This monthly Current Awareness Bulletin is produced by the Library, Musgrove Park Academy to provide staff with a range of resources focussing on end of life care. It includes recently published guidelines and research articles, news and policy items.

This guide provides a selection of resources relevant to the subject area and is not intended to be a comprehensive list. All websites have been evaluated and details are correct at the time of publications.

Details correct at time of going to print. Please note that resources are continuously updated.

For further help or guidance, please contact a member of library staff.

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Issue 8
September 2016
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This is a list of journal articles on the topic of end of life. Some articles are available in the library or on-line via an OpenAthens password by following the full-text link. If you would like an article which is not available as full-text then please contact library staff.

Please note that abstracts are not always available for all articles.

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**Title:** End-of-life care in patients with advanced lung cancer.  
**Citation:** Therapeutic advances in respiratory disease, Oct 2016, vol. 10, no. 5, p. 455-467, 1753-4666 (October 2016)  
**Author(s):** Lim, Richard B L  

**Abstract:** Despite advances in the detection, pathological diagnosis and therapeutics of lung cancer, many patients still develop advanced, incurable and progressively fatal disease. As physicians, the duties to cure sometimes, relieve often and comfort always should be a constant reminder to us of the needs that must be met when caring for a patient with lung cancer. Four key areas of end-of-life care in advanced lung cancer begin with first recognizing ‘when a patient is approaching the end of life’. The clinician should be able to recognize when the focus of care needs to shift from an aggressive life-sustaining approach to an approach that helps prepare and support a patient and family members through a period of progressive, inevitable decline. Once the needs are recognized, the second key area is appropriate communication, where the clinician should assist patients and family members in understanding where they are in the disease trajectory and what to expect. This involves developing rapport, breaking bad news, managing expectations and navigating care plans. Subsequently, the third key area is symptom management that focuses on the goals to first and foremost provide comfort and dignity. Symptoms that are common towards the end of life in lung cancer include pain, dyspnoea, delirium and respiratory secretions. Such symptoms need to be anticipated and addressed promptly with appropriate medications and explanations to the patient and family. Lastly, in order for physicians to provide quality end-of-life care, it is necessary to understand the ethical principles applied to end-of-life care interventions. Misconceptions about euthanasia versus withholding or withdrawing life-sustaining treatments may lead to physician distress and inappropriate decision making. © The Author(s), 2016.

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**Title:** The physician as patient in palliative care: A retrospective case-note audit.  
**Citation:** Palliative medicine, Oct 2016, vol. 30, no. 9, p. 889-892, 1477-030X (October 2016)  
**Author(s):** McMichael, Lachlan C, Zambrano, Sofia C, Crawford, Gregory B  

**Abstract:** Dying physicians may present unique challenges to palliative care teams. Studies of dying physicians are scarce, but those that exist suggest a potential absence of a coordinating clinician, prolongation of curative treatments, resistance to palliative care input and barriers to discussing psychosocial needs. The aim was to describe and examine the care provided to physician-patients referred to an Australian palliative care service, and to identify issues faced by the physician-patient and by the treating team. A retrospective case-note audit of the case notes of medical practitioners...
referred for palliative care and dying between January 2007 and April 2013 was conducted. There
was evidence of medically qualified friends or family members initiating referrals and directing
treatment decisions. There was some evidence of increased consultant-led decision-making and
bypassing of usual referral pathways and systems for providing after-hours advice and calling
consultants directly. There also appeared to be some reluctance by junior doctors to make decisions,
because of the patient's desire for consultant-level advice only. This study adds to the growing body
of literature that identifies the potential difficulties associated with caring for medical practitioners. By
understanding some of the complexity of this particular doctor-patient relationship, clinicians can
approach the management of physician-patients facing the end of their lives with a more sound
understanding of their particular care needs. © The Author(s) 2016.

Title: Progress and divergence in palliative care education for medical students: A
comparative survey of UK course structure, content, delivery, contact with patients
and assessment of learning.

Citation: Palliative medicine, Oct 2016, vol. 30, no. 9, p. 834-842, 1477-030X (October 2016)

Author(s): Walker, Steven, Gibbins, Jane, Barclay, Stephen, Adams, Astrid, Paes, Paul,
Chandratilake, Madawa, Gishen, Faye, Lodge, Philip, Wee, Bee

Abstract: Effective undergraduate education is required to enable newly qualified doctors to safely
care for patients with palliative care and end-of-life needs. The status of palliative care teaching for
UK medical students is unknown. To investigate palliative care training at UK medical schools and
compare with data collected in 2000. An anonymised, web-based multifactorial questionnaire. Results
were obtained from palliative care course organisers at all 30 medical schools in 2013 and compared
with 23 medical schools (24 programmes) in 2000. All continue to deliver mandatory teaching on 'last
days of life, death and bereavement'. Time devoted to palliative care teaching time varied (2000: 6-
100 h, mean 20 h; 2013: 7-98 h, mean 36 h, median 25 h). Current palliative care teaching is more
integrated. There was little change in core topics and teaching methods. New features includ
'involvement in clinical areas', participation of patient and carers and attendance at multidisciplinary
team meetings. Hospice visits are offered (22/24 (92%) vs 27/30 (90%)) although they do not always
involve patient contact. There has been an increase in students' assessments (2000: 6/24, 25% vs
2013: 25/30, 83%) using a mixture of formative and summative methods. Some course organisers
lack an overview of what is delivered locally. Undergraduate palliative care training continues to
evolve with greater integration, increased teaching, new delivery methods and wider assessment.
There is a trend towards increased patient contact and clinical involvement. A minority of medical
schools offer limited teaching and patient contact which could impact on the delivery of safe palliative
care by newly qualified doctors. © The Author(s) 2016.

Title: The meaning of occupation for patients in palliative care when in hospital.

Citation: Palliative & supportive care, Oct 2016, vol. 14, no. 5, p. 541-552, 1478-9523 (October 2016)

Author(s): Eriksson, Lina, Öster, Inger, Lindberg, Margareta

Abstract: The aim of this study was to describe how patients in palliative care relate to occupation
during hospitalization and to define the meaning it has for them. Eight inpatients in palliative care with
various cancer diagnoses were interviewed one time. These interviews were transcribed and analyzed using qualitative content analysis. Patients experience occupations as meaningful when in hospital during the last period of their lives. They would like to be able to handle their own needs as much as possible. Staff behavior, the design of the environment, the lack of accessible occupations, and the degree to which patients can decide whether to receive or decline visits affect the possibility to make their wishes a reality. Our results also revealed that patients experience a sense of loss of their role, as well as a lack of control and participation. Our results confirm the importance of occupation and of patients having the option to and being given opportunities to take care of themselves when in palliative care. Further studies are needed to enable us to understand how organized occupations might influence patients' experience of being in a hospital during the final period of life.

Title: The potential therapeutic value for bereaved relatives participating in research: An exploratory study.
Citation: Palliative & supportive care, Oct 2016, vol. 14, no. 5, p. 479-487, 1478-9523 (October 2016)
Author(s): Germain, Alison, Mayland, Catriona R, Jack, Barbara A

Abstract: Conducting research with the bereaved presents an immediate ethical challenge, as they are undoubtedly a vulnerable group, associated with high levels of distress and susceptible to both physical and mental health issues. A comprehensive understanding of the potential therapeutic benefits for bereaved relatives participating in palliative care research is limited, and therefore the ethics of engaging this group remain questionable. This paper describes a secondary analysis of qualitative data collected in the Care of the Dying Evaluation (CODE) project, examining the experiences of patients who died at home. It explores the motivations and potential benefits for bereaved relatives participating in research with reference to the recently developed concepts in bereavement theory. Cognitive interviews were conducted with 15 bereaved relatives and secondary analysis using a content analysis framework was employed to classify the data. The results center around six recurring concepts identified as adaptive in current bereavement theory: an opportunity to share the narrative accounts of the final hours of their relative's life; a search for sense and meaning in loss; an ongoing bond/attachment with the deceased; altruistic motivations; oscillation between loss and restorative orientations; and a sense of resilience. Overall, the participants found that taking part in the research was valuable and that it could be described as offering therapeutic benefits. The need for bereaved relatives to take part in research studies should be encouraged, as they provide an accurate proxy for the patient's experience of end-of-life care while also providing a valuable account of their own perspective as family member and carer. In addition, we highlight the need for ethics committees to be aware of the potential benefits for bereaved relatives participating in research of this kind.

Title: Music therapy for end-of-life care: An updated systematic review.
Citation: Palliative medicine, Oct 2016, vol. 30, no. 9, p. 877-883, 1477-030X (October 2016)
Author(s): McConnell, Tracey, Scott, David, Porter, Sam

Abstract: Music therapy during palliative and end-of-life care is well established and positive benefits for patients have been reported. Assess the effectiveness of music therapy versus standard care alone or standard care in combination with other therapies for improving psychological, physiological
and social outcomes among adult patients in any palliative care setting. In order to update an existing Cochrane systematic review, we searched MEDLINE, CINAHL, EMBASE, PsycINFO, CENTRAL, ClinicalTrials.gov register and Current Controlled Trials register to identify randomised or quasi-randomised controlled trials published between 2009 and April 2015. Nine electronic music therapy journals were searched from 2009 until April 2015, along with reference lists and contact was made with key experts in music therapy. Only studies published in English were eligible for inclusion. Two reviewers independently screened titles, abstracts, assessed relevant studies for eligibility, extracted data and judged risk of bias for included studies. Disagreements were resolved through discussion with a third reviewer. Data were synthesised in Revman using the random effects model. Heterogeneity was assessed using I(2). Three studies were included in the review. Findings suggest that music therapy may be effective for helping to reduce pain in palliative care patients (standard mean deviation = -0.42, 95% confidence interval = -0.68 to -0.17, p = 0.001). Available evidence did not support the use of music therapy to improve overall quality of life in palliative care. While this review suggests that music therapy may be effective for reducing pain, this is based on studies with a high risk of bias. Further high-quality research is required. © The Author(s) 2016.

Title: Improving the wellbeing of staff who work in palliative care settings: A systematic review of psychosocial interventions.
Citation: Palliative medicine, Oct 2016, vol. 30, no. 9, p. 825-833, 1477-030X (October 2016)
Author(s): Hill, Rebecca C, Dempster, Martin, Donnelly, Michael, McCorry, Noleen K

Abstract: Staff in palliative care settings perform emotionally demanding roles which may lead to psychological distress including stress and burnout. Therefore, interventions have been designed to address these occupational risks. To investigate quantitative studies exploring the effectiveness of psychosocial interventions that attempt to improve psychological wellbeing of palliative care staff. A systematic review was conducted according to methodological guidance from UK Centre for Reviews and Dissemination. A search strategy was developed based on the initial scans of palliative care studies. Potentially eligible research articles were identified by searching the following databases: CINAHL, MEDLINE (Ovid), PsycINFO and Web of Science. Two reviewers independently screened studies against pre-set eligibility criteria. To assess quality, both researchers separately assessed the remaining studies using the Quality Assessment Tool for Quantitative Studies. A total of 1786 potentially eligible articles were identified - nine remained following screening and quality assessment. Study types included two randomised controlled trials, two non-randomised controlled trial designs, four one-group pre-post evaluations and one process evaluation. Studies took place in the United States and Canada (5), Europe (3) and Hong Kong (1). Interventions comprised a mixture of relaxation, education, support and cognitive training and targeted stress, fatigue, burnout, depression and satisfaction. The randomised controlled trial evaluations did not improve psychological wellbeing of palliative care staff. Only two of the quasi-experimental studies appeared to show improved staff wellbeing although these studies were methodologically weak. There is an urgent need to address the lack of intervention development work and high-quality research in this area. © The Author(s) 2016.

Title: Assessment of a learning intervention in palliative care based on clinical simulations for nursing students.
Citation: Nurse education today, Oct 2016, vol. 45, p. 219-224, 1532-2793 (October 2016)
Author(s): Sarabia-Cobo, Carmen María, Alconero-Camarero, Ana Rosa, Lavín-Alconero, Lucía, Ibáñez-Rementería, Isabel

Abstract: Major deficiencies exist in undergraduate nursing education for Palliative Care. Opportunities to care for dying patients are often unavailable to students in traditional clinical settings. Palliative care simulation is an innovative strategy that may help to prepare undergraduate nursing students to provide quality palliative/end of life care. It is valuable to explore the student nurses’ beliefs, feelings and satisfaction regarding the impact that simulation clinic applied to palliative care has and how it influenced their overall experience of caring for a dying patient and the patient's family.

This study aimed to evaluate a learning intervention in palliative care using a low-fidelity clinical simulation for undergraduate nursing students from a Spanish university, based on the analytics of their expectations and learning objectives. Sixty-eight students participated in this mixed descriptive design study, they participated in a palliative care simulation scenario and completed three questionnaires which assess the knowledge and expectations before the simulation and the subsequent satisfaction with the performance and learning received. The intervention in question met students' learning expectations, singling out social abilities as important tools in palliative care training, and the students were satisfied with the presented case studies. Our results suggest that low-fidelity clinical simulation intervention training in palliative care is an appropriate and low-cost tool for acquiring competitive skills. Learning in the simulation scenarios provides a mechanism for students to improve student communication skills. Copyright © 2016 Elsevier Ltd. All rights reserved.

Title: Evidence still insufficient that advance care documentation leads to engagement of healthcare professionals in end-of-life discussions: A systematic review.
Citation: Palliative medicine, Oct 2016, vol. 30, no. 9, p. 807-824, 1477-030X (October 2016)
Author(s): Lewis, Ebony, Cardona-Morrell, Magnolia, Ong, Kok Y, Trankle, Steven A, Hillman, Ken

Abstract: Administration of non-beneficial life-sustaining treatments in terminal elderly patients still occurs due to lack of knowledge of patient's wishes or delayed physician-family communications on preference. To determine whether advance care documentation encourages healthcare professional's timely engagement in end-of-life discussions. Systematic review of the English language articles published from January 2000 to April 2015. EMBASE, MEDLINE, EBM REVIEWS, PsycINFO, CINAHL and Cochrane Library and manual searches of reference lists. A total of 24 eligible articles from 10 countries including 23,914 subjects met the inclusion criteria, mostly using qualitative or mixed methods, with the exception of two cohort studies. The influence of advance care documentation on initiation of end-of-life discussions was predominantly based on perceptions, attitudes, beliefs and personal experience rather than on standard replicable measures of effectiveness in triggering the discussion. While health professionals reported positive perceptions of the use of advance care documentations (18/24 studies), actual evidence of their engagement in end-of-life discussions or confidence gained from accessing previously formulated wishes in advance care documentations was not generally available. Perceived effectiveness of advance care documentation in encouraging end-of-life discussions appears to be high but is mostly derived from low-level evidence studies. This may indicate a willingness and openness of patients, surrogates and staff to perceive advance directives as an instrument to improve communication, rather than actual evidence of timeliness or effectiveness from suitably designed studies. The assumption that advance care documentations will lead to higher physicians' confidence or engagement in communicating with patients/families could not be objectively demonstrated in this review. © The Author(s) 2016.
Title: Palliative Care and Moral Distress in the Intensive Care Unit.
Citation: Journal of Hospice & Palliative Nursing, 2016, vol./is. 18/5(405-412), 15222179
Author(s): Wolf, Alexander T.

Title: Creating a safe space: A qualitative inquiry into the way doctors discuss spirituality.
Citation: Palliative & Supportive Care, 2016, vol./is. 14/5(519-531), 14789515
Author(s): Best, Megan, Butow, Phyllis, Olver, Ian

Abstract: Objective: Spiritual history taking by physicians is recommended as part of palliative care. Nevertheless, very few studies have explored the way that experienced physicians undertake this task. Method: Using grounded theory, semistructured interviews were conducted with 23 physicians who had experience in caring for advanced cancer patients. They were asked to describe the way they discuss spirituality with their patients. Results: We have described a delicate, skilled, tailored process whereby physicians create a space in which patients feel safe enough to discuss intimate topics. Six themes were identified: (1) developing the self: physicians describe the need to understand and be secure in one's own spirituality and be comfortable with one's own mortality before being able to discuss spirituality; (2) developing one's attitude: awareness of the importance of spirituality in the life of a patient, and the need to respect each patient's beliefs is a prerequisite; (3) experienced physicians wait for the patient to give them an indication that they are ready to discuss spiritual issues and follow their lead; (4) what makes it easier: spiritual discussion is easier when doctor and patient share spiritual and cultural backgrounds, and the patient needs to be physically comfortable and willing to talk; (5) what makes it harder: experienced physicians know that they will find it difficult to discuss spirituality when they are rushed and when they identify too closely with a patient's struggles; and (6) an important and effective intervention: exploration of patient spirituality improves care and enhances coping. Significance Of Results: A delicate, skilled, tailored process has been described whereby doctors endeavor to create a space in which patients feel sufficiently safe to discuss intimate topics.
If you are unable to find a book, or require a book that is not on this list, please ask library staff who will be able to locate the book for you using interlibrary loan.

Please note that some books detailed below may not be available in your local library and would need to be ordered for you.

**Introducing Palliative Care**
Twycross, R et al
2016, 5th ed

*From the back of the book:*
Introducing Palliative Care is a highly successful and well-established introductory text for palliative care. Over two decades, it has been used by medical students, doctors, nurses, and other health professionals in the UK and beyond. This fifth edition (IPC5) sees a move from single authorship to a collaborative project between the palliativedrugs.com Editorial team and eight new contributors. IPC5 covers the Association for Palliative Medicine of Great Britain and Ireland's recommended curriculum for medical undergraduates. It is thus a key resource for medical students, which will also serve them well as junior hospital doctors and beyond. IPC5 has much expanded sections on ethics, the law, children, symptom management and contains The Essential Palliative Care Formulary. Although medically oriented, there is much of use to undergraduates and graduates of other disciplines. The clinical focus is on advanced cancer but the general principles and most of the details are equally applicable to patients dying from other incurable progressive life-threatening conditions.

**Paediatric Palliative Medicine**
Hain, R
2016

*From the back of the book:*
This second edition of Paediatric Palliative Medicine is full of easily-accessible, detailed information, and covers all aspects of the care of children with life-limiting illnesses. It is designed to equip clinicians with the knowledge, and its evidence base, to improve clinical care. It includes a quick reference drug formulary and detailed information on medical conditions and symptom control. There are also specific management plans to guide professionals, whether the child is in their own home, in a hospital, or a hospice. Many children with long term conditions have symptoms which need management, and the principles of palliative care for children need to be known by all who are involved in their care. The unique significance of this handbook is its capacity to guide professionals who have not trained or had experience of caring for the dying child, as well as for students and trainees interested in paediatric palliative care. Children's palliative medicine encompasses symptom control but is not limited to it. This handbook also provides a wealth of information on the philosophy and models that support delivery of palliative medicine to children, as well as the learning and coping skills required in palliative care. Fully updated with an expanded formulary and a new chapter on the intensive care unit, this new edition continues to be the authoritative reference tool in paediatric palliative care.

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Protocols from September 2016

The effectiveness and cost-effectiveness of inpatient specialist palliative care in acute hospitals for adults with advanced illness and their caregivers

GUIDELINES

NICE Guidelines

Current Guideline

NG31- Care of dying adults in the last days of life - December 2015

Updated Guideline

CG140- Palliative care for adults: strong opioids for pain relief - updated August 2016

UPTODATE

What's new from our clinical decision-making tool on the topic of end of life care.

UpToDate (Access for Musgrove Park Staff only)

Please contact library staff for details on how to access these resources; you will need an Athens password.

REPORTS, PUBLICATIONS AND RESOURCES

SCIE (Social Care Institute for Excellence) End of Life Care

National Council for Palliative Care
European Association for Palliative Care

European Association for Palliative Care

14th World Congress of the European Association for Palliative Care - information from the 14th World Congress of the European Association for Palliative Care, held in May 2015

Royal College of Physicians

Palliative and end of life care toolkit

National Institute for Health Research

Themed review - Better Endings: Right care, right place, right time

NHS England

Transforming end of life care in hospitals: the route to success ‘how to’ guide

e-Learning for Healthcare

End of life care: e-learning modules to support NICE Guideline NG31 Care of Dying Adults in the Last Days of Life

Ambitions for Palliative and End of Life Care: A national framework for local action 2015-2020
New ambitions raise the bar for end of life care. National framework for action urges local leadership to be at forefront of improvement in end of life care.

The National Palliative and End of Life Care Partnership, made up of statutory bodies including NHS England, the Association of Adult Social Services, charities and groups representing patients and professionals has developed a framework for action in making palliative and end of life care a priority at local level.

Each community is prepared to help - Guidance on Ambition 6 of the national framework
New guidance has been published which includes practical advice aimed at strengthening the capacity of communities to care for dying people and their families. The guidance – entitled Each Community is Prepared to Help - has been produced by the National Council for Palliative Care (NCPC), Public Health Palliative Care UK and Hospice UK. It contains a range of practical ideas for working with hospices, hospitals, Health & Wellbeing Boards, Clinical Commissioning Groups and other relevant organisations in rolling out community development in end of life care.

NEW National Council for Palliative Care report
The National Council for Palliative Care (NCPC) have published a new report Staff prepared to care? Capacity and competence in the end of life care workforce.

CQC Review A different ending: End of life care review
This review of end of life care found that people from certain groups in society sometimes experience poorer quality care because providers do not always understand or fully consider their needs. In light
of this, the report argues that some commissioners and providers might not be fulfilling their duties under the Equality Act 2010 as all public bodies have a legal duty to consider the needs of a range of equality groups when carrying out their day-to-day work. The review identified examples of good practice, but found that action is needed to make sure everyone has the same access to high quality, personalised care at the end of their lives, regardless of their diagnosis, age, ethnic background, sexual orientation, gender identity, disability or social circumstances.

**NHS Employers End-of-life care information and training**

End-of-life care is an important subject. It gives more choice to patients on how and where they die, and ensures that they receive high quality care as they approach the end of their lives. We are working with Health Education England on a new programme of work which aims to support and encourage NHS organisations to invest in the education and training of staff to deliver high quality, end-of-life care.

**End-of-life care training**

NHS Employers has produced a short video featuring Salford Royal Foundation Trust and its collaborative approach to delivering end-of-life care training to providers across the region. The video shows how end-of-life care training is delivered across organisational boundaries to ensure patients receive the same quality of care – known locally as the Salford standard - no matter which provider delivers the care.

**Palliative Care is still largely misunderstood by the public in N. Ireland**

More than half of adults recently surveyed in Northern Ireland (51%) report that they have a basic or minimal understanding of what palliative care involves. Eighty-three percent of respondents did not believe that there is sufficient public understanding of palliative care.

The results of the survey, commissioned by All Ireland Institute of Hospice and Palliative Care (AIHPC) earlier this month, were announced at the launch of Palliative Care Week which will take place across the island of Ireland from October 3-8.
The latest from popular Twitter pages dedicated to end of life care:

**PLEASE NOTE LINKS WORK BETTER IN CHROME BROWSER**

End of Life Studies [@EndofLifeStudy](http://twitter.com/EndofLifeStudy)
Public Health Palliative Care [@PHPalCare](http://twitter.com/PHPalCare)
European Association for Palliative Care [@EAPCOnlus](http://twitter.com/EAPCOnlus)
Cicely Saunders Institute [@CSI_KCL](http://twitter.com/CSI_KCL)
Palliative Medicine Journal [@PalliativeMedJ](http://twitter.com/PalliativeMedJ)

Ongoing training: events throughout the year-
[http://www.endoflifecareintelligence.org.uk/events/](http://www.endoflifecareintelligence.org.uk/events/)

**15th World Congress of the European Association for Palliative Care** - 11th-13th May 2017, Madrid

**5th International Public Health and Palliative Care Conference** - 18th-20th September 2017, Ottawa, Ontario, Canada- Includes links to past conferences and presentations
Looking for the latest evidence-based research but haven’t got time to trawl the databases?

Do you need a literature search carried out?

Do you need to find evidence to support an improvement?

Do you want to know how something has been done elsewhere and whether it worked?

Library staff provide a literature search service for busy clinicians who are pressed for time.

To request a search please complete and return the appropriate form, providing as much information as possible. Alternatively if you would like an assisted search training session, where we will sit down with you and go through the steps of a literature search, then please contact the library.

Please click here to access a literature search request form. Simply complete and email back to us.

Most electronic resources are available via an Athens password. You can register for this via the Library intranet page, or from home at www.swice.nhs.uk and following the link for Athens self-registration.

Please note that registering from home will take longer as it will need to be verified that you are NHS staff/student on placement.

The library offers training on how to access and use Athens resources, as well as an introductory course on critical appraisal. You can book a course through the Learning and Development intranet page, or by contacting the library directly.