

ESSS Outline

Psychosocial and family centred therapies for young people with cancer and their families

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Introduction

This evidence summary seeks to address the following question: What are the recommended approaches for psychosocial and family centred therapies to support young people with cancer and their families deal with the long term effects of a cancer diagnosis?

About the evidence presented below

The evidence below includes academic and third sector sources. Search terms focused on the intersection between psychosocial and family centred therapies and young people and cancer. These included terms like "art therapies AND paediatric oncology", "young people/children with cancer/paediatric oncology AND family support", "pediatric oncology and transitions", "young people/children with cancer/paediatric oncology and psychosocial interventions/support", etc. The evidence was identified through databases like Google Scholar and SCIE. Many of the resources were identified through snowballing.

Background

Cancer and the resulting treatment experiences are disruptive to children and adolescents' social development, emotional health, and academic progress (<u>Gurney et al 2009</u>). However, adverse effects in these domains can linger throughout a person's lifetime. Consistent scientific evidence suggests that many adult survivors of childhood cancer have later difficulties in educational achievement, friendships and social interactions, employment and financial independence, intimate relationships and marriage, and independent living (<u>Gurney et al 2009</u>).

The effects of cancer among children and young people also have a ripple effect on the whole family, affecting parents' emotional and psychological well-being and that of siblings (Salem et al., 2020).

The following outline considers a range of interventions aimed at supporting the emotional and social needs of children with cancer and their families to counter some of these long-term adverse effects.

Evidence

Family and sibling support

Ritchie M A (2001) 'Sources of Emotional Support for Adolescents With Cancer', Journal of Paediatric Oncology Nursing, 18, 3, 105–110

The review considers that psychosocial interventions for young people with cancer should include:

- Identifying key individuals in the lives of patients
- Creating opportunities for patients to talk about their feelings
- Encouraging their communication with family and friends.

For the adolescent who is experiencing cancer, the inclusion of parents, especially mothers, in the cancer experience of these individuals cannot be stressed enough. It is important to recognise that adolescents do not exchange their existing social circle to exclude parents but expand it to include peers.

The review identified that it is crucial to provide opportunities for the adolescent to have sustained contact with same-age peers. This includes encouraging phone calls to and visits from friends and providing the needed privacy for peer-to-peer interaction. Asking these adolescents about friends and how often they have contact with them emphasises the nurse's understanding of their importance to them.

Ryan D, Chafe R, Hodgkinson K, et al (2018) Interventions to improve the aftercare of survivors of childhood cancer: a systematic review.

Pediatr Hematol Oncol J 2018, 3, 90-8

This is a comprehensive review of interventions for aftercare. However, most of these interventions are in a clinical setting. This includes a range of interventions supporting the social skills of survivors (see pages 91-92) through telephone counselling, family therapy and cognitive-behavioural therapy. For example, Santacroce et al. (2009) evaluated a social development intervention that focused on a telephone directed coping skills training. They found in-person, long-term follow-up supported by telephone-delivered psychosocial care is a useful way to provide care to CCS and their parents.

Overall, the review found that interventions aimed at social skills had varying degrees of impact.

Salem H et al (2020) Home-based cognitive behavioural therapy for families of young children with cancer (FAMOS): A nationwide randomised controlled trial, *Pediatric Blood & Cancer*, 68(3), p.e28853.

This study evaluates the effect of a psychotherapeutic intervention, FAMily-Oriented Support (FAMOS) on parents of young children after cancer treatment.

Families were assigned to up to seven sessions of FAMOS, a cognitive-behavioural manualised home intervention, for 6 months (some were assigned to a control group of usual psychosocial care). The primary outcome was parents' symptoms of posttraumatic stress disorder (PTSD) at 6 and 12 months after enrolment. The secondary outcomes were parents' symptoms of depression and anxiety.

The study enrolled 109 families (204 parents). The FAMOS intervention reduced parents' symptoms of PTSD and depression but not anxiety compared to the control group.

Toft T, Alfonsson S, Hovén E and Carlsson T (2019) Feeling excluded and not having anyone to talk to: Qualitative study of interpersonal relationships following a cancer diagnosis in a sibling. *European Journal of Oncology Nursing*, 42, 76-81

This study explores siblings' interpersonal relationships following a cancer diagnosis in the family.

The siblings reported feeling excluded while wanting to maintain a relationship with their ill sibling. They also wanted to be involved in the care of their ill sibling. Siblings, nonetheless, felt a sense of pressure as they were simultaneously expected to manage household chores and attend school.

Siblings also reported feeling stigmatised and exposed in social contexts. Having the possibility to talk about their experiences and receiving social support was described as essential in order to cope with the situation.

The study concludes that having a space where siblings are free to communicate their feelings and experiences is highly appreciated and desired. Social support from peers with similar experiences may be particularly appreciated and could be a potentially effective psychosocial intervention.

Alderfer MA, Hodges JA (2010) Supporting Siblings of Children with

Cancer: A Need for Family-School Partnerships. School Ment Health Jun 1,

2, 2, 72-81

This study explores the mental health needs of siblings of children with cancer. Siblings discuss their perceptions of how much social support they receive and the importance of social support across home and school sources. The study reveals essential associations between social support and more positive emotional, behavioural, and academic functioning. These findings suggest that family-school partnerships may be valuable to address the mental health needs of siblings of children with cancer.

Wawrzynski SE, Schaefer MR, Schvaneveldt N and Alderfer MA (2021)
Social support and siblings of children with cancer: A scoping review.

Psycho-Oncology

Studies report many common challenges for siblings, including changes in social support. These include some of the following:

- Less instrumental support after a sibling cancer diagnosis. This
 involved reduced support in getting to activities and doing schoolwork
 as well having to step up and provide more instrumental support for
 the family like taking on more responsibilities such as babysitting or
 chores.
- Low levels of emotional support leading to fear, jealousy, and worry about parents and their siblings with cancer. This was often compounded by a lack of informational support about their sibling's diagnosis and treatment and being confronted by questions from peers.

- Less companionship and time with friends. Siblings shared feeling worried and excluded when they did not understand what was happening with the child with cancer.
- Sibling support needs change over time.

To address these challenges, siblings expressed a desire to have honest and open communication with their parents about cancer. Instrumental support with homework and emotional support over time is also crucial. Siblings also conveyed the need for companionship support through physical affection and time with parents and siblings. Finally, siblings and nurses suggested that appraisal support and validation through acknowledgement for sibling achievements and contributions around the house helped siblings feel "seen" by parents.

The review identifies the following key areas of intervention which showed positive results for siblings of children with cancer:

- Interventions that focused on problem-focused coping and skill building resulted in siblings reporting greater confidence, self-reflection, and control of their emotions.
- After participating in educational interventions that provided informational support, siblings were noted to have less fear, anxiety, and preoccupation with cancer.
- Furthermore, offering informational support in the school setting was shown to improve emotional support for siblings by creating a shared understanding among peers at school.
- Emotional support was facilitated in groups by creating a safe space where siblings were encouraged to share their feelings.
- When interventions included parents, siblings reported improved perceptions of their relationships and communication with their parents. These siblings also garnered appraisal support simply by having an intervention focused on them, making them feel noticed and validated.

Of note, the review finds that parents with some financial hardship reported a lack of knowledge and information regarding sibling supportive programs, while parents without financial hardship reported logistical concerns like siblings' school schedules or distance from the hospital.

Clarke S, Mitchell W, Sloper P (2005) Psychosocial support services for children and young people with cancer and their families. SPRU, University of York.

This study explored patterns of psychosocial service provision for children and young people with cancer and their families throughout the UK. They identify some key areas in need of development:

Social and emotional support

Parents of children at all ages and stages of treatment wanted more counselling options and support opportunities, including formal options, such as key workers, and more informal support provided by befrienders. Young people wanted staff to facilitate more opportunities to talk to other young people with cancer. Parents also felt that more support for other family members as needed, especially siblings of teenagers, for example, someone to talk to siblings.

Information

Parents generally wanted more age-appropriate information in a variety of formats and information targeted at a range of family members, including siblings and grandparents. Young people noted a lack of video information, especially around cancer and its treatment. More specifically, parents wanted an internet search service and a list of recommended internet sites.

Transitions

Before returning home, parents would welcome an end of treatment meeting with staff and other parents, and when their child returns to school, parents wanted more information and an education coordinator to oversee the

transition. With regard to fertility issues, parents wanted more support for themselves and their children and more information on fertility for teenagers.

Digital support

After completing cancer treatment (and during), adolescents and young adult cancer survivors are vulnerable to psychological distress. Digital interventions may address the gap in tailored, evidence-based supportive interventions. The following studies consider some of the evidence on this topic and the most common approaches used.

McCann L, McMillan KA, Pugh G (2019) Digital Interventions to Support

Adolescents and Young Adults With Cancer: Systematic Review JMIR

Cancer, 5,2, e12071

This review identifies and assesses the quality of existing digital health interventions developed specifically for adolescents and young adults, aged between 13 and 39 years, living with or beyond a cancer diagnosis.

Types of interventions identified include:

- A website featuring logs and diaries, game-like brain training exercises, written assignments where individual feedback was received from psychologists, weekly tips and tricks, and songwriting and video making exercises. (One study looking at psychotherapy interventions (Seitz et al 2014) reported that more than 80% of participants were satisfied with the intervention, and more than 80% indicated that the intervention, involving written assignments, was relatively helpful in relieving the symptoms of posttraumatic stress disorder, anxiety, and depression.)
- Video games mostly focused on physical activity and cancer knowledge.
- Mobile or tablet apps (focused chiefly on symptoms management)
- Wearables (mostly focused on physical activity)
- Social media (physical activity)
- Virtual reality (VR), including the development of VR counselling.

This review found that AYAs' subjective experience using digital platforms was typically positive.

Ramsey WA, Heidelberg RE, Gilbert AM, Heneghan MB, Badawy SM,
Alberts NM (2020) eHealth and mHealth interventions in pediatric cancer:

A systematic review of interventions across the cancer

continuum.Psycho-Oncology, 29, 17–37

This review explores paediatric cancer patients' and survivors' perceptions, attitudes, and concerns related to eHealth and mHealth interventions.

The review identifies several studies looking at emotional distress, including anger, anxiety, depression and stress.

Three studies found significant decreases in anxiety, which included using social robotic-assisted therapy, therapeutic play involving virtual reality computer games and web-based cognitive behavioural group therapy. The interventions that significantly reduced anxiety were developed with the specific aim of anxiety reduction instead of being an ancillary outcome.

Significant decreases in depression were observed across studies utilising electronic and mobile Health. These interventions included social robotics, web-based cognitive behavioural therapy groups, therapeutic play involving virtual reality computer games, and wearable technology targeting physical activity promotion as part of a cancer survivor–tailored weight management intervention.

This review concludes that electronic and mobile health interventions can help improve mental and physical health outcomes of youth undergoing cancer treatment and child, adolescent, and young adult survivors of childhood cancer.

Sansom-Daly UM et al (2021) The Recapture Life Working Party. Online, Group-Based Psychological Support for Adolescent and Young Adult Cancer Survivors: Results from the Recapture Life Randomized Trial.

Cancers, 13, 10, 2460

The study evaluates an online, group-based cognitive-behavioural therapy intervention ('Recapture Life'). Forty cancer survivors between the ages of 15–25 years participated. No positive impacts on participants' quality of life emerged immediately following the intervention, but Recapture Life participants reported developing adaptive coping skills.

Recapture Life participants also reported higher negative impact of cancer, anxiety and depression at a 12-month follow-up. Additional analyses suggested that survivors benefitted differently from the two online interventions (Recapture Life vs peer-support group) depending on how recently they had completed their cancer treatment.

They conclude that different survivor sub-groups may find group-based, telehealth psychological interventions more or less helpful at different points in survivorship.

Canter, KS, McIntyre, R, Babb, R, et al (2022) A community-based trial of a psychosocial eHealth intervention for parents of children with cancer.

Pediatr Blood Cancer., 69, e29302

Parents and caregivers of children with cancer are at risk for a range of adverse psychosocial outcomes, including increased distress, anxiety, and depression.

This study reports on a specific intervention: The Electronic Surviving Cancer Competently Intervention Program (eSCCIP). This brief, hybrid eHealth intervention for parents includes four online modules (an orientation module and three core content modules) and three telehealth sessions with an interventionist (e.g., a licensed psychologist or social worker).

The modules are interactive, featuring a mix of video content and engaging skills practice. These include skills or strategies like a thought-reframing approach or a multifamily video discussion group (an edited conversation between parents who share their experiences with paediatric cancer).

Skills practice includes game-like activities, interactive examples, and free-response questions. Each module incorporates family systems theory by focusing on family relationships and interconnectedness and provides information and training on cognitive-behavioural skills (e.g., thought reframing).

Exploratory analyses suggest that participation in eSCCIP may contribute to decreases in acute distress, symptoms of anxiety, and symptoms of PTSD.

Seitz DC, Knaevelsrud C, Duran G, Waadt S, Loos S, Goldbeck L (2014)
Efficacy of an internet-based cognitive-behavioral intervention for
long-term survivors of pediatric cancer: a pilot study. Support Care
Cancer, 22, 8, 2075-83

This study examines the impact of an Internet-based psychological intervention ("Onco-STEP") for adolescent and young adult survivors in reducing (post-traumatic stress) PTSS and anxiety.

This intervention involved former paediatric cancer patients older than 15 years manifesting clinically relevant PTSS or anxiety. The cognitive-behavioural treatment consists of ten writing sessions. It was comprised of two modules: the first aiming to reprocess the traumatic cancer-related experiences and the second aiming to build coping strategies with current cancer-related fears. Treatment was delivered via written messages on a secure Internet platform. Outcomes were assessed by the Post-traumatic Stress Diagnostic Scale, the Hospital Anxiety and Depression Scale, and the Fear of Progression/Relapse Questionnaire.

A total of 20 participants completed the intervention. PTSS, anxiety, and fear of progression/relapse decreased by the end of the intervention. In addition,

they found a significant decrease in symptoms of depression. Except for the improvement in depression, all effects were sustained three months after treatment.

Alternative therapies

There is a range of alternative therapies being used to support children with cancer and their families. These include camp experiences, wilderness therapy, art therapy and animal therapy.

Nature-based interventions

Neville AR, Moothathamby N, Naganathan M, Huynh E and Moola FJ (2019) "A place to call our own": The impact of camp experiences on the psychosocial wellbeing of children and youth affected by cancer-A narrative review. Complementary therapies in clinical practice, 36, pp 18-28

Specialised camps for children with cancer are becoming increasingly popular. They provide a stress-free, outdoor environment where children can interact with each other while experiencing 'normal' childhood activities.

This review shows that a variety of camp programs and methodologies exist. Some camps have activities specifically tailored to helping campers with their cancer diagnoses. In contrast, other camps included various outdoor and arts-based activities, more typical of a traditional overnight summer camp. No adverse outcomes were reported in any case by the review.

Overall, camp participation led to improved social health, enhanced constructions of the self, quality of life, sense of normalcy, and attitude. Although absences from school and social events can lead to impaired interactions with others, the review shows that camps can improve a child's social health and functioning.

These findings indicate that camps may be an effective therapeutic modality to preserve wellbeing and improve constructions of self during the cancer experience.

Jong M, Lown EA, Schats W, Mills ML, Otto HR, Gabrielsen LE, & Jong MC (2021) A scoping review to map the concept, content, and outcome of wilderness programs for childhood cancer survivors. PloS one, 16, 1

Various interventions can improve the quality of life for childhood cancer survivors, including wilderness therapy. Previous studies have described positive outcomes linked with various wilderness-related therapies for cancer survivors. This scoping review maps the concept, content and result of wilderness therapy for childhood cancer survivors.

There are a wide variety of program activities that can be grouped into five categories:

- 1. challenge/risk activities such as kayaking
- 2. free time/leisure activities such as using mobile devices
- 3. experiential learning activities such as map and compass orienting
- 4. physical activity such as hiking
- 5. psychotherapeutic work, such as the use of metaphors.

All or nearly all programs were camp-based, took place in nature, and had a closed group structure with facilitators and participants being together from beginning to end. The program length varied between 3–14 days, and the group size was between 6–11 participants.

The most commonly reported health benefits were increased social involvement, self-esteem, self-confidence, self-efficacy, social support, and physical activity. Health-related outcomes that decreased upon participation in a wilderness program included discomfort, psychological distress, and alienation.

This review demonstrates the potential ability of camp to buffer psychosocial losses for children affected by cancer.

Blaschke, S (2017) The role of nature in cancer patients' lives: a systematic review and qualitative meta-synthesis. *BMC Cancer* 17, 370

This review explores the role of nature in cancer patients' lives. It highlights seven interrelated core themes:

Connecting with what is valued

The importance of contact with nature is supportive in different ways, such as transforming emotional and psychological health and creating a more optimistic outlook on life in general. Nature functioned as a platform for social connections bringing patients, friends and family together and helped peer bonding amongst cancer survivors who participated in structured nature activities.

• Being elsewhere, seeing and feeling differently

Participants gained relief from their immediate cancer experiences by being somewhere else. Nature is seen as a welcome temporary escape that can distance patients from the strain and, at times, unnecessary discomfort imposed by clinical settings and procedures.

• Exploration, inner and outer excursions

This review highlights the importance of 'extraordinary' nature experiences and distant locations, shifting patients' outlook. Play provides a context in which to place the extraordinary event of cancer diagnosis and approach new perspectives.

Other themes explored were:

- Feeling at home and safe in nature as opposed to the sense of anxiety cancer diagnosis often involves,
- Using nature in ways that help cancer patients understand and communicate their life situations differently,
- A sense that nature can strengthen ties with normality and sustain positive health behaviours,

• A feeling of nature as a source of positive enriching experiences.

As such, nature can support individuals to navigate the clinical and personal consequences of cancer.

Gabrielsen LE, Eskedal LT, Mesel T, Aasen GO, Hirte M, Kerlefsen RE,
Palucha V & Fernee CR (2019) The effectiveness of wilderness therapy as
mental health treatment for adolescents in Norway: a mixed methods
evaluation, International Journal of Adolescence and Youth, 24, 3, 282-296

This paper investigates the effectiveness of a Norwegian wilderness therapy programme, Friluftsterapi, offered to adolescents within a specialised mental health care setting. Interestingly, interview data revealed that the intervention's processing takes time, and several months are required before the impact is fully internalised and translated into improved daily functioning. The Friluftsterapi experience is perceived as valuable, and it appears to contribute to improving the mental health of many participants.

Below is a table from Leiv et al (2019) detailing their approach across two iterations of the programme:

	Friluftsterapi	Friluftsterapi 2.0
Selection	Focus on client motivation	Focus on client motivation and ability
Dosage and intensity	18 days over an 8- to 10-week period	10 ½ days over a 3-week period
Structure	High degree of structure with pre-specified daily programmes composed of many different elements	Low degree of structure, allowing for freer daily programmes that typically include less elements
Therapeutic factors	Wilderness, physical self and psychosocial self. Accessed through adventurous activities, individual and group therapy	Wilderness, physical self and psychosocial self. Accessed through introspective and experiential activities, and individual and group therapy
Main expedition	6 days/5 nights in semi-wilderness on a predefined route from A to B	7 days/6 nights in wilderness without a predefined route. The group returns to the starting point

Quantitative data collection	Voluminous test-battery- Pre-test- Post-test- 12 month follow-up test- Day-to-day clinical measurements- HRV & executive functions	Condensed test-battery- Pre-test- Post-test- Discharge from the treatment test- 12 month follow-up test- Day-to-day clinical measurements
Qualitative data collection	- Extensive participant observation- Individual interviews with adolescents and parents at post-test and at 10-month follow-up Topics: perceived outcome in relation to the context and therapeutic mechanisms	Limited participant observation- Individual interviews with adolescents at post-test and 12-month follow-up- Focus group interviews at 3 month follow-up- Topics: Perceived outcome in relation to context and therapeutic mechanisms; specific experiences

Art based interventions

<u>Aguilar BA (2017) The Efficacy of Art Therapy in Pediatric Oncology</u> <u>Patients: An Integrative Literature Review, *J Pediatr Nurs.* 36, 173-178</u>

The findings of this review suggest that children who participated in various drawing interventions exhibited enhanced communication with family members and healthcare providers. Additionally, children could better express underlying emotions, develop more effective coping skills, and experience a reduction in adverse side effects.

This review argues that implementing a drawing intervention or other forms of art into the holistic care of children with cancer may maximise the quality of life and allow for a more tolerable lifestyle.

Shojaei Z, Golparvar M, Bordbar MR and Aghaei A (2019) The effect of cognitive-behavioral art-play therapy and cognitive-behavioral story therapy on pain perception and hope in children with cancer, *J Pediatr Nurs*, 6, 1, 39-47

This study examines the effects of cognitive-behavioural art-play therapy and cognitive-behavioural story therapy on pain perception and hope in children with cancer.

The authors found that cognitive-behavioural art-play therapy can increase feelings of hope among children with cancer. Both cognitive-behavioural art-play therapy and cognitive-behavioural story therapy can reduce the pain perception of children with cancer.

Sourkes M (1991) Truth to Life, *Journal of Psychosocial Oncology*, 9, 2, 81-96

This article gives a practical and valuable guide to using art therapy among children with cancer. It reflects on three structured art therapy techniques:

- 1. The mandala (colour-feeling wheel)
- 2. The change-in family drawing
- 3. The "scariest" drawing

A letter-writing technique is also explored.

The art therapy techniques presented in this article can be adapted for individuals ranging from 3-year-olds to adults and are effective in family or group settings and individual sessions. The authors caution that although art therapy techniques may be simple to administer, they evoke complex and powerful responses. Therefore, they should be delivered by a therapist who has developed skills in the area.

Favara-Scacco C, Smirne G, Schilirò G and Di Cataldo A (2001) Art therapy as support for children with leukemia during painful procedures. *Med.*Pediatr. Oncol., 36, 474-480

This study reflects on an art therapy (AT) intervention to support children with leukaemia during painful procedures. The art intervention involved engagement with children before, during, and after their treatment (in this case, punctures). There were several stages to the art intervention:

- Clinical dialogue to calm children and help them cope with painful procedures
- Visual imagination to activate alternative thought processes and decrease the attention towards overwhelming reality

- Medical play to clarify illness, eliminate doubts, and offer control over threatening reality
- Structured drawing to contain anxiety by offering a structured, predictable reality (the drawing) that was controllable by children
- Free drawing to allow children to externalise confusion and fears
- Dramatisation to help children accept and reconcile themselves to body changes.

AT was shown to be a helpful intervention that can prevent permanent trauma and support children and parents during intrusive interventions.

Animal assisted therapy

Animal assisted therapy (AAT) is often present in a clinical setting and used to improve perception of pain and to help with hospitalisation and isolation (McCulloch et al 2018). For example, Chubak et al (2017) found that children with cancer reported feeling less distressed and significantly decreased worry, fear, sadness, fatigue, and pain after visiting a therapy dog in the inpatient ward. Nonetheless, there is little evidence of animal-assisted therapy's wider impact on children with cancer (Chubak & Hawkes, 2016). There is also limited evidence on the use of AAT in a family context.

McCullough A et al (2018) 'Measuring the Effects of an Animal-Assisted Intervention for Pediatric Oncology Patients and Their Parents: A Multisite Randomized Controlled Trial', Journal of Pediatric Oncology Nursing, 35, 3, 159–177

This study examined the effects of an animal-assisted intervention (AAI) on the stress, anxiety, and health-related quality of life for children diagnosed with cancer and their parents. Newly diagnosed patients aged 3 to 17 years (n = 106), were randomised to receive either standard care plus regular visits from a therapy dog (intervention group), or standard care only (control group). Data were collected at set points over 4 months of the child's treatment.

Over the study period, children in both groups experienced less stress but no change in quality of life, regardless of whether they visited with a therapy dog. However, study data show that certain aspects of stress among parents in the intervention group significantly improved with time.

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<u>Psychological Support for Adolescent and Young Adult Cancer Survivors: Results from the</u>
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Wawrzynski SE, Schaefer MR, Schvaneveldt N and Alderfer MA (2021) Social support and siblings of children with cancer: A scoping review. *Psycho-Oncology*

Accessing resources

We have provided links to the materials referenced in the summary. Some materials are paywalled, which means they are published in academic journals and are only available with a subscription. Some of these are available through The Knowledge Network with an NHS Scotland OpenAthens username. The Knowledge Network offers accounts to everyone who helps provide health and social care in Scotland in conjunction with the NHS and Scottish Local Authorities, including many in the third and independent sectors. You can register here. Where resources are identified as 'available through document delivery', these have been provided to the original enquirer and may be requested through NHS Scotland's fetch item service (subject to eligibility).

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Suggested reference: [Bocioaga, A] (2022) ESSS Outline: Title. Iriss. https://doi.org/10.31583/esss.xxxxxxxxx



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