late effects awareness as a key barrier to effective self-management and continued engagement with survivorship care (Barnett *et al* 2016; Law *et al*., 2023; Smith, Critoph and Hatcher. 2023).

Lea *et al*. (2020) and Smith *et al*. (2025b) identified gaps in survivorship education, particularly around its timing, repetition, and developmental appropriateness. Survivors and families regularly felt they were hearing about late effects for the first time at the end of treatment, although information was provided earlier in the disease trajectory. This correlates with findings produced by Figueroa Gray *et al*. (2024) and Smith *et al*. (2022a). Gianinazzi *et al*. (2022) highlight that long-term follow-up is essential as the cancer treatments place survivors at increased risk of morbidity and early mortality. They argue that empowering survivors with knowledge of their medical history and potential late effects supports healthier behaviours, informed lifestyle choices and improved engagement with follow-up care. Likewise, Carpenter *et al*. (2025) reports that engaging families and providing early actionable late effects information allowed adolescents and families to manage their health post-treatment. Despite these recommendations the findings from this review and the wider literature shows that many AYAs remain unaware of their personal risks and lack understanding of the purpose and structure of follow-up care.

AYAs and TYAs reported limited confidence in the GPs understanding of late effects and follow-up care needs. Most studies highlighted that TYAs and AYAs opted for follow-up support and late effects information directly from their oncologist or CNS who they perceived as more knowledgeable. A study conducted in Switzerland by Christen *et al*. (2016) revealed similar findings to this review reporting that AYA

survivors prefer to continue follow-up with their oncologist that managed their care throughout treatment. Conversely, Murnane *et al*. (2018) was the only study within the review where both AYAs and HCPs reported the critical role that GPs play in managing long-term health outcomes in AYA cancer survivors. Placing the GP as the most appropriate to manage the late effects post-treatment. Lea *et al*. (2020) report that follow-up for young cancer survivors should be conducted by an HCP who had a relationship with the patient during treatment, however not justifying whether which specific HCP. Nevertheless, Aase, Ingebretsen and Hauken. (2022) reported that some GPs admit their lack of awareness and knowledge of late effects leaving young adult cancer survivors feeling lonely and uncertain. Additionally, Vollmer Dahlke *et al*. (2017) reported that HCPs found AYA care complex and required more education to support this population.

The European Society for Medical Oncology (ESMO) recommends targeted training to enhance HCPs competence in AYA oncology. They recommend specific focus on provider-patient communication, psychosocial care and cognitive behavioural therapy (CBT) to address anxiety related to cancer recurrence (Košir *et al*., 2025). To address this, the AYA Zorgnetwork (2026) in the Netherlands introduced mandatory E-learning modules for all nurses involved in the care of AYAs to ensure consistent, age-appropriate support. However, one study within the review provided AYA survivorship education for HCPs, the uptake was minimal with clinicians and nurses expressing concerns regarding lack of time to complete these online modules (Vollmer Dahlke *et al*., 2017). Thus, the inclusion of an AYA-specific module, as

recommended at the ESMO and The European Society for Paediatric Oncology (SIOPE) congress, within all medical curricula is essential to ensure that clinicians across multiple disciplines are equipped to meet the unique needs of this population (Ferrari *et al*., 2021; Košir *et al*., 2025). Lastly, this review underlines disparities worldwide in education provision for AYA oncology. The introduction of education and training can increase competence, reduce variation in practice, and equip HCPs to deliver comprehensive, age-appropriate care.

AYA and TYA survivors reported that the late effects information they received was inadequate or not developmentally appropriate in relation to fertility, health promotion, disease prevention and surveillance for recurrence or secondary malignancies (Smith *et al*., 2022a; Figueroa Gray *et al*., 2024). SCPs were valued by AYAs and TYAs for providing individualised, age-appropriate information on potential late effects, health promotion and follow-up schedules. However, several AYAs were either unaware of SCPs or had never received one (Vollmer Dahlke *et al*., 2017; Hydeman *et al*., 2019; Aase, Ingebretsen and Hauken, 2022). The wider literature reflects the findings of this review emphasising that only between 20% and 40% of young adult cancer survivors received an SCP (Berg *et al*., 2016). Similarly, Shay, Parsons and Vernon (2017) reported that only 30% of AYA survivors received a SCP. This study sample was relatively large with (n=1395) participants, stressing the persistent gap in information and guidance provided to this population. Furthermore, Baird *et al*. (2019) and Law *et al*. (2023) identified the absence of SCP as a significant unmet informational need.

Several barriers to implementation of SCPs were reported by HCPs on a national and international level including lack of time, limited resources and IT limitations (Beaupin *et al*., 2018; Baird *et al*., 2019). Despite clear recommendations from the National Institute of Clinical Excellence (NICE), Children's Oncology Group (COG), NHS England and ESMO guidelines (NICE, 2014; COG, 2023; NHS England, 2023; Košir *et al*., 2025) that all children and young adult cancer survivors should be issued a SCP, this review and wider literature shows that several AYAs and TYAs remain without an SCP. Improvements in SCP provision for all TYAs and AYAs could further support self-management of late effects and navigation into survivorship care. Additionally, it would support GPs and PCPs in effectively managing late effects and long-term follow-up care.

Fear of recurrence, anxiety related to future health and desire to distance oneself from the cancer were commonly reported reasons for disengagement (Psihogios *et al*., 2019). These findings align with the broader literature, which stresses the scepticism in relation to follow-up care, fear of cancer recurrence and anxiety related to returning to hospital as a common barrier for disengagement (Berg *et al*., 2016; Smits-Seemann *et al*., 2017; Smith, Critoph and Hatcher., 2020; Beauchemin *et al*., 2025). The SR conducted by Smith, Critoph and Hatcher (2020) also highlighted that AYAs felt discouraged by HCPs to attend follow-up or encountered ambiguity in follow-up discussions. Lea *et al*. (2020) recommended that all HCPs should be providing

information on a regular basis throughout treatment in relation to follow-up, potentially reducing anxiety and support improved engagement with follow-up services.

Opposing life demands, financial difficulties, availability of services and relationships with the HCPs was identified as additional barriers to survivorship care (Ke *et al*., 2020; Figueroa Gray *et al*., 2024; Murnane *et al*., 2025). This is echoed in the wider literature where Smith, Critoph and Hatcher, (2020) identified employment, family and childcare commitments as barriers to engaging with follow-up care. Beauchemin *et al.* (2025) further identified travel and geographical location of survivorship care as a constraint to accessing survivorship services despite nearly 50% of participants continuing with survivorship care.

Financial barriers were a commonly reported barrier to survivorship care in the studies carried out in the USA (Vollmer Dahlke *et al*., 2017; Figueroa Gray *et al*., 2024). This is attributed to lack of health insurance or insurance not covering survivorship care, contributing to insurance debts (Kaul *et al*., 2017; Beaupin *et al*., 2018; Schmidt *et al*., 2018; Casillas *et al*., 2022; Beauchemin *et al*., 2025). Similarly, Berg *et al*. (2016) affirms that financial barriers related to health insurance costs are challenging, especially when young adults lose coverage under their parent's insurance plans. These financial pressures contribute to disengagement from survivorship and follow-up late effects care. The Affordable Care Act (ACA) was passed in 2010 this service aimed to bridge some of these financial challenges and ensured that young adults

could remain on their parents' insurance plan until they turned 26 (Blood Cancer United, 2025). Nonetheless, those aged between 26 and 39 still requiring survivorship care may face financial difficulty in relation to insurance costs (Kaddas *et al*., 2020). Highlighting the need for further additional support and information in relation to healthcare insurance coverage post the age of 25, thus encouraging survivors to engage in recommended follow-up care.

The absence of services available for AYA survivors was endorsed within the wider literature as fragmented and inconsistent. It was reported that AYAs are unsure whom to contact following treatment, how to access support and lacked clear recommendations from HCPs regarding late effects and follow-up care (Smits-Seemann *et al*., 2017; Beaupin *et al* 2018; Lea *et al*., 2020; Fitch *et al*., 2021; Law *et al*., 2023; Camp *et al*., 2023). Smith, Critoph and Hatcher. (2020) reported that services available were adult-orientated and not developmentally appropriate for AYAs. Beaupin *et al*. (2018) reported that although survivorship services were available 30% of patients did not receive ongoing care from either their oncologist or PCP and were lost to survivorship follow-up. Similarly, Berg *et al*. (2016) reported that only 46% of participants attended a survivorship clinic. Conversely Vollmer Dahlke *et al.* (2017) reported positive outcomes for those that had access to a specialised AYA programme (ACCESS AYA). This programme received charitable funding bridging the financial barriers and enabling all AYAs in Texas access to the programme (Hamilton, 2012), reflecting the need for more equitable access to survivorship services.

This review recognised the need for holistic multi-professional survivorship care that extended beyond surveillance for recurrence (Walsh *et al*., 2019). Survivors emphasised the need for services addressing their physical, psychosocial and practical aspects of life post treatment (Walsh *et al*., 2019; Smith *et al*., 2022a). This was asserted by Law *et al*. (2023) and Košir et al. (2025) underlining holistic care as essential to support AYAs facing multidimensional challenges post treatment. The national cancer plan for England has recognised the inconsistency in provision and committed to standardising the delivery of psychological support as part of a patient's follow-up (Department of Health and Social Care and NHS England, 2026). Despite recommendations from NHS England (2023) that all TYAs should have access to psychological support post treatment, this remains inconsistent

Peer support was identified as an effective mechanism for addressing holistic care needs, reducing isolation, supporting regaining identity and normalising late effects (Hydeman *et al*., 2019; Figueroa Gray *et al*., 2024). These findings were reiterated by Barnett *et al*. (2016) who reported improvement with self-advocacy, wellbeing and long-term health as a result of peer engagement. Carpenter *et al*. (2025) also found that connections with other survivors supported participants understanding of late effects and helped them to prepare for potential late effects. Specialised AYA programmes were identified as a way of delivering holistic survivorship care and connecting young people with

others who share similar experiences (Vollmer Dahlke et al., 2017; Aagesen *et al*., 2024). Furthermore, the Princess Margaret AYA programme in Canada was deemed an effective model in delivering holistic survivorship care; this programme addressed both medical and psychosocial issues including fertility, sexual health, diet and return to employment, while also supporting young people to build peer networks (Mitchell *et al*., 2018).

The findings from the SR identifies significant unmet holistic care needs and highlight the absence of effective survivorship models to address them. Košir et al. (2025) concur that holistic supportive care for AYA survivors remains inconsistent across countries, resulting in the exclusion of vital resources such as psychological support, financial guidance and fertility support. Lea *et al*. (2020) proposed that all young people have a standardised holistic needs assessment completed at the end of treatment. This would enable HCPs to identify any psychosocial challenges the young person is facing and provide support in a well-timed manner. Still, the findings from this study reveals this is not routine practice in AYA cancer care.

Communication, coordination and transition of care were the final theme derived from the review. AYA survivors narrated they were unsure who was responsible for their follow-up care and ongoing concerns, that information on late effects and survivorship was not communicated effectively, and SCPs were absent or inconsistent (May *et al*., 2018; Aase, Ingebretsen and Hauken. 2022). Lea *et al*. (2020) supports this,

stating AYAs found post treatment challenging, and were unaware whom to contact should they require support or information. Absence of information received regarding late effects is highlighted consistently within the broader literature (Smits-Seemann *et al*., 2017; Gianinazzi *et al*., 2022). PanCare (2024) and Košir *et al*. (2025) recommend the use of SCP, which provides information regarding possible late effects and HCP contact information for any concerns. Therefore, improving the provision of information for AYA cancer survivors.

AYAs reported lack of continuity of care in survivorship with frequent changes between hospital physicians and lack of handover between oncology teams and GPs (Ramsay *et al*., 2018; Collaço *et al*., 2025). This aligns with findings described across the wider literature (Kaul *et al*., 2017; Beaupin *et al*., 2018; Camp *et al*., 2023). Smith *et al*. (2025b) calls the attention to the need for improved communication between oncologist and PCP to enhance follow-up care. On the other hand, Stamer *et al.* (2024) states an effective method of follow-up via eHealth where patients experienced continuity of care from their usual trusted provider, this approach was deemed more accessible and enhanced health knowledge and confidence in managing their own care.

Transitions of care either from paediatric to adult services and from active treatment to GP or PCP were described as challenging for AYA survivors (Psihogios *et al*., 2019; Aase, Ingebretsen and Hauken, 2022). Beauchemin *et al*. (2022) similarly reported that transitioning from paediatric to adult services affected engagement with survivorship due

to lack of trust in new provider. They also reported that engagement with services was affected if patients were transitioned to PCP instead of a specific survivorship programme. A SR by De Beijer *et al*. (2025) found that survivors perceived their transition from paediatric to adult services poor or difficult. Berg *et al*. (2016) highlighted loss of continuity of care as a key issue during transition from paediatric to adult services. Conversely, two studies highlighted positive experiences with transition (Ramsay *et al*., 2018; Murnane *et al*., 2025), the findings identified alongside the wider literature recognises inconsistencies and poor coordination in transition pathways. Košir *et al*. (2025) stresses the importance of clear referral pathways and transition policies across paediatric, AYA and adult services to improve coordination and patient experience.

Digital communication was identified as a facilitator to enhance coordinated care within survivorship services (Collaço *et al*., 2025). This is corroborated by Berg *et al*. (2016) who draws the attention to the use of technology to send reminders for appointments, potentially supporting and driving engagement with survivorship services. Barnett *et al*. (2016) noted that survivors place high importance on digital tools, providing flexibility and ease of access to communicate with HCPs. Košir *et al*. (2025) and NCI (2025b) has supported the use of digital tools and platforms as a means of providing remote patient support, improving patient engagement and continuity of care.

A further facilitator to improve survivorship and late effects care was a centralised platform providing reliable up-to-date information, and the introduction of a care navigator role to facilitate coordinated transitions and support continuity of care (Ke *et al*., 2020). ESMO guidelines recommend the use of a centralised national knowledge hub providing consistent, evidence-based information that meets the unique needs of AYA survivors. ESMO guidelines also propose the use of artificial intelligence tools, which can support with health literacy (Košir et al., 2025).

The nurse navigator role was implemented in Texas to support patients transitioning into survivorship, they provide a SCP, treatment summary and support coordinated care between specialists (Hamilton, 2012). This project has identified that a care navigator role is not routinely embedded across services. Kosir et al. (2025) recommend the provision of a dedicated care coordinator across services, supporting continuity of care and ensuring equitable access to psychosocial care. Therefore, improving long-term health and quality of life.

4.3 Reflections on the role of advanced practitioner

Within my professional role the findings from this review provides valuable insights into TYA/AYA cancer survivor's experiences post-treatment. While, included studies did not refer specifically to late effects clinics or survivorship clinics, gaps in coordinated follow-up, psychosocial support and structured pathways were highlighted as being

fragmented or insufficient. This review underscores the need to implement national policy and evidence-based guidelines to ensure consistent, standardised survivorship and late effects care. Following this SR, and with approval from hospital governance, I plan to collect verbal feedback and patient satisfaction data to assess the current available services for TYAs. In the long term, a primary research project may be undertaken to further understand the needs of this population in relation to survivorship and late effects services.

4.4 Strengths

Several strengths to this project were identified, firstly this is the first SR to explore AYA and TYA cancer survivors' experiences of late effects and survivorship clinics post treatment. The results from a qualitative SR can provide valuable insights into patient experiences to inform policy and the development of clinical guidelines (Munn *et al*., 2018). Finally, SRs can identify gaps in the literature, therefore informing future primary research.

4.5 Limitations

From my professional experience working closely with TYAs with cancer, my observations of the importance of survivorship and late-effects services may have influenced the selection of studies for this SR. Conducting this SR independently potentially could have introduced bias in the selection of studies and data extraction. Involving a second

researcher would have supported crosschecking and helped keep bias to a minimum.

Time constraints, including completing the review within six months whilst being employed full time, limited a more comprehensive database search potentially omitting additional relevant studies.

This SR has produced valuable insights into the holistic needs of TYA and AYA survivors. However, for future research a primary study may yield valuable results determining the need for AYA survivorship care and late-effects services.

4.6 Summary of chapter

This chapter recognised key findings from the four themes that emerged in relation to the wider literature base. The results from this SR and broader literature acknowledged the inconsistency of survivorship care and information provision for late effects. AYA and TYA survivors' value holistic follow-up care that extends beyond surveillance for recurrence, focusing more on their psychosocial wellbeing. SCPs were identified to increase information provision for AYAs supporting self-management of late effects and navigation into survivorship follow-up. Despite clinical guidelines recommending that all AYAs should receive an SCP, this remains inconsistent. Multiple hindrances impeding access and engagement to survivorship services were recognised including competing responsibilities, availability of services and financial difficulties. AYAs and TYAs identified an absence of coordinated care and desired smother transitions from either paediatric to adult services or

from active treatment to survivorship services. Ultimately, they advocated the need for peer support and connecting with other survivors. These themes and findings from the SR are evident within the broader literature, focusing the need of coordinated, age-appropriate survivorship services to monitor for late effects and provide holistic follow-up care. The next chapter will provide key findings, recommendations for future research and conclude this SR.

Chapter 5: Conclusion and Recommendations

5.1 Summary of Key findings

Four key themes emerged from the (n=15) included studies; lack of knowledge, understanding and being prepared for late effects, barriers to accessing and engaging with survivorship care services, holistic care needs in survivorship and communication, coordination and transition of care. The findings highlight that TYA and AYAs have multidimensional needs that extends beyond surveillance for recurrence.

This review acknowledged that many survivors felt insufficiently prepared for late effects as a consequence of their cancer treatment. Limited information received on late effects elevated uncertainties in progressing to follow-up care. Furthermore, survivorship education was inconsistent which contributed to challenges in navigating post treatment healthcare and late effects health risks. Additionally, psychosocial, practical and organisational barriers affected engagement with survivorship services, including fear of recurrence, competing life responsibilities, financial burden and the lack of availability of age-appropriate services.

This SR highlighted the importance of holistic, developmentally appropriate survivorship care that addressed the physical, psychological and social needs of TYAs and AYAs. Vital for this care was peer support, specialised survivorship programmes and multidisciplinary services that

are equipped to deliver care and education relevant to their life stage including fertility, employment and identity formation.

Fragmented communication between HCPs and poorly coordinated transitions between oncology, primary care and community services were a key challenge. Survivors described uncertainty regarding who was responsible for follow-up care and reported feeling unsupported during the transition from active treatment to survivorship. The findings indicate that improving communication, coordination and structured pathways for transition is essential to improve continuity of care for this population group.

5.2 Recommendations

There is a clear need to strengthen the training, education and awareness of all HCPs supporting AYAs and TYAs. Increasing HCP knowledge of survivorship and late effects will ensure young people are supported as they transition post-treatment. Engagement in education can be promoted through in-house training, weekly education sessions and adding an AYA specific module to the medical curricula.

The publication of this SR could encourage other researchers to build upon this work by expanding the search to include additional databases. This review could also support engagement in conducting further SRs on the gaps identified within this review. Additionally, the dissemination of the findings from this SR could be presented at conferences both locally

and nationally to raise awareness of TYAs and AYAs survivorship and late effects needs.

The SR has acknowledged the need for further primary research into the experiences of follow-up care for AYAs and TYAs post cancer treatment. As the age ranges vary for TYAs and AYAs worldwide, and limited primary research within the UK. Primary research on post-treatment support is essential within the UK looking specifically at those aged 13-24.

5.3 Conclusion

This review has provided an entirely new insight into AYA and TYA survivorship. The SR has recognised the need for a standardised approach and terminology for survivorship and late effects care and the need for the implementation of policy and guidelines worldwide. Furthermore, identifying the need for more coordinated and developmentally appropriate survivorship services that support the multidimensional needs of AYA and TYA cancer survivors. The review emphasises the need for improved survivorship education for young cancer survivors, HCPs and parents. The requirement for improved coordination between HCPs and improved access to specialised AYA services or programmes. Therefore, providing a holistic care model that can support young survivors in managing their long-term health and quality of life.

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Walsh, C. *et al*. (2019) 'Shifting needs and preferences: Supporting young adult cancer patients during the transition from active treatment to survivorship care', *Journal of Adolescent and Young Adult Oncology*, 8(2), pp.114–121. Available at: https://doi.org/10.1089/jayao.2018.0083.

Appendices

Appendix I: CASP questions

Q. 1 Clear aim, statement	Q. 2 Appropriate methodology	Q.3 Appropriate design	Q.4 Appropriate recruitment strategy	Q.5 Appropriate methods of data collection	Q.6 Consideration of researcher participant relationship	Q.7 Ethical issues	Q.8 Rigorous data analysis	Q.9 Clear statement of findings	Q.10 Value of research

Appendix II: CASP appraisal of included studies

Study (Author, year)	Q. 1 Clear aim, statement	Q. 2 Appropriate methodology	Q.3 Appropriate design	Q.4 Appropriate recruitment strategy	Q.5 Appropriate methods of data collection	Q.6 Consideration of researcher participant relationship	Q.7 Ethical issues	Q.8 Rigorous data analysis	Q.9 Clear statement of findings	Q.10 Value of research
Psihogios *et al*. (2019) Preferences for cancer survivorship care among adolescents and young adults who experienced healthcare transitions and their parents.	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes
Brauer *et al*. (2019) Improving to where?": treatment-related health risks and perceptions of the future among adolescents and young adults	Yes	Yes	Yes	Can't tell	Yes	No	Yes	Yes	Yes	Yes

after hematopoietic cell transplantation.										
Ramsay *et al*. (2018) Follow-Up Care Provider Preferences of Adolescent and Young Adult Cancer Survivors.	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes
Figueroa Gray *et al*. (2024) A Patient-Centered Conceptual Model of AYA Cancer Survivorship Care Informed by a Qualitative Interview Study	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes
May *et al*. (2018) Adolescent and Young Adult Cancer Survivors' Experiences of the Healthcare System: A Qualitative Study.	Yes	Yes	Yes	Can't tell	Yes	No	Yes	Yes	Yes	Yes

Aagesen *et al*. (2024) Development of a rehabilitation programme for young adult cancer survivors using co-production.	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes
Smith *et al*. (2022a) Perspectives of adolescent and young adult cancer survivors: review of community-based discussion boards	Yes	Yes	Yes	Yes	Can't tell	Yes	Yes	Yes	Yes	Can't tell
Vollmer Dahlke *et al*. (2017) Adolescent and Young Adult Cancer Survivorship Educational Programming: A Qualitative Evaluation.	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes
Dorfman *et al*. (2022) Symptom Communication Preferences and	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes

Communication Barriers for Young Adult Cancer Survivors and Their Health Care Providers.										
Walsh *et al*. (2019) Shifting Needs and Preferences: Supporting Young Adult Cancer Patients During the Transition from Active Treatment to Survivorship Care.	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Murnane *et al*. (2025) Optimizing Support for Adolescent and Young Adult Cancer Survivors: Recommendations on Exercise, Nutrition, and Post-Treatment Care Needs from a Qualitative Study.	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes

Collaço *et al*. (2025) Article SUPPORT MY WAY: Supporting Young People After Treatment for Cancer: What Is Needed, When This Is Needed and How This Can Be Best Delivered.	Yes	Yes	Yes	Can't tell	Yes	Yes	Yes	Yes	Yes	Yes
Hydeman *et al*. (2019) Survivorship Needs of Adolescent and Young Adult Cancer Survivors: A Concept Mapping Analysis.	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes
Ke *et al*. (2020) Optimizing Survivorship Care Services for Asian Adolescent and Young Adult Cancer Survivors: A Qualitative Study.	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes

Aase, Ingebretsen and Hauken. (2022) "There Should Have Been a More Holistic Approach"—A Qualitative Study of Young Adult Cancer Survivors' Experiences of Follow-up After Cancer Treatment.	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes

Based on CASP checklist.

Critical Appraisal Skills Programme (CASP) (2018) *CASP Qualitative Checklist*. Available at: https://casp-uk.net/casp-tools-checklists/ (Accessed: 25 May 2025).

Appendix III: SERP Proposal Approval

From: SNMP-SERP <SNMP-SERP@rgu.ac.uk>
Sent: Thursday, October 30, 2025 2:06 pm
To: SKYE NEWTON (2329223) <s.newton@rgu.ac.uk>
Subject: RE: (2329223) Proposal and Tripartite agreement

Hi Skye,

Thank you for sending this through. As you are conducting a systematic review you do not need ethical approval from the SERP Committee so do not need to submit any documentation for this. You also do not require this to be peer reviewed.

Kind regards,
Zoe

Zoe Henderson
School/Research Administrator
School of Health, Robert Gordon University, Ishbel Gordon Building, Garthdee Road, Aberdeen, AB10 7QG
Email**:** z.henderson1@rgu.ac.uk

My work hours are 8.30-4pm Mon-Fri

www.**rgu.**ac.uk

Appendix IV: Example of CASP appraisal

Paper Title:	Adolescent and Young Adult Cancer Survivors' Experiences of the Healthcare System: A Qualitative Study
Author:	May *et al* 2018
Appraisal Date:	17/11/25

Section A Are the results valid?	
1. Was there a clear statement of the aims of the research?	☐ Yes ☐ No ☐ Can't Tell The study aimed to explore AYA cancer survivors' experiences of the healthcare system after treatment, focusing on barriers, facilitators, and needs in follow-up survivorship care.
CONSIDER: • *what was the goal of the research?* • *why was it thought important?* • *its relevance*	
2. Is a qualitative methodology appropriate?	☐ **Yes** ☐ **No** ☐ **Can't Tell** Yes as it requires exploring subjective experiences, perceptions, and meaning. Making it well suited to qualitative methods.

CONSIDER: • *If the research seeks to interpret or illuminate the actions and/or subjective experiences of research participants* • *Is qualitative research the right methodology for addressing the research goal?*	
3. Was the research design appropriate to address the aims of the research?	☒ Yes ☐ No ☐ Can't Tell Semi-structured telephone interviews enables in-depth understanding of AYAs' interactions with healthcare and survivorship services.
CONSIDER: • *if the researcher has justified the research design (e.g., have they discussed how they decided which method to use)*	
4. Was the recruitment strategy appropriate to the aims of the research?	☐ Yes ☐ No ☒ Can't Tell Purposive sampling through electronic medical records to identify AYA survivors. Appropriate for this study to address the aim of the research and this study group. An HCP identified patients relevant to take part in the study and identified patients not eligible due suicide risk or significant distress based on risk assessment at baseline. Possible bias on participant selection. Fails to mention if participants declined participation.
CONSIDER: • *If the researcher has explained how the participants were selected* • *If they explained why the participants they selected were the most appropriate to provide access to the type of knowledge sought by the study* • *If there are any discussions around recruitment (e.g. why some people chose not to take part)*	

5. Was the data collected in a way that addressed the research issue?	☐Yes ☐ No ☐ Can't Tell Semi-structured interviews allowed exploration of AYAs' experiences. The interview guide focused on interactions with healthcare, unmet needs, and systemic barriers aligned with the aims. Interviews were recorded and transcribed verbatim.
CONSIDER: • *If the setting for the data collection was justified* • *If it is clear how data were collected (e.g. focus group, semi-structured interview etc.)* • *If the researcher has justified the methods chosen* • *If the researcher has made the methods explicit (e.g. for interview method, is there an indication of how interviews are conducted, or did they use a topic guide)* • *If methods were modified during the study. If so, has the researcher explained how and why* • *If the form of data is clear (e.g. tape recordings, video material, notes etc.)* • *If the researcher has discussed saturation of data*	
6. Has the relationship between researcher and participants been adequately considered?	☐Yes ☐ No ☐ Can't Tell A nurse and oncologist at each site reviewed the potential patients for participation in the study. The researcher officer conducted the interviews. There is no explanation of the researcher role or relationship with participants. Potential bias of study sample recruited.
CONSIDER: • *If the researcher critically examined their own role, potential bias and influence during (a) formulation of the research questions (b) data collection, including sample recruitment and choice of location*	

• *How the researcher responded to events during the study and whether they considered the implications of any changes in the research design*	
Section B: What are the results?	
7. Have ethical issues been taken into consideration?	☒ Yes ☐ No ☐ Can't Tell The study received ethics approval from the Institutional Review Board of all 10 recruiting hospital sites. Participants completed the written consent form.
CONSIDER: • *If there are sufficient details of how the research was explained to participants for the reader to assess whether ethical standards were maintained* • *If the researcher has discussed issues raised by the study (e.g. issues around informed consent or confidentiality or how they have handled the effects of the study on the participants during and after the study)* • *If approval has been sought from the ethics committee*	
8. Was the data analysis sufficiently rigorous?	☒ Yes ☐ No ☐ Can't Tell The authors used thematic analysis to analyse the data. Several researchers were involved in the coding process, which helps increase the credibility of the findings. They used NVivo to organise the data and identify emerging themes. Miles and Huberman's conceptual framework, which guided how themes were structured, informed their analysis. The research team also held regular meetings to discuss any differences in coding and resolve discrepancies.

CONSIDER: • *If there is an in-depth description of the analysis process* • *If thematic analysis is used. If so, is it clear how the categories/themes were derived from the data* • *Whether the researcher explains how the data presented were selected from the original sample to demonstrate the analysis process* • *If sufficient data are presented to support the findings* • *To what extent contradictory data are taken into account* • *Whether the researcher critically examined their own role, potential bias and influence during analysis and selection of data for presentation*	
9. Is there a clear statement of findings?	☐ Yes ☐ No ☐ Can't Tell The findings are presented clearly with quotations supporting the themes. The findings clearly outline experiences with oncology teams, follow-up services, communication barriers, unmet needs, and transition experiences.
CONSIDER: • *If the findings are explicit* • *If there is adequate discussion of the evidence both for and against the researcher's arguments* • *If the researcher has discussed the credibility of their findings (e.g. triangulation, respondent validation, more than one analyst)* • *If the findings are discussed in relation to the original research question*	
Section C: Will the results help locally?	
10. How valuable is the research?	☐ Yes ☐ No ☐ Can't Tell The findings reveal AYA experiences with survivorship services, gaps in follow-up care, barriers (e.g., communication, access, transition problems), emotional and informational needs, coordination

	across paediatric and adult services and the desire for structured survivorship care and better transitions.

CONSIDER:

- *If the researcher discusses the contribution the study makes to existing knowledge or understanding (e.g., do they consider the findings in relation to current practice or policy, or relevant research-based literature*
- *If they identify new areas where research is necessary*
- *If the researchers have discussed whether or how the findings can be transferred to other populations or considered other ways the research may be used*

APPRAISAL SUMMARY: *List key points from your critical appraisal that need to be considered when assessing the validity of the results and their usefulness in decision-making.*

Positive/Methodologically sound	**Negative/Relatively poor methodology**	**Unknowns**
The aim is clear in exploring AYA cancer survivors experience of healthcare post treatment Qualitative interviews appropriate to gain subjective experiences Data analysis sufficient and rigorous, multiple	No explanation of the role of the research officer and professional background. No mention of prior relationships.	Recruitment via nurse and oncologist, possibility selection bias. No discussion around any participants that declined to participate. Not clear how transferable

researchers, coding, thematic analysis, Nvivo, Miles and Huberman's conceptual framework Ethical approval and written consent gained. Findings relevant to AYA cancer survivor experiences.		findings are to other countries outside Australia. Age range 15-25 so may not be transferable to the older AYAs aged 25-39. Healthcare free within Australia so may not be transferable to USA.

Appendix V: Thematic table

Themes Authors	Lack of knowledge, understanding and being prepared for late effects	Barriers to accessing and engaging with survivorship care services	Holistic care needs in survivorship	Communication, coordination and transition of care
Psihogios *et al*., 2019	X	X	X	X
Brauer *et al*., 2019.	X			
Ramsay *et al*., 2018.	X	X		X
Figueroa Gray *et al*., 2024	X	X	X	
May *et al*., 2018	X			X
Aagesen *et al*., 2024		X		X
Smith *et al*., 2022a	X		X	
Vollmer Dahlke *et al*., 2017	X	X	X	X
Dorfman *et al*., 2022.	X			
Walsh *et al*., 2019.			X	X
Murnane *et al*., 2025.	X	X		X
Collaço *et al*., 2025.		X	X	X
Hydeman *et al*., 2019.	X	X	X	

Ke *et al*., 2020.		X	X	X
Aase, Ingebretsen and May, 2022.	X	X		X