A beginner's guide to successful palliative care research

February 2011

Scottish Partnership for Palliative Care

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Contents

Section1: Introduction

1.1 Background

The evidence base for palliative care is stronger in the UK than in most countries. However, it has been argued that the progress of research in palliative care has been relatively slow in comparison to other specialties (Hanks et al, 2010), and that research in palliative care would be helped by high quality research skills amongst a greater number of practitioners (Field et al, 2001 cited in Johnston et al, 2005). There are various ethical issues that pose particular challenges in the area of palliative care research. There have also been many palliative care studies which have been locally based or small in scale, and therefore difficult to generalise (Johnston et al, 2005). Multi-disciplinary and multi-centre collaboration is particularly helpful in providing useful palliative care research. It is essential that palliative care in Scotland continues to build on the current research base, producing high quality research to allow practitioners to provide evidence-based care. It is through this cycle of research, implementation and evaluation that practice is improved and patient care enhanced.

1.2 Purpose

This document provides basic guidance for health and social care professionals on how to begin to engage in palliative care research. It is not intended to be a complete guide to conducting palliative care research, but is designed to help people to get started. It aims to assist those who have not had much previous experience in palliative care research to:

- understand the research process
- identify potentially useful ideas for research
- utilise other people's research
- write a research proposal
- gain research approval from appropriate bodies
- source funding for palliative care research
- undertake research while continuing their clinical role or secondment
- write up research
- disseminate research findings.

1.3 Definitions

This document is designed to provide guidance on 'research', and does not provide guidance on 'clinical audit' or 'service evaluation'. Definitions of these three terms are provided in the glossary (see Appendix 1).

1.4 Caveat

Efforts have been made to ensure that the information in this document is correct at the time of publication. It is likely that some of this information will become out-of-date over time. To minimise the effects of this, the document directs readers to external sources when possible, with the aim of enabling readers to access information that is likely (but not guaranteed) to be updated as changes occur.

Section 2: Understanding the research process

2.1 An overview of the research process

Before thinking about undertaking a piece of research it is helpful to have an idea of what steps are involved and the kinds of issues that may have to be considered along the way. It is a good idea to identify potential collaborators and sound out some ideas with others before beginning. Different stages in the research process are set out below. Though these are set out in a flowchart, the stages do not necessarily follow on from each other in a straightforward fashion, since many stages will overlap or happen simultaneously, and the exact order in which things happen will depend on circumstances.

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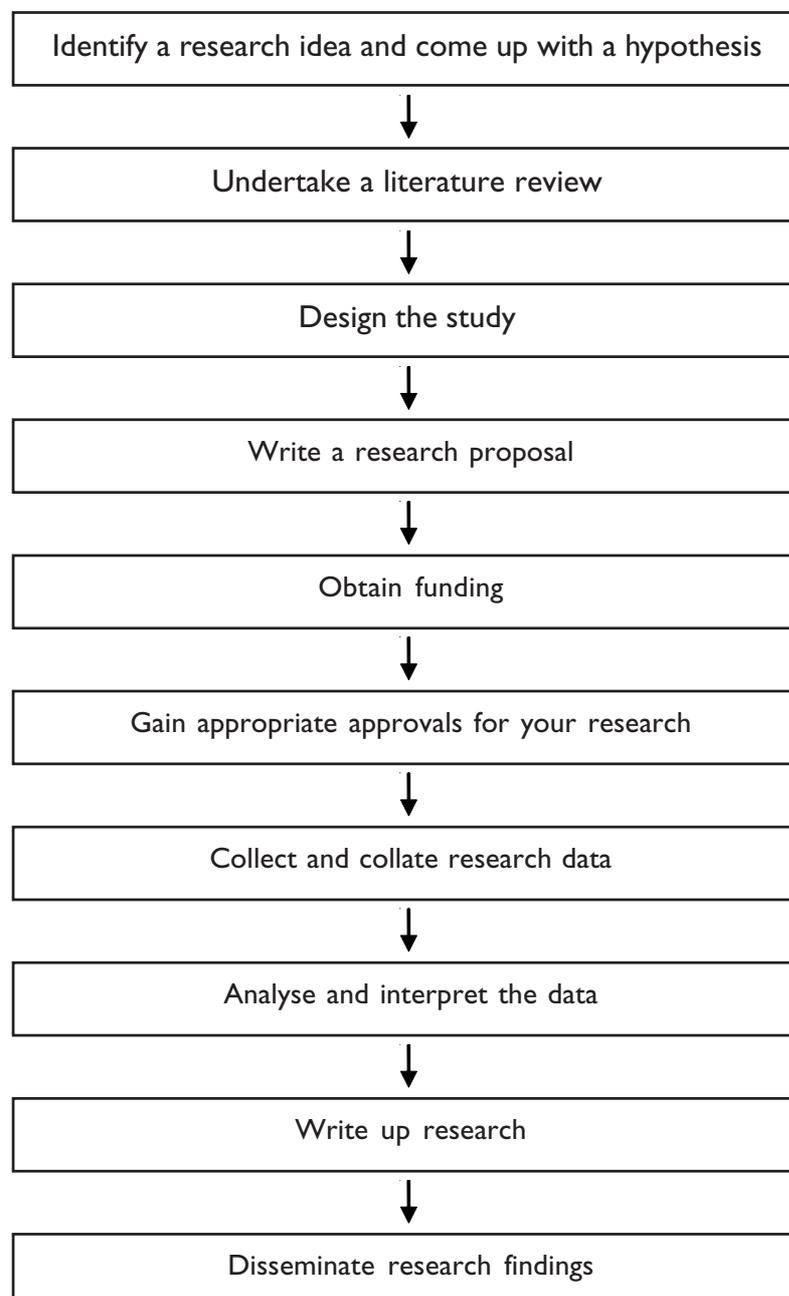
2.1.1 Identifying a research idea and coming up with a hypothesis (see section 5)

The first step in any research project is to choose an area that interests you and come up with the specific research question that you wish to answer. At this stage you should be clear about your aim, your hypothesis, why this research matters and how it will be of use once it is completed. It is advisable to discuss your ideas with others who have had research experience, to think about who will supervise or mentor you during this research and to consider who you will collaborate with (multi-disciplinary, multi-centre?) when undertaking the research since it is advisable to collaborate with someone more experienced than yourself. If you don't know who to speak to, you could begin by contacting one of the key palliative care research collaboratives or academic centres listed in section 5.2. (For more information about collaboration see sections 4.2.1 and 5.) Now is probably also a good time to think about some of the authorship issues outlined in Section 15.

At this stage it is also a good idea to think about the timing of your project. It can be difficult to predict how long a project will take, so if you are inexperienced at research, you may wish to seek advice from someone with more experience. Researchers need to allocate dedicated time in which to undertake research, even if it is just one day per week. So you need to think roughly how long will it realistically take you to complete each stage of the research, and can you make this time available? Dedicated time for your research will need to be negotiated with the appropriate line management. If the decision is made to proceed, then it is advisable to form a steering group to oversee the project and lend support and advice.

2.1.2 Undertaking a literature review (see section 6)

It is important that your research builds on the existing knowledge base, and it is therefore essential to conduct a review of relevant literature before you firm up your ideas and begin your research. This will help you to identify gaps in previous projects, avoid pointlessly repeating other people's research, and ascertain whether there is any merit in trying to repeat a research finding from an earlier study. At this stage it is also important to keep a detailed record of helpful sources so that you can reference them within your final report or include them in your final bibliography. (See section 13.)

2.1.3 Designing the study (see sections 7, 8 and 9)

You must design a study appropriate to the question you are asking and think carefully about the most appropriate methodology to use for your research. What definitions and measures will you use, and how will you ensure these are reliable and valid? How will you recruit participants for your study? How will you analyse your results? Recruitment and attrition can cause difficulties in palliative care research (see section 4), and possible problems and their solutions should be considered at the outset. It is important to speak to a statistician or other appropriate expert before you begin, since they can help to ensure that you collect all the information you require, identify how to handle missing data, and also help you to avoid collecting unnecessary data. If you are unsure how to access a statistician, you could begin by contacting one of the key palliative care research collaboratives or academic centres listed in section 5.2. Feasibility work to determine if the subjects you wish to study are present and how frequently they may be encountered, or a pilot study will need to be undertaken.

2.1.4 Patient/public involvement

Patient and Public Involvement (PPI) has become increasingly common in many parts of the NHS and Social Care, but has played a less consistent role in palliative and end of life care. This is partly because of the special challenges that involvement presents in this context (see section 4). However, demonstrating patient and public involvement in research is increasingly a requirement of funders and an indicator of good practice, and steering committees usually include a patient or member of the public.

So, why do we need to be concerned about involving patients and carers in the provision, commissioning and evaluation of palliative and end of life care? Patients, carers and the public can contribute important expertise and help to ensure that research is of the highest value. Active public involvement in research is different from simply taking part in a research study. For example, it can mean:

- helping researchers to identify and ask the right questions in the right way
- making sure that health and social care research is relevant to patients, people using services and the public
- getting involved in the research process itself, for example designing, managing, undertaking or disseminating research.

Patients and carers often want to 'give something back' to the organisation or people who cared for them, and patient and public involvement does not have to be on a large, formalised scale - any attempt to learn what patients, carers and the public want from services is valid.

Further resources on patient/public involvement

The National Council for Palliative Care and NHS Centre for Involvement (2009) *A Guide to Involving patients, carers and the public in palliative care and end of life care services. Including a Practical Educational Tool.* (WWW[1]) (Available from: http://www.ncpc.org.uk)

Scottish Health Council (2010) *The Participation Toolkit.* (WWW)
(Available from: http://www.scottishhealthcouncil.org/shc/pfpi/toolkit/Participation_Toolkit)

Johnston, B. (2008) Editorial: Involving patients in care and research. *International Journal of Palliative Nursing*, 14(4), pp160

Johnston, B., Forbat, L. and Hubbard, G. Involving and engaging patients in cancer and palliative care research: workshop presentation. *International Journal of Palliative Nursing,* 2008, 14(11), pp554-557

INVOLVE
INVOLVE is a national advisory group which supports greater public involvement in NHS, public health and social care research. For more information see website: www.invo.org.uk

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2.1.5 Writing a research proposal (see section 10)

Once you have undertaken the necessary groundwork as outlined above, you will be able to write the first draft of a research proposal. Your collaborators will provide feedback and advice as the proposal takes shape. The requirements of the research proposal will differ depending on the organisation from which you intend to seek funding, and it is important to investigate what format and content will be required by whichever funding body you are applying to. If the research is for a higher degree you will wish to discuss your proposal with someone more experienced, for example your supervisor and/or your proposed sponsor, before submission.

2.1.6 Obtaining funding (see section 11)

You will need to find a source of funding to enable you to undertake your research. Section 11 of this guidance document provides directions to possible sources of funding for palliative care research. Ensure that the amount of funding you apply for is realistic to cover the entire cost of the research, including the time it will take to write up findings.

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[1] 'WWW' indicates that this resource has been published on the World Wide Web.

2.1.7 Gaining appropriate approvals for your research (see section 3)

It is essential that you seek and obtain written ethical approval from the appropriate research ethics committee before you commence recruitment for the research. Failure to do so will lead to disciplinary action from your professional body and make it impossible to publish your research. No research project can go ahead without gaining research and development (R&D) approval from the appropriate body, and more information about this is available in section 3. You should notify R&D once you have received ethics approval, though it may be useful to liaise with them in advance of ethics approval. It is also important to gain management approval from the organisation in which you intend to carry out your research. You should also look into whether you will need to apply for a Disclosure Scotland certificate specifically for the purposes of your research.

2.1.8 Collecting and collating research data

You must ensure that you follow the research proposal previously agreed and make sure that participants are looked after appropriately. Also, as outlined within the Scottish Government's *Research Governance Framework for Health and Community Care* (Chief Scientist Office, 2006), it is essential to protect the integrity and confidentiality of clinical and other records and data generated by the research, and report any failures in these respects, or suspected misconduct, through the appropriate systems. Part of this will be thinking about how you will keep data secure. With regard to clinical trials, various documents identify specific requirements regarding the management of clinical trial records, and a useful guide to these is provided within the European Forum for Good Clinical Practice update paper *Guidelines for retention of clinical trial records at investigator study sites* (Records Management and Archiving Working Party of EFGCP, 1995).

Do not collect data for the sake of 'not missing anything'. Ensure that you only collect what is necessary to answer the research questions. At this stage it is advisable to carefully devise a data recording form such as a spreadsheet or database into which you can enter your data for subsequent analysis. The need for this will depend upon the type of research you are performing.

2.1.9 Analysing and interpreting the data (see section 12)

Once you have collected data you can begin analysis. In some studies it may be appropriate to analyse data as you go along, so that early data can inform later aspects of the study. What does the information collected tell you? Does it answer the set question? Are the findings duplicated in other research? What recommendations or suggestions can you make as a result of the research? What are the limitations of your research?

2.1.10 Writing up research (see section 13)

Having completed your research, you can now complete a write-up of your findings. Different styles of write-up will be appropriate depending on the type of research undertaken and the intended audience for your research. It is important to provide the full details of any sources you refer to within your report.

2.1.11 Disseminating research findings (see section 13)

It is important that you think about how your findings will be useful in a practical sense, and that you disseminate your research findings so that others can learn and benefit from your work. Common ways of doing this are to take research findings to relevant conferences in the form of a display poster or oral presentation, or to publish research as a journal article. It is also important to arrange for participants in the research to receive feedback on outcomes if they wish, and to provide feedback to the organisations who have hosted the research.

Further resources on the research process

National Institute for Healthcare Research Flowchart
More detailed information about the research process is available from the National Institute for Healthcare Research at the following website:
http://www.rdinfo.org.uk/flowchart/Flowchart.html

Clinical Trials Toolkit
The Medical Research Council and the Department of Health have produced a Clinical Trials Toolkit which provides a useful overview of the process of undertaking a clinical trial, along with useful information about each stage. For more information see website:
http://www.ct-toolkit.ac.uk/route_maps/map_landing.cfm?cit_id=250

Hanks, G., Kaasa, S. and Forbes, K. (2010) 'Research in palliative care' in G. Hanks, N.I. Cherry, N.A. Christakis, M. Fallon, S. Kaasa and R.K. Portenoy (eds) *Oxford Textbook of Palliative Medicine,* Fourth Edition, Oxford: Oxford University Press, pp 361

Section 3: Research governance

Research Governance can be defined as:

'the broad range of regulations, principles and standards of good practice that exist to achieve, and continuously improve, research quality across all aspects of healthcare in the UK and worldwide.' (Clinical Research Governance Office, n.d.[2] [a])

3.1 Research Governance Framework for Health and Community Care

Various legislation exists relating to research governance, including legislation regulating the use of human tissue, laws controlling data protection (including the storage and transfer of personal data), and the Adults with Incapacity (Scotland) Act 2000, which provides ways to help safeguard the welfare and finances of people who lack capacity to take some or all decisions for themselves.

If you are unfamiliar with the range of legislation and regulations governing research, a good place to start is the Scottish Government's *Research Governance Framework for Health and Community Care*. This document: *'sets out a framework for the governance of research in health and community care…it applies to clinical and non-clinical research; research undertaken by the NHS or community care staff using the resources of health and community care organisations; and any research undertaken by industry, charities, research councils and universities within the health and community care systems that might have an impact on the quality of those services…*

…The framework is of direct relevance to all those who host, conduct, participate in, fund and manage research. It is not just for investigators, managers or any one professional group…It sets out the responsibilities of all involved in research i.e. researcher, sponsor, funder, employers and organisations providing care.'
(Chief Scientist Office, 2006)

This framework seeks to promote improvements in research quality and provides a context for the encouragement of creative and innovative research and for the effective transfer of learning, technology and best practice to improve care. The framework aims to forestall poor performance, adverse incidents, research misconduct and fraud, and to ensure that lessons are learned and shared when poor practice is identified.

This document is available on the website of the Chief Scientist Office:
http://www.sehd.scot.nhs.uk/cso/

3.2 Good Clinical Practice

'Good Clinical Practice (GCP) is an international ethical and scientific quality standard for designing, recording and reporting trials that involve the participation of human subjects. Compliance with this standard provides public assurance that the rights, safety and well being of trial subjects are protected… and that the clinical trial data and reported results of clinical investigators are credible.' (ICH Expert Working Group, 1996)

Europe adopted the ICH-GCP in 1996, and due to the *EU Clinical Trials Directive*, 2001, and the *Medicines for Human Use (Clinical Trials) Regulations*, 2004, compliance with ICH-GCP is now a legal obligation in the UK and Europe for all trials of investigational medicinal products. (Clinical Research Governance Office, n.d. [b]) Staff involved in any aspect of clinical trial work are therefore advised to be suitably qualified to ensure that they comply with GCP.

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[2] 'n.d.' stands for 'no date' and indicates that no publication date was available for this reference.

Any trial using a drug comes under Medicines and Healthcare Products Regulatory Agency (MHRA) guidance and has to be conducted in accordance with MHRA standards. For more information about this see the MHRA website: http://www.mhra.gov.uk/index.htm

Your professional body may also have specific guidelines regarding good clinical practice.

Additional resources on Good Clinical Practice

A full copy of the ICH consolidated guideline on Good Clinical Practice E6 (R1) (ICH Expert Working Group, 1996) is available on the ICH website:
http://private.ich.org/cache/compo/475-272-1.html#E5

A good place to find out further information about GCP is the website of the *European Medicines Agency* (EMEA): www.emea.europa.eu

With regard to clinical trials, various documents identify specific requirements regarding the management of clinical trial records, and a useful guide to these is provided within the European Forum for Good Clinical Practice update paper *Guidelines for retention of clinical trial records at investigator study sites. (*Records Management and Archiving Working Party of European Forum for Good Clinical Practice, 1995) This can be accessed at:
http://gcp-rma.org/pubs.aspx

Courses

Your local Research & Development department may be able to provide you with information about GCP training courses that will provide you with a suitable GCP qualification. It is advised that individuals refresh their GCP training every two years.

3.3 Research and Development (R&D) approval

Researchers wishing to conduct research with NHS patients must obtain NHS research and development (R&D) approval from the relevant NHS Board. Since hospice patients are NHS patients, this includes any research being conducted in a hospice. If your research will cover more than one NHS Board area, you will need to obtain R&D approval from all the affected NHS Boards.

NHS Research Scotland (NRS)

NHS Research Scotland (NRS) is an initiative developed to streamline the process of obtaining R&D approval for multi-centre research studies in Scotland. The process is managed by the NRS Permissions Coordinating Centre (Permissions CC). As a single and centralised point of contact for researchers and companies wishing to conduct multi-centre clinical research in Scotland, NRS Permissions CC liaises directly with NHS Board R&D offices to help streamline the Scottish R&D permission process. More information about NRS is available on the NRSPCC website:
http://www.nhsgrampian.org/nhsgrampian/
nrspcc.jsp?pContentID=7170&p_applic=CCC&p_service=Content.show&

Integrated Research Application System (IRAS)

For a long time, applying for approvals to conduct a piece of research involved filling in a large number of forms, many of which required the same details, and it was the researcher's responsibility to duplicate this information on the application of each separate review body's application form.

IRAS was launched with the aim of introducing a single Integrated Research Application System to capture all the information needed by researchers to seek permissions and approval to conduct health and social care research in the UK.

The Integrated Research Application System (IRAS):

- is a single system for applying for the permissions and approvals for health and social care community care research in the UK
- enables you to enter the information about your project once instead of duplicating information in separate application forms
- uses filters to ensure that the data collected and collated is appropriate to the type of study, and consequently the permissions and approvals required
- helps you to meet regulatory and governance requirements.

(Integrated Research Application System, 2010)

IRAS captures the information needed for the relevant approvals from various review bodies as listed on their website: https://www.myresearchproject.org.uk/

3.4 Ethical approval

NHS Research Ethics Committees (RECs) have been established throughout the UK with the purpose of safeguarding the rights, dignity and welfare of people participating in research in the NHS. RECs are entirely independent of the researcher and the organisation funding and hosting the research. Members of RECS are trained in research ethics and often have the sort of experience which will be useful in scrutinising the ethical aspects of a research proposal. Members could include patients, members of the public, hospital doctors, GPs, statisticians, pharmacists, academics and people with specific ethical expertise gained through a legal, philosophical or theological background.

The dignity, rights, safety and well-being of participants must be the primary consideration in any research study. It is therefore essential that you obtain ethical approval from the appropriate research ethics committee before commencing your research. This will require you to ethically justify your proposal and follow standard processes for obtaining ethical approval. This can be a lengthy process, and is likely to take at least two to three months, sometimes longer if changes and re-submission are required.   Plenty of time should therefore be allowed for completing the process and awaiting approval. Many members of the ethics committee will have little or no background knowledge of your research topic and you should bear this in mind when considering what language to use in your submission. Going through a rigorous funding application process can give you access to experts which will help to improve your ethics application. Conducting research without ethical approval can lead to severe consequences from your professional body, and journals will not publish research which has not obtained necessary ethical approval at the outset.

You will be notified when your proposal will be considered and should attend the meeting of the REC at which your proposal is being discussed, since your availability to answer questions and clarify points in person can save a huge amount of time and effort.

There may be situations where the NHS Ethics Committee says the proposal is not a piece of research and hence does not require ethics approval. In this case the research can proceed and be published, usually stating that the ethics committee deemed that the study did not require ethical approval.

Integrated Research Application System
Researchers wishing to create new applications for ethical review should use the Integrated Research Application System (IRAS). For more information see section above and the IRAS website: https://www.myresearchproject.org.uk/

3.5   Other Approvals

Management approval

It is important to gain management approval within the organisation in which you intend to carry out your research.

Disclosure Scotland

You should look into whether you will need to apply for a Disclosure Scotland certificate specifically for the purposes of your research. It is likely that if you are operating on a non-NHS contract you will have to apply for a Disclosure Scotland certificate in addition to any you already hold. This may also apply to some individuals holding NHS contracts. The Disclosure Scotland website is: http://www.disclosurescotland.co.uk/

NHS Honorary Contracts and Research Passports

Depending on your contractual arrangement with the NHS organisation hosting your research, you may need a Research Passport or an Honorary Research Contract.

'The *Research in the NHS - Human Resource (HR) Good Practice Resource Pack* describes the Research Passport system. The scheme streamlines procedures associated with issuing honorary research contracts or letters of access to researchers who have no contractual arrangements with NHS organisations who host research, and who carry out research in the NHS that affects patient care, or requires access to NHS facilities.' (National Institute for Healthcare Research, n.d.)

For more information see the relevant section of the website of the *National Institute for Healthcare Research:* http://www.nihr.ac.uk/systems/Pages/systems_research_passports.aspx

Section 4: Some challenges to undertaking palliative care research

Undertaking any research project comes with challenges, and palliative care is no exception. This section aims to set out some of the challenges that are likely to be particularly relevant to anyone undertaking research in the field of palliative care.

4.1 Ethical issues

One of the key factors limiting palliative care research in the past has been a concern that people are particularly vulnerable as they approach the end of their lives, and that asking them to participate in research at this difficult time is ethically questionable for a number of reasons. For example:

- it has been argued that some potential participants may feel desperation at their situation, and be willing to participate in trials that are unlikely to benefit them
- patients may be vulnerable to trying to please their clinicians by taking part in research, and given the often close relationship formed between palliative care practitioners and their clients, this may be more of a problem in palliative care research than in other areas
- it may be difficult to ensure that patients have given truly informed consent to participate in research, since defects in cognitive function may be hidden
- difficulties may also emerge explaining the research to patients, since not all will be entirely aware of or have fully acknowledged their condition and prognosis.

It is important for palliative care researchers to fully understand the principles of 'informed consent', which is an ongoing agreement by a person to receive treatment, undergo procedures or participate in research, after risks, benefits and alternatives have been adequately explained to them and steps taken to ensure that what has been explained has been understood.

Further information about informed consent

Medical Research Council (2007) *MRC Ethics Guide 2007 Medical Research involving adults who cannot consent* (WWW) Available from: www.mrc.ac.uk

Royal College of Nursing (2005) *Informed consent in health and social care research RCN guidance for nurses* (WWW) Available from: http://www.rcn.org.uk

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There are many ethical issues which are particularly relevant to palliative care research and have been discussed at length in the literature (for more information see *Additional Resources* below). The *Oxford Textbook of Palliative Medicine* (Hanks et al eds., 2010) sets out five ethical aspects that should be considered when undertaking palliative care research:

- the study's potential benefits to future patients
- the study's potential benefits to subjects
- the study's risks to subjects
- subjects' decision-making capacity
- the voluntariness of subjects' choices about research participation.

It is advisable to be aware of the relevant issues before you begin your research. In addition, all research projects will be examined by a Research Ethics Committee before they are approved (see section 3.4).

Though palliative care patients may be perceived as 'vulnerable', many would argue that 'shielding' patients from making decisions about participating in research diminishes an individual's autonomy, and that some patients facing the end of their life may wish to make a valuable contribution to society by participating.

It is currently generally accepted that, whatever the sensitivities around palliative care research, in the long run palliative care patients will be disadvantaged if there is a lack of evidence to support improvements and initiatives in palliative care. Therefore, though palliative care research poses many challenges from an ethical point of view, this should not discourage researchers from undertaking research in this field. Though there are many ethical issues to be considered, it is possible to conduct useful, ethical, palliative care research.

Additional Resources on ethical issues

Casarett, D. (2010) 'Ethical issues in palliative care research' in G. Hanks, N.I. Cherry, N.A. Christakis, M. Fallon, S. Kaasa and R.K. Portenoy (eds) *Oxford Textbook of Palliative Medicine,* Fourth Edition, Oxford: Oxford University Press, pp 416-421.

Preston, N., Payne, S. and Todd, C. (2009) Conducting research in palliative care patients: a burden or an opportunity? *International Journal of Palliative Nursing,* 15(11), pp. 524-526.

4.2 Recruitment

Recruiting participants to participate in palliative care research is often perceived as potentially difficult, especially for non-clinical researchers, or for clinical researchers wishing to recruit participants from outwith their own setting. This should not discourage researchers from undertaking research in this area.

4.2.1 Gaining the co-operation of staff

Some difficulties may arise accessing patients through their appropriate care professional. The doctor with overall responsibility for the patient must give their written consent before a researcher can approach any patient, and the researcher then has to check with the immediate caring staff if the potential recruit is fit enough to be approached with a view to participation. Some health professionals may feel protective of patients, feeling that they are too vulnerable to participate (see section 4.1).

- It is essential to secure the co-operation of the health care professionals involved in caring for the patients and to inform potential referral sources, even if this involves time-consuming meetings, explanations or negotiations.

- Professionals are more likely to encourage participation in your research if they are convinced that the research question is an important one.

- Extra workload to the physician has in the past been cited as one main reason for not entering patients into trials, so simple referral routines may encourage more referrals. (Jordhøy et al, 1999)

- If possible secure the co-operation of an influential person to champion your research and encourage colleagues to co-operate.

- Putting ongoing time and effort into recruiting participants, for example by regular 'screening visits' at relevant departments can pay off. (Jordhøy et al, 1999)

- It is increasingly considered good practice for researchers from different areas to collaborate with each other, since this can increase the numbers recruited to each study.

4.2.2 Gaining the co-operation of patients

Palliative care patients are often clinically unstable, have complex symptomatology, or suffer from mental and physical exhaustion, making it difficult for many to participate in or complete a research study. However, many will be able and willing to take part in research if it has been set up properly.

Studies should be designed taking into account the characteristics of the target population for recruitment. It has been suggested that in order to ensure trials are 'patient friendly', patients should be involved in developing protocols and setting up the research agenda, and that 'the ideal trial design in palliative care needs to reflect clinical practice, have wide inclusion and exclusion criteria, few extra hospital visits, be of short duration, of multi-centre design and use simple brief assessments'. (Ling, Rees and Hardy, 2000)

Clearly and carefully worded patient participation letters may aid recruitment.

4.2.3 Further suggestions to aid recruitment

The family of a patient can influence a patient's decision regarding whether to participate in research, and it is important to communicate with family and carers to help them understand the relevance and benefits of the research. It is important to understand that a patient's involvement in research is likely to indirectly involve the wider family, who are also likely to be under many pressures related to the patient's illness. Your study should therefore include provisions for informing and including family members with of course the patient's consent.

Where only a small number of patients have been recruited to your study, the usefulness of the research can be increased by using validated research tools, making it more likely that your research can be included in a meta-analysis in the future.

It is vital to monitor your recruitment rate to be certain that you are keeping to your planned time scale. If the rate is not sufficient you may be able to improve your recruitment techniques. (Jordhøy et al, 1999)

Further resources on recruitment:

Scottish Dementia Clinical Research Network (SDCRN)
The SDCRN promotes clinical research in dementia across Scotland. It runs a register of potential research participants from both urban and rural areas to help recruitment to high quality studies. For more information see website: www.sdcrn.org.uk

Ewing, G., Rogers, M., Barclay, S., McCabe, J., Martin, A. and Todd, C. (2004) Recruiting patients into a primary care based study of palliative care: why is it so difficult? *Palliative Medicine,* 18(5), pp452-459

Ling, J., Rees E., and Hardy, J. (2000) What influences participation in clinical trials in palliative care in a cancer centre? *European Journal of Cancer*, 36(5), pp 621-626.

Jordhøy, M.S., Kaasa, S., Fayers, P., Øvreness, T., Underland, G. And Ahlner-Elmqvist, M. Challenges in palliative care research; recruitment, attrition and compliance: experience from a randomized control trial. *Palliative Medicine*, 13(4), pp 299-310.

Section 4.3: Patient attrition

Given that participants in palliative care research are living with advanced illness, it is not unusual for participants to withdraw from research due to death or impairment due to progressive disease. This is known as 'patient attrition', and is unavoidable in palliative care research. Attrition rates of up to

60% and higher are not uncommon for palliative care research.

Jordhøy et al (1999) suggest taking the following steps to minimise the chances of the sample size dropping so low as to compromise the validity of the trial:

- The first assessment after baseline should be consistent with the shortest intervention time period likely to give a clinically significant effect.
- Define eligibility criteria that can ensure patients' entry at a time when survival will be long enough for the supposed effect both to occur and to be assessed. This can be problematic, since survival estimates are frequently inaccurate.
- Allow for significant attrition when calculating sample size.

It is also wise to consider attrition when designing your study, giving particular consideration to the practicalities of the follow-up elements of your research. If possible, design the study with an element of flexibility, so that it is as straightforward as possible for subjects to participate in all parts of the research. For example, if you are planning to ask participants to complete a questionnaire, you may wish to give them the option of a telephone interview rather than a face-to-face interview since some people may find this easier. Options such as these need to be considered at the outset so that they can be included in your ethics application.

More information about attrition

Jordhøy, M.S., Kaasa, S., Fayers, P., Øvreness, T., Underland, G. And Ahlner-Elmqvist, M. Challenges in palliative care research; recruitment, attrition and compliance: experience from a randomized control trial. *Palliative Medicine*, 13(4), pp 299-310.

Ahlner-Elmqvist, M., Bjordal, K., Jordhøy, M.S., Kaasa, S. and Jannert, M. (2009) Characteristics and implications of attrition in health-related quality of life studies in palliative care *Palliative Medicine,* 23(5) pp432–440

Section 4.4: Emotions of participants and staff

4.4.1 Handling sensitive subjects

Palliative care research often includes the discussion of subjects that both the participant and the researcher might find difficult or emotive. For example, some participants in research may not understand that they are dying, or may not wish to be reminded of the fact. Researchers should bear in mind this kind of concern when designing information sheets and questionnaires. Researchers must be sensitive to the emotions and cues of the participant, taking care to make the interaction positive for all concerned. This is something that researchers without much experience of working within palliative care may find difficult. Failure to observe the emotional state of interviewees can cause real harm, and it is important for an interviewer to competently finish interviews so as to leave the interviewee in a safe emotional state and with access to follow-up support if required. (Kendall et al 2007)

4.4.2 Follow-up support for patients

When speaking to patients, particularly as part of qualitative research, a researcher may uncover information about their condition that was previously unknown. As an ethics committee will point out, it is unethical to ask a question and have no response to the answer, and it is therefore important to plan in advance a protocol for further assessment and care of individuals. Clearly there are rules of confidentiality to be upheld, and therefore any follow-up can only take place if appropriate permissions have been granted. Follow-up might comprise discussion with an appropriate care team member. It

may also include referral to specialist palliative care services, but there can be a considerable conflict of role if the researcher feels obliged to provide this type of assessment and treatment. This can also add considerably to the time burden of the research and should therefore be considered in planning the project.

All research requires a plan for what happens to the patients at the end of the project, and this is equally important in palliative care research. For example, if you are evaluating a patient support service, who will provide support when the project ends? It can be unethical to withdraw an effective intervention when the funding runs out.

4.4.3 Follow-up support for staff

Palliative care research, particularly qualitative research, is likely to expose research staff to difficult or troubling issues, and this exposure can be very distressing, especially for researchers or support staff who are not used to palliative care populations. Training and emotional support for staff should therefore be built into the project, with access to formal counselling as well as informal debriefing and peer support (Kendall et al, 2007).

Further resources

Addington-Hall, J. (2002) Research sensitivities to palliative care patients *European Journal of Cancer Care*, 11(3, September), pp 220-224.

Section 5: Identifying potentially useful ideas for research

The first step in any research process is to identify a specific research question that you wish to answer. You may already have a clear idea of what you want to look at, but when initially forming your ideas it is always a good idea to look around at what other research is currently being done. If, on the other hand, you're still unsure of exactly what research you want to do you could try contacting other researchers, organisations or collaboratives to find out their current research plans and priorities.

Once you have a rough idea of the area you are interested in, a literature review should allow you to see what research has already been done in this area, and make judgements on what research might be useful for the future.

5.1 Key journals

Looking at recent editions of journals will help you to gain awareness of what research is currently being done. A list of some of the key journals which publish palliative care research is provided at Appendix 2.

5.2 Useful organisations

The following organisations are well known for doing research in palliative care and you may wish to contact them to find out their current research plans and priorities:

Cancer Care Research Centre University of Stirling: www.cancercare.stir.ac.uk

The Cancer Care Research Centre (CCRC) was established so that people affected by cancer could help shape the future of cancer services in Scotland. It works with large numbers of people affected by cancer across Scotland and carries out research in the key areas of Families, Children and Relationships, Cancer as a Long Term Condition and Symptom Improvement.

University of Glasgow Centre for Oncology and Applied Pharmacology:
www.gla.ac.uk/departments/cancerpathology/oncology/

The Centre for Oncology and Applied Pharmacology (COAP) consists of 3 lab-based Cancer Research UK funded programmes and the Clinical Trials Unit (CTU) based at the Beatson West of Scotland Cancer Centre. In addition COAP is part of the Experimental Cancer Medicine Centre with a particular emphasis on patients' sample collection and processing to GLP standards as part of prospective early phase and translational clinical studies. The centre has very strong links with the Beatson Institute for Cancer Research, and the CTU is the hub of the West of Scotland Cancer Research Network, and is also a partner in Cancer Clinical Trials Unit for Scotland (CACTUS).

Edinburgh Supportive and Palliative Care Research Group: https://dcnapp4.dcn.ed.ac.uk/pregabalin/
At July 2010 the Group has 4 Senior Researchers, along with 4 MD/PhD students and research staff in 20 centres in the UK. It has an important European collaboration (Research and International PhD programme) and a unique basic science collaboration in Edinburgh. The group has the largest portfolio of Investigator-led RCT's in palliative care in the UK. The studies cover the range of difficult to control cancer pain syndromes - neuropathic and bone pain and have the appropriate basic science component behind their development and understanding. A range of methodologies is also used. In addition the group has cachexia, breathlessness and patient acceptability work. A programme of supportive oncology is now also in place with a Medical Oncologist in a Clinician Scientist Supportive Oncology post to facilitate this. Novel breakthroughs in the area of chemotherapy-induced peripheral neuropathy have been reported by the group.

Palliative Care Research Society: www.pcrs.org.uk

The Palliative Care Research Society is dedicated to promoting research into all aspects of palliative care and to facilitating its dissemination. Membership of the society is open to any individual or organisation who is interested in furthering the society's aims.

Primary Palliative Care Research Group, University of Edinburgh: www.homepages.ed.ac.uk/smurray1/

The Primary Palliative Care Research Group aims to conduct research relevant to the key challenges facing end-of-life care. As a multi-disciplinary team drawn from hospital, hospice, primary care and social science settings, its experience and expertise is in seeking patient and carer perspectives using qualitative longitudinal methods and integrating these with professional views in order to make recommendations for service development. They also trial and evaluate complex interventions to inform national developments in palliative care.

The Compass Collaborative: www.compasscollaborative.com/

The COMPASS collaborative unites researchers from 12 UK universities in order to develop treatments that will improve the wellbeing of people affected by cancer and other serious illnesses both in hospital and at home.

The Cancer Experience Collaborative: www.ceco.org.uk/

CECO is an equal partnership between researchers at five universities, clinical organisations and user representatives. It aims to work together to make substantive progress in research capacity and the quality of research in supportive and palliative care.

Scottish Primary Care Research Network: http://www.sspc.ac.uk/spcrn/

This network was formerly known as the Scottish Practices and Professionals Interested in Research (SPPiRE). Its key aim is to facilitate national research activity in primary care, undertaking projects with other Scottish networks and colleagues in England.

5.3 Conferences and study days

Attending conferences and study days can be a good way to meet other people doing research and to find out recent developments. Some relevant conferences are listed in section 14.2.

Additional resources on identifying potential ideas

Johnston, B., Nimmo, S., Baughan, P. and Kearney, N. (2005) *A scoping review of palliative care in Scotland: final report*, Stirling: Cancer Care Research Centre.

This project undertook a thorough review of palliative care literature published between January 1990 and April 2005. The aim was to specify the extent of palliative care research in Scotland in order to identify gaps in the evidence. This report identifies a number of research priorities, and you may find it useful if you are exploring potentially useful ideas for research.

CHAIN - Contact, Help, Advice and Information Network
CHAIN is an online network for people working in health and social care. It is based around specific areas of interest, and gives people a simple and informal way of contacting each other to exchange ideas and share knowledge. For more information on CHAIN and joining the network visit this website:
http://chain.ulcc.ac.uk/chain/index.html

Psychosocial research

Some future areas for psychosocial research are suggested within:

Kissane, D.W., Street, A.F. and E. Schweers Cornelius. (2010) 'Research into psychosocial issues' in G. Hanks, N.I. Cherry, N.A. Christakis, M. Fallon, S. Kaasa and R.K. Portenoy (eds) *Oxford Textbook of Palliative Medicine,* Fourth Edition, Oxford: Oxford University Press, pp 403-415

Section 6: Utilising other people's research

6.1 Electronic literature searches

It is important to know what previous research has already been done that is relevant to your research, and carrying out a thorough literature search is therefore essential. Electronic literature searches are the most efficient way of finding existing research articles. Provided below is some guidance on how to approach conducting an electronic literature search.

a) Define the topic

Make sure you are clear about the topic you are interested in.

b) List all the sources to be searched

Various searchable databases of research articles exist and each is focused on a slightly different area. For example:

- **CINAHL** The Cumulative Index to Nursing and Allied Health (CINAHL) database provides authoritative coverage of the literature related to nursing and allied health professions, from 1982 to the present.
- **MEDLINE** is the U.S. National Library of Medicine's premier bibliographic database covering the fields of medicine, nursing, dentistry, veterinary medicine, the health care system, and the preclinical sciences, from 1965 to the present. Practical guidance on searching MEDLINE is provided in:
  Greenhalgh, T. (1997) How to read a paper. The Medline database. *BMJ* 1997;315:180
- **EMBASE** is a biomedical and pharmacological bibliographic database providing access to the most up-to-date information about medical and drug-related subjects.

These three databases are well-respected, and a good list of other searchable databases is available at: www.knowledge.scot.nhs.uk

When searching for relevant literature, it is advisable to search two electronic databases, beginning with the database most relevant to your particular discipline (eg MEDLINE if you are a doctor, CINAHL if you are a nurse), and then backing this up by searching a second database. All of these databases will ask you for an ATHENS password before they allow you to begin your search. You can apply for an ATHENS password through your librarian at work, or through the NHS Scotland e-library: www.knowledge.scot.nhs.uk

c) List key words

To use any of the searchable databases described above, you will need to enter a number of key words. The search engine will then use these key words to find articles that are likely to be of interest to you. It is advisable to write down these key words before you start so that you remember what searches you have performed and which ones you have still to try.

d) Record references found

Once you have used the searchable database to bring up a list of articles and resources that might be of interest, you'll need to make a record of the name of the article, its author(s), and where and when it was published. This will enable you to find the article in a journal or other publication. Most search engines will allow you to print off lists of references with article abstracts which you can then read through and select the relevant papers at your leisure.

RefWorks is a tool to assist in the recording of references. It is: 'a web-based bibliography and database manager that allows you to create your own personal database by importing references

from text files or online databases and other various sources. You can use these references in writing papers and automatically format the paper and the bibliography in seconds.' (RefWorks, n.d.) RefWorks is available free to registered users of NHS Education Scotland's *The Knowledge Network* website: www.knowledge.scot.nhs.uk

e) Prioritise relevant material

Most of the searchable databases described above will have a facility to provide you with the abstract of each of the articles found. Reading through the abstract will help you to work out how relevant a particular article is likely to be to the subject you are researching. In this way you can work out which articles you should read in full, and which articles you don't need to read at all.

f) Work out a plan to obtain literature

The searchable databases will only provide you with the publication details, author, title, and possibly the abstract, of the resources relevant to the key words you have entered. If you want to read an article in full, you will have to access it yourself by finding a copy of the journal in a library. By registering with the NHS Scotland e-library you can access a large collection of journals on-line and for free: www.knowledge.scot.nhs.uk If you are unable to access the journal you require on the e-library or via a local specialist library, the National Library of Scotland is likely to hold a copy, since they tend to request copies of all printed items published in the UK. If you cannot access the National Library in person, for a fee, you can request that the relevant article be posted to you.

g) Review the material found

For more information about reviewing literature, see section 6.3 below.

At this stage it is also important to keep a detailed record of all the sources you find helpful since your final report should include a detailed reference list (see section 13). You will need to include details such as author, title, page number, publisher and date of publication. If referencing a web-based resource it is helpful to make a note of the date it was accessed.

Practical tip:

There are courses designed to teach literature search techniques. If you are interested, your local University, NHS or Hospice librarian may be able to direct you to a good course in your area.

Useful resources

NHS Scotland e-library
The NHS Scotland e-library is a free resource, available on the NHS Education for Scotland Knowledge Network website: www.knowledge.scot.nhs.uk
This website provides a variety of useful information, including a full list of searchable databases, and access to many of these databases. The e-library also provides free access to a wide range of journals, as long as you log-in using your ATHENS password. (Information about eligibility and instructions for joining the e-library is available on the website.)

RefWorks
RefWorks is a tool to assist in the recording of references, and is available free to registered users of NHS Education Scotland's *The Knowledge Network* website. The homepage of *The Knowledge Network* website provides a link to RefWorks:
http://www.knowledge.scot.nhs.uk/home.aspx

6.2 Manual literature searches

Though electronic literature searches are the most efficient way to look for references, they do sometimes miss articles that may be of relevance. You should therefore also look through the reference section of key papers in the field to check for useful articles that the search engine may have missed.

6.3 Literature review skills/ Critical reading

When reviewing the literature, some research you come across will be of more use to you than others. It is therefore important to think carefully about what you are reading and evaluate its worth before you use it as a basis for your own research. Some questions to bear in mind when critically evaluating a piece of research are listed below.

- Why are you reading this paper?
- What type of article is it? (Literature review, primary research, secondary research or other.)
- Is there a clearly defined question? What do the authors set out to ask? What do they *actually* ask?
- Is other relevant literature in this field discussed in the literature review? Is the literature reviewed up to date?
- What is the study design? Is it a quantitative or qualitative study? What research method is used? Is the method appropriate to answer the research question? Was the sampling method valid?
- Was the study valid and reliable in design? Was it biased? What are the strengths and weaknesses of the design?
- Is it clearly written and presented? Are weaknesses in the design noted and discussed? Is there balanced discussion regarding whether the results agree or disagree with previous works? Are ethical issues considered?
- Is the research relevant to your patient population?

- What are the conclusions of the study? Does the study find something new or does it confirm previous research findings? Are the findings relevant? Are the findings important enough to immediately change practice, i.e. for patient safety or wellbeing?

- Who funded the study? Can the research be considered objective, or might financial considerations have compromised an investigator's professional judgment and independence in the design, conduct, or publication of research?

- Do you trust the findings of this study, or do you have reservations? Would you change your practice as a result of this study? Would you inform anyone else about the findings of this study?

Further resources on literature review skills

Courses
The Scottish Intercollegiate Guidelines Network (SIGN) sometimes offers courses on topics such as critical appraisal and interpreting evidence. For further information, see the SIGN website: http://www.sign.ac.uk/

SIGN 50
Scottish Intercollegiate Guidelines Network (2008) *SIGN 50 A Guideline developer's handbook* Edinburgh: NHS Quality Improvement Scotland.
This contains lots of useful information, for example on literature searches, checklist templates and notes for assessing the quality of systematic reviews, randomised control trials, and other types of studies. It can be accessed on the SIGN website: http://www.sign.ac.uk/

BMJ articles
In 1997, the BMJ published a useful series of articles on the subject of 'How to read a paper':

Greenhalgh, T and Taylor R. (1997) Papers that go beyond numbers (qualitative research). *BMJ* 1997;315:740

Greenhalgh, T. (1997) Papers that summarise other papers (systematic reviews and meta-analyses). *BMJ* 1997;315:672

Greenhalgh, T. (1997) How to read a paper. Papers that tell you what things cost (economic analyses). *BMJ* 1997;315:596

Greenhalgh, T. (1997) How to read a paper. Papers that report diagnostic or screening tests. *BMJ* 1997;315:540

Greenhalgh, T. (1997) How to read a paper. Papers that report drug trials. *BMJ* 1997;315:480

Greenhalgh, T. (1997) How to read a paper. Statistics for the non-statistician. II: 'Significant' relations and their pitfalls. *BMJ* 1997;315:422.

Greenhalgh, T. (1997) How to read a paper. Statistics for the non-statistician. I: Different types of data need different statistical tests. *BMJ* 1997;315:364

Greenhalgh, T. (1997) Assessing the methodological quality of published papers. *BMJ* 1997;315:305

Greenhalgh, T. (1997) How to read a paper. Getting your bearings (deciding what the paper is about). *BMJ* 1997;315:243

Greenhalgh, T. (1997) How to read a paper. The Medline database. *BMJ* 1997;315:180

6.4 Accessing routine data

There are various ways to access existing stores of data that may be of use to you in your research. For example:

Information Services Division (ISD) of NHS National Services Scotland is Scotland's national organisation for health information, statistics and IT services. ISD Scotland works in partnership with a wide range of organisations, using national datasets to support the collection and management of information. ISD collects 3 types of information: Patient and Activity Data, Workforce and Earnings Data, and NHSScotland Complaints Data. Much of this data is published on the ISD website. For more information see: www.isdscotland.org

The **General Register Office for Scotland** (GROS) is responsible for the registration of births, marriages, civil partnerships, deaths, divorces, and adoptions in Scotland. They use Census and other data to publish information about population and households, and much of this information is published on their website: www.gro-scotland.gov.uk

Healthtalkonline is designed to let the public share in other people's experiences of health and illness. The information on Healthtalkonline is based on qualitative research into patient experiences, led by experts at the University of Oxford. For more information see: www.healthtalkonline.org

The **Freedom of Information Act 2000** and the **Freedom of Information (Scotland) Act 2002** deal with access to official information and give individuals or organisations the right to request information from any public authority. The Acts also recognise that there will be valid reasons why some kinds of information may be withheld. For more information about freedom of information in Scotland see: http://www.itspublicknowledge.info/home/ScottishInformationCommissioner.asp
For more information about freedom of information for UK-wide public bodies (including those with offices in Scotland) see: www.ico.gov.uk.

A **Caldicott Guardian** is a senior person responsible for protecting the confidentiality of patient and service-user information and enabling appropriate information-sharing. The Guardian plays a key role in ensuring that the NHS satisfies the highest practicable standards for handling patient identifiable information. Any research involving the use of routinely collected patient data must be approved by the Caldicott Guardian of that particular dataset. For more information see:
Scottish Government, NHSScotland & eHealth (2010) *NHSScotland Caldicott Guardians: Principles into Practice* (WWW) Available from: http://www.knowledge.scot.nhs.uk/caldicottguardians.aspx

NHS Evidence – supportive and palliative care is a website which collects together in one place some of the most recent evidence relating to supportive and palliative care. It is delivered by a small Project Team with reference to an Editorial Panel, supported by input from an expanding email list of stakeholders. Together, those involved are aiming to develop a broad-based 'Community of Practice'. For more information see: http://www.library.nhs.uk/palliative/

Section 7: Choosing appropriate methodology

7.1 Quantitative research

Information is given below about various methods that can be described as 'quantitative'. Of these methodologies, some are generally considered to result in more reliable evidence than research using other methodologies (see 'hierarchies of evidence' in the 'further resources' box below). Meta-analyses, systematic reviews and randomised controlled trials (RCTs) are generally considered the most reliable sources of evidence. However, RCTs in palliative care have been described as 'notoriously difficult to conduct' (McQuay et al, 2010) (see section 4 for an outline of some of the issues), and since systematic reviews are based on RCTs there are currently a relatively small number of systematic reviews in palliative care available to inform practice (McQuay et al, 2010).

However, there is general agreement that it is important that researchers are not discouraged from conducting RCTs in palliative care because of the challenges involved, since it is vital to be able to provide evidence-based palliative care.

7.1.1 Meta-analysis

Meta-analysis is a method which uses statistical techniques to combine the results from previous independent studies to give a quantitative estimate of a particular intervention or variable on a defined outcome. A meta-analysis is likely to produce a stronger conclusion than can be provided by any one individual study.

7.1.2 Systematic Review

A systematic review is a review of previous research that aims to be principled, methodical and explicit. It addresses a clearly defined research question and uses explicit and standardised methods to identify and review the literature. It involves objective means of searching the literature, applying predetermined inclusion and exclusion criteria to this literature, critically appraising the relevant literature, and extraction and synthesis of data from the evidence base to formulate findings. (National Information Center on Health Services Research and Health Care Technology, n.d. and ePPIcentre, n.d.)

7.1.3 Randomised Controlled Trial (RCTs)

Clinical trials evaluate the effectiveness and safety of healthcare interventions by giving different interventions to different groups of patients and comparing the effects of these interventions over time. The RCT is the most common type of clinical trial, and is designed to compare two treatments by randomly allocating a treatment to participants in the trial and then monitoring the effects of each. (Some further resources that may be of use when conducting RCTs are included in the 'further resources' box below.)

If you are undertaking a clinical trial, you may wish to consider registering this in a database of clinical trials. Failure to report RCTs is increasingly seen as scientific and ethical misconduct, and the pressure to register trials to reduce biased under-reporting is growing. Contributing to a comprehensive database of trials can also lead to opportunities for collaboration and reduce duplication of research effort. For more information see website: www.controlled-trials.com (Also see 'registering clinical trials' within the 'further resources' box below.)

7.1.4 Cohort Study

A cohort study compares a particular outcome (such as asthma) in groups of individuals who are alike in many ways but differ by a certain characteristic (for example, middle class children living

7.1.5 Case-Control Study

A case-control study compares two groups of people: those with the disease or condition under study (cases) and a very similar group of people who do not have the disease or condition (controls). Researchers study the medical and lifestyle histories of the people in each group to learn what factors may be associated with the disease or condition. For example, one group may have been exposed to a particular substance that the other was not. This type of study is also known as a 'retrospective study'. (National Cancer Institute, n.d.)

7.1.6 Case Series

A case series is a group or series of case reports involving patients who were given similar treatment. Reports of case series usually contain detailed information about the individual patients. This includes demographic information (for example, age, gender, ethnic origin) and information on diagnosis, treatment, response to treatment, and follow-up after treatment. (National Cancer Institute, n.d.)

7.1.7 Case Reports

A case report is a detailed report of the diagnosis, treatment, and follow-up of an individual patient. Case reports also contain some demographic information about the patient (for example, age, gender, ethnic origin). (National Cancer Institute, n.d.) Case reports are not strictly research and are not a robust source of evidence. However, they do raise questions which can lead to further research, and are often used to guide practice in palliative care when there is a lack of more robust evidence.

7.1.8 Survey research

Most survey research involves the use of questionnaires, which are a quick and cost effective way of gathering data from a relatively large number of subjects. If using questionnaires it is worth bearing in mind that only a small percentage of those who receive the questionnaires are likely to return them. Also, there are limits to the type of information a questionnaire can collect, and respondents may not follow the questionnaire's instructions for completion. Since high quality questionnaires are difficult to create and must be piloted and tested for validity and reliability, it is a good idea to search the relevant literature to see if a suitable questionnaire already exists. However, it is important to check whether or not you need to obtain permission to use a particular assessment tool.

Further resources on quantitative research

Clinical Trials Toolkit
The Medical Research Council and the Department of Health have produced a Clinical Trials Toolkit which will lead you through the various stages of trial design. It provides practical help when trying to meet the requirements of the *UK Medicines for Human Use (Clinical Trials) Regulations 2004*. These regulations implement the *EU Clinical Trials Directive* in the UK. For more information see website: http://www.ct-toolkit.ac.uk/

CONSORT Statement
The CONSORT Statement comprises a checklist and flow diagram which offer an evidence-based, minimum set of recommendations for reporting randomised controlled trials. The checklist items focus on reporting how the trial was designed, analysed, and interpreted; the flow diagram displays the progress of all participants through the trial. For more information see website: http://www.consort-statement.org/

Further resources on quantitative research

McQuay, H.J., Moore, A. and Wiffen, P. (2010) 'The principles of evidence-based medicine' in G. Hanks, N.I. Cherry, N.A. Christakis, M. Fallon, S. Kaasa and R.K. Portenoy (eds) *Oxford Textbook of Palliative Medicine,* Fourth Edition, Oxford: Oxford University Press, pp 375-385

Hierarchies of evidence
Research using certain methodologies is generally considered to be of a higher quality and to result in more reliable evidence than research using other methodologies. The Scottish Intercollegiate Guideline Network (SIGN) have published a guide to how they rate different methodologies in terms of the quality of the evidence they provide. This list is published in Annex B of: Scottish Intercollegiate Guidelines Network (2008) *SIGN 50 A Guideline developer's handbook* Edinburgh: NHS Quality Improvement Scotland.
It can be accessed on the SIGN website: www.sign.ac.uk

The Cochrane Collaboration
The Cochrane Collaboration is an international not-for-profit organisation that aims to prepare, maintain and disseminate systematic reviews of the effects of health care. The PaPaS review group was set up to support the production of Cochrane Systematic reviews in Pain, Palliative and Supportive Care on behalf of the Cochrane Collaboration. For more information see website: http://papas.cochrane.org

Trials methodology hubs
The Medical Research Council plans to increase support for the national methodological platform in clinical trials research by establishing Hubs in trials methodology research. Scotland's methodology hub is located in Edinburgh. For more information see website: www.methodologyhubs.mrc.ac.uk

Courses
Wellcome Trust Clinical Research Facilities sometimes run relevant courses. For up-to-date information see their website: www.wellcome.ac.uk/index.htm

Registering clinical trials

EudraCT
EudraCT is a database of all clinical trials taking place in the European Community from 1 May 2004 onwards. It was established in accordance with Directive 2001/20/EC. For more information, including how to obtain a EudraCT number see website: http://eudract.emea.europa.eu/

metaRegister of Controlled Trials
The metaRegister of Controlled Trials is designed to assist in the identification of ongoing and unpublished RCTs. All trials that are registered are given an International Standards Randomised Controlled Trial Number (ISRCTN) to help differentiate between different trials. For more information see website: www.controlled-trials.com

Trials can also be registered at: www.clinicaltrials.gov

7.2 Qualitative Research

Qualitative research is a popular method in palliative care. It is widely held to involve a naturalistic interpretive approach, concerned with understanding the meanings people attach to phenomena such as actions, decisions, beliefs and values within their social world (Richie and Lewis, 2003). It is also widely held to be a useful stage in theoretical development prior to designing and implementing an intervention.

It is important to recognise that there is no single accepted way of doing qualitative research. Indeed, how researchers undertake qualitative research depends on a range of factors, including their beliefs about the nature of the social world and what is known about it (ontology), and their beliefs about the nature of knowledge and how it is obtained (epistemology). The purpose and goals of the study and the characteristics of the research participants will influence how the research is undertaken, as will factors such as who is funding the research, and who is the intended audience for the research. The experience level of the researcher and their working environment will also affect how research is undertaken. Furthermore, it is argued that qualitative researchers need to be aware of the philosophical and theoretical underpinnings and background to the approach chosen.

Ensuring the quality of qualitative research is important, although views differ as to the best way quality can be assured. Maintaining consistency between the philosophical starting point and the methods chosen has been argued as a way of ensuring quality. Others argue that quality work is produced if the full range of research tools and methods of assuring quality are considered prior to conducting and analysing the research. The key thing to remember is that the methods chosen must fit the research question and not a research question chosen to fit a method or theory. A consistent and transparent approach must also be adopted.

Methods used to collect data in qualitative research include interviews and observation. How the interviews and observation are conducted and analysed will depend on the methodology used, and qualitative research is an umbrella term for a variety of different methods which differ in their philosophical background and approach. Commonly used qualitative research approaches in palliative care include:

- **grounded theory** - drawn from sociology and, in particular, social interaction theory, with the purpose of the research being to produce an inductive theory

- **phenomenology** - drawn from existential philosophy, the researcher describes and interprets phenomena from the viewpoint of the subject. This approach is often termed a 'study of lived experience'.

- **narrative inquiry** - a story telling or life history approach

- **ethnography** - the researcher studies a subject's world from the viewpoint of the subject, and this usually involves participant observation.

Further resources on qualitative research

Hierarchies of evidence
Research using certain methodologies is generally considered to be of a higher quality and to result in more reliable evidence than research using other methodologies. The following article describes some insights into which methods of qualitative research are considered the most reliable:

Daly, J., Willis, K., Small, R., Green, J., Welch, N., Kealy, M. and Hughes, E. (2007) A hierarchy of evidence for assessing qualitative health research. *Journal of Clinical Epidemiology,* 60(1) pp43-49

Further resources on qualitative research

Longitudinal studies using serial interviews
The Primary Palliative Care Research Group in Edinburgh has conducted a number of longitudinal qualitative studies, using serial interviews with patients and their families and informal carers. For basic guidelines for this approach see the following articles:

Murray, S.A., Kendall, M., Carduff, E., Worth, A,. Harris, F.M., Lloyd, A., Cavers, D., Grant, L. and Sheikh, A. (2009) Use of serial qualitative interviews to understand patients' evolving experiences and needs. *BMJ* 2009; 339:b3702

Kendall, M., Murray, S.A., Carduff, E., Worth, A., Harris, F.M., Lloyd, A., Cavers, D., Grant, L., Boyd, K. and Sheikh, A. (2009) Use of multiperspective qualitative interviews to understand patients' and carers' beliefs, experiences, and needs. *BMJ* 2009; 339:b4122

Further reading:
Pope, C. and Mays, N. (2009) Critical reflections on the rise of qualitative research. *BMJ* 2009; 339:b3425

Lewin, S., Glenton, C., Oxman, A.D. (2009) Use of qualitative methods alongside randomised controlled trials of complex healthcare interventions: methodological study. *BMJ* 2009; 339:b3496

7.3 Other types of research

7.3.1 Action Research

Action research addresses practical issues in a real world setting. For example, an action research project might be set up to address identified inefficiencies within a workplace environment. The research project would first plan interventions aimed at increasing efficiency, then take action on these interventions, then observe the results of these actions, evaluate these results, and then critically reflect on whether interventions had been successful in increasing efficiency, and what other actions could be taken to further increase efficiency. Then, this cycle of planning, action, observing, evaluating and critical reflection would be undertaken again, possibly several times. Action research requires the active involvement of relevant practitioners (in this example staff employed within the workplace), and is a way to increase awareness of how changing practices can be beneficial.

7.3.2 Case Studies

Yin (1984) as sited by Soy (1997) defines the case study research method as: 'an empirical inquiry that investigates a contemporary phenomenon within its real-life context; when the boundaries between phenomenon and context are not clearly evident; and in which multiple sources of evidence are used'. Case studies emphasise detailed contextual analysis, and case study research can help researchers understand complex issues. Social scientists, in particular, have made wide use of this research method to examine real-life situations, using their findings as a basis for the application of ideas and extension of methods.

7.3.3 Mixed Methodologies

It may suit some studies to use a combination of methodologies, or to combine quantitative methods with qualitative methods to gain a fuller picture of the situation. For example, quantitative research can allow generalisation of some qualitative work, and qualitative research can explore in more depth issues highlighted by quantitative work.

Section 8: Using appropriate measures

It is essential for the credibility of the project's final results that appropriate measures and assessment tools are used throughout the research. Using credible tools makes it more likely that your research can be included in meta-analysis in the future, thus adding to the quality of the body of palliative care research evidence available.

8.1 Reliability, validity and application

A **reliable** research tool produces comparable results time and again in similar groups. A method is **valid** when it measures what it set out to measure. **Application** of a tool also needs to be standardised, since different people can apply the same (validated) tool in different ways and obtain different results. Therefore, if a tool is used by more than the primary researcher (for example a trials nurse or ward doctor) it is essential that they receive appropriate training and ongoing support in how to use the tool. This is especially important when applying more qualitative methods, when it can be helpful to mention as part of the write-up who undertook each interview.

It is a good idea to use assessment tools that already have established their validity and reliability, since the more validated are the tools that are used, the more credible the finished research will be. However, it is important to check whether or not you need to obtain permission to use a particular assessment tool. Most of the relevant websites will have an application form for this purpose that can be submitted electronically.

8.2 Symptom measurement and assessment

A person's symptoms and the distress they cause is a major part of their experience of illness. Given the importance of assessing and relieving symptoms in clinical care, symptom measurement is an essential element of much palliative care research, including survey research as well as clinical trials.

The measurement of symptoms needs to be undertaken with an understanding of the multi-dimensional nature of symptoms and quality of life, and should reflect the complexity of patient perceptions (Ingham et al, 2010). There are various factors that should be considered when planning research involving the measurement and assessment of symptoms, and additional complications arise when cognitive impairment affects a patient's ability to report their symptoms. Directions to some further resources relating to symptom measurement and assessment are provided below.

Further information on symptom measurement and assessment:

Max, M.B. and Lynn, J. (eds.) (n.d.) *Interactive Textbook on Clinical Symptom Research.* (WWW)
National Institute of Dental and Craniofacial Research,
National Institutes of Health, Department of Health and Human Services, FIRSTGOV. Available from: http://painconsortium.nih.gov/symptomresearch/

Ingham, J.M., Anthoulla, M. And Portenoy, R.K. (2010) 'The measurement of pain and other symptoms' in G. Hanks, N.I. Cherry, N.A. Christakis, M. Fallon, S. Kaasa and R.K. Portenoy (eds) *Oxford Textbook of Palliative Medicine,* Fourth Edition, Oxford: Oxford University Press, pp 422-442

Herr, K., and Ersek, M. (2010) 'Measurement of pain and other symptoms in the cognitively impaired' in G. Hanks, N.I. Cherry, N.A. Christakis, M. Fallon, S. Kaasa and R.K. Portenoy (eds) *Oxford Textbook of Palliative Medicine,* Fourth Edition, Oxford: Oxford University Press, pp 462-475

8.3 Health-related quality of life measures

A person's 'quality of life' is about their general sense of well-being. Health-related quality of life (HRQoL) focuses on the health-related aspects of this, such as symptom levels and functioning. Various tools exist which measure HRQoL, but many have been described as inadequate for use in palliative care because they include physical, psychological and social elements of a person's life, but exclude elements such as family involvement, coping, loss, grief and spirituality.

Still, measures of HRQoL are the most commonly used outcome measures in quantitative palliative care research (Grande and Todd, 2000). However, care should be taken when selecting which HRQoL measure to use since patients and carers may experience problems in completing the measures, resulting in loss of data.

Many HRQoL instruments are available which measure the same or similar constructs. However, validity testing is often poor. A reasonable approach is to choose one of the more commonly used HRQoL tools and carefully examine its content in relation to the purpose for which it has been chosen. When choosing an appropriate HRQoL measure for a palliative care study, you may wish to consider the following factors:

- What patient population are you working with, and what HRQoL measure is likely to work best with this group?
- How long does it take to complete the instrument you have chosen? Most HRQoL measures are self-reported, this currently being accepted as the best way of measuring HRQoL, but this can present problems for very ill patients who may not have the energy to complete the assessment.
- If a patient is unable to complete the measure themselves, do you wish to use a proxy-rating? You may wish to do some research into the advantages and disadvantages of proxy-ratings before you decide.

You may also wish to bear in mind that complications can arise when analysing the results of HRQoL measures. In a palliative care context, in many cases an improvement in quality of life can't be expected - an intervention may therefore be more likely to result in a slowing down, stabilisation or change in symptoms which can be harder to identify.

Additional Resources on using appropriate measures

Polit, D.F. and Beck, C.T. (2008) *Nursing research: Principles and Methods* 8th ed. Philadelphia: Lippincott Williams & Wilkins.

Brief Pain Inventory
The Brief Pain Inventory is an evaluation instrument specifically for cancer patients. It can be used to provide information on pain intensity, pain relief, pain quality, the patient's perceptions of the cause of the pain, and the extent to which pain interferes with function.

Its authors are the Pain Research Group, Department of Neurology, University of Wisconsin-Madison (Based on Wisconsin Brief Pain Questionnaire). The Brief Pain Inventory (BPI) copyright is held by Dr. Charles S. Cleeland (1991). The BPI may not be used or reproduced without permission from Charles S. Cleeland, PhD, or his designee. Fees for use may apply.

For more information see:
http://www.mdanderson.org/education-and-research/departments-programs-and-labs/departments-and-divisions/symptom-research/symptom-assessment-tools/brief-pain-inventory.html

Additional Resources on using appropriate measures

Health Related Quality of Life

Kaasa, S. and Havard Loge, J. (2010) Quality of life in palliative care – principles and practice in G. Hanks, N.I. Cherry, N.A. Christakis, M. Fallon, S. Kaasa and R.K. Portenoy (eds) *Oxford Textbook of Palliative Medicine,* Fourth Edition, Oxford: Oxford University Press, pp 443-461

Survey research

For pain and palliative care research tools see the website of the International Association for Hospice and Palliative Care:

http://www.hospicecare.com/resources/pain-research.htm

For Functional Assessment of Chronic Illness Therapy (FACIT) questionnaires, see the FACIT website: http://www.facit.org/

Psychosocial Research

An analysis of the various instruments in use in psychosocial research is provided within: Kissane, D.W., Street, A.F. and E. Schweers Cornelius. (2010) 'Research into psychosocial issues' in G. Hanks, N.I. Cherry, N.A. Christakis, M. Fallon, S. Kaasa and R.K. Portenoy (eds) *Oxford Textbook of Palliative Medicine,* Fourth Edition, Oxford: Oxford University Press, pp 403-415

Section 9: Using appropriate definitions

It is important that you are clear about defining the terms you will use within your research. This ensures that you are consistent in your use of terms, and also ensures that anyone who reads your research understands exactly what you mean and there is no ambiguity. For example, the concept of 'end of life' means different things to different people, and where one health professional might define it as the last 48 hours, another might use this term to refer to the last six months. (Kendall et al, 2007)

Where possible, it is important to use internationally recognised definitions since these will have a lot more credibility than any you make up yourself.

9.1   Criteria for eligibility to enter a study

Inclusion and exclusion criteria are a set of conditions that must be met in order for a person to be eligible to participate as a subject in a piece of research. When defining the inclusion criteria for participation in your research you should ensure that they are clear, and there is no scope for ambiguity or misinterpretation that could lead to inappropriate participants being admitted, or appropriate participants being refused.

For example, some health professionals may have difficulty accepting that a patient is truly 'terminal' and that a cure will not be possible and therefore be reluctant to recommend that patient for palliative care research. Therefore, when drawing up inclusion criteria it is important that these criteria are precise enough to encompass all relevant potential participants, and that they do not rely on subjective criteria.

One inclusion criteria for a piece of research might be that all patients must have certain similarities. For instance, inclusion criteria could be that all participants must be men, and/or that they all must be over 50, and/or that they must all have the same type of illness. In order to maximise the size of your sample, it is important that you only specify within your inclusion criteria heterogeneities that will affect the outcome you are looking at.   For example, depending on its purpose, a study looking at bone pain in patients may not need to be concerned with which type of cancer the patient has, as long as they are experiencing bone pain.

> ### Additional Resources on definitions
>
> The following book contains some information about appropriate definitions:
> Addington-Hall, J., Bruera, E., Higginson, I.J., and Payne, S. (eds) (2007) *Research Methods in Palliative Care.* New York: Oxford University Press

Section 10: Writing a research proposal

Different disciplines and institutions have different requirements regarding the format of their research proposals. It is therefore important to investigate the specific requirements of your own circumstances before you draft and submit your proposal. However, there are some broad themes which should always be addressed, and funding panels tend to judge research proposals in relation to the key themes of quality, relevance and feasibility. This section provides some general guidance on writing research proposals, based on a Cancer Research UK proposal for a piece of **quantitative** research.

1 Project Title

Give the research project a succinct title. Usually an acronym is beneficial in addition to a single sentence title.

2 Area of Research

It is useful to describe the area of research you will be looking at, and at this stage to argue the case why the proposed subject is of importance and requires to be addressed.

3 What is the principal research question?

Although this is often very difficult to clarify, *the importance of isolating the principal research question cannot be overemphasised*. This will be beneficial to those examining your proposal and will also assist you in formulating your idea. This is often best written as a single question.

4 Why is your research needed now?

At this point you can add weight to your proposal. Citing relevant literature is very helpful and highlights why your research is needed. Often papers suggest areas of further work and if these correspond to your area of interest it will support your application.

5 Quote Literature

If not included above, mention specific papers that aid your cause, and remember that depending on the robustness and design of the research they describe, some papers are likely to carry more weight than others (see section 6.3 for information about critical reading and hierarchies of evidence). Systematic reviews and meta-analysis (see section 7.1) will demonstrate you have researched the background well. Discuss the need for your research in relation to the results of these. Remember that in the majority of cases those assessing your proposal will be aware of seminal papers.

6 How will the results of the research be used?

Will the results of the research change clinical practice? Will they inform decision making? Or feed into other work? Funding bodies will be interested in the future uses of your research. For example, if you are requesting to perform detailed laboratory-based research, an organisation which normally supports research with a direct impact on patient care is likely to examine the application less favourably.

7 Summary of the research

Describe your research in no more than 100 words.

8 What is the design of your research?

Is this a quantitative study or a qualitative study? State what type of methodology you will be using (see section 7 for more details) and then explain in more detail about your planned methodology. For example, if this is a randomised trial, discuss how patients will be randomised. Mention any possible sources of bias and measures taken to limit these. Be succinct.

9 Is there a trial intervention?

Describe what will be undertaken by the participants in your research. If there is a control condition, describe this also.

10 Inclusion/Exclusion criteria

List both inclusion and exclusion criteria. (See section 9.1 for more information.) One of the inclusion criteria in all palliative care research will be the written and informed consent of all participants.

11 Duration of research

How long will patients be involved in the research? How long is the study going to take, including set-up, recruitment, data-analysis and reporting?

12 Patient Care

How often will patients be reviewed and followed up? Patient care is the priority and you must be able to demonstrate that those patients involved in your research will receive excellent clinical care.

13 Outcome measures

How will the effects of the research be assessed? The primary outcome measure is usually a single point whilst it is acceptable to have multiple secondary outcome measures.

14 How will you assess the outcome measures?

State any tools, questionnaires etc that are going to allow you to quantify the outcome measures.

15 Proposed sample size

You need to ensure that your sample size is big enough to give results that are statistically significant. (Also see section 4.3) Involvement from a statistician is usually needed to help calculate the required sample size and it is essential to include details of this calculation within the research proposal.

16 Recruitment

You have to demonstrate that you will be able to recruit enough subjects to make the project feasible. Give information about the incidence of the issue to be studied in the available population. Provide details of where and how patients will be recruited and over what period. (Also see section 4.2) Also mention the likely drop-out rate.

17 Compliance

Mention whether you expect there to be any problems with participants not complying fully with the conditions of the trial (eg forgetting to take medication) and how these will be minimised.

18 Data analysis

Give details of the planned analyses and how these will be done. Statistical input is usually needed here.

19 Miscellaneous

Mention any commercial involvements and conflicts of interest.

20 Future work

Will this research lead to any future work as a result of its findings?

21 How will results of the work be disseminated?

Where will the research be presented? Will results be presented in a poster? Or a peer reviewed publication? Or somewhere else? Will there be any opportunity for patients to be informed of results of the research?

22 Enclosures

The curriculum vitae (CV) of the main researcher and others involved are usually required. These should document previous research experience if applicable. Letters of support from sponsors (e.g. institution where you will be based during research) and other learned bodies will be of value. Letters from patient/lay bodies who have read and approved the value/relevance of your research must be included.

Section 11: Sourcing funding for research and fellowships

This section is designed to help you in your search for possible sources of funding for your research. The list below is not exhaustive, but hopefully it will provide you with some ideas.

11.1 Possible sources of funding (general)

Breast Cancer Campaign

Breast Cancer Campaign supports various awards in universities, medical schools/teaching hospitals and research institutes in the UK. For more information see website:
http://www.breastcancercampaign.org/

Breakthrough Breast Cancer

Breakthrough supports researchers through programme grants, project grants and personal awards. For more information see website: www.breakthroughresearch.org.uk

British Heart Foundation

The British Heart Foundation aims to play a leading role in the fight against diseases of the heart and circulation by supporting pioneering, vital research into its causes, prevention, diagnosis and treatment. For more information see website: www.bhf.org.uk

British Lung Foundation

The British Lung Foundation funds research into understanding, treating and preventing lung disease. For more information see website: www.lunguk.org

Cancer Research UK

Cancer Research UK provides various grants. For more details see website:
http://science.cancerresearchuk.org/gapp/

CHAIN - Contact, Help, Advice and Information Network

Some funding may be available through CHAIN. For more information see website:
http://chain.ulcc.ac.uk/chain/index.html

Chest, Heart and Stroke Scotland

Chest, Heart & Stroke Scotland funds vital medical research into every aspect of the diagnosis, treatment and prevention of chest, heart and stroke illness. For more information see website:
www.chss.org.uk

Chief Scientist Office

The Chief Scientist Office (part of the Scottish Government Health Directorates) makes available various types of funding. For more information see website: http://www.sehd.scot.nhs.uk/cso/

The Compass Collaborative

You may also be able to get information about funding through the Compass Collaborative:
www.compasscollaborative.com/

Dimbleby Cancer Care

Dimbleby Cancer Care makes funds available each year for a number of research projects relating to the care and support of cancer patients. Full details and application forms are on the website
www.dimblebycancercare.org

Help the Hospices

Help the Hospices runs a grants programme. For more information see website:
http://www.helpthehospices.org.uk/grants/

Marie Curie Cancer Care

Marie Curie is committed to increasing knowledge and understanding about the best ways to care for patients at the end of life. For more information about possible research funding that may be available see website: www.mariecurie.org.uk

MND Scotland

MND Scotland has a keen interest in supporting research. For more information see website: www.mndscotland.org.uk

MS Society Scotland

The MS Society is the biggest funder in Scotland of research into the causes, cure and care of multiple sclerosis. MS Society funded research grants can only be held by recognised NHS and academic institutions. For more information see websites: www.mssocietyscotland.org.uk and www.mssociety.org.uk

National Institute for Healthcare research (NIHR) Fellowship Scheme

This scheme offers four levels of fellowship:

- Research Training Fellowship (NIHR-RTF)
- Post-Doctoral Fellowship (NIHR-PDF)
- Career Development Fellowship (NIHR-CDF)
- Senior Research Fellowship (NIHR-SRF)

For more information see website: http://www.nccrcd.nhs.uk/nihrfellow/index_html

Macmillan Cancer Support

Macmillan awards various research grants. For more information see website:
www.macmillan.org.uk/research

The Melville Trust for Care or Cure of Cancer

In the past, this Trust has invited applications for Melville Trust Research Fellowships in cancer research with the object of encouraging young clinical and other scientists to undertake innovative research work in the care or cure of cancer. The Trustees have also invited applications for grants in cancer research whether related to care or cure. More information can be requested by contacting Tods Murray LLP on melvilletrust@todsmurray.com

The Nuffield Foundation

The Nuffield Foundation's *New Career Development Fellowship Scheme* aims to promote excellence in UK social science research capacity. The Scheme is designed to foster the leading intellectual social scientists of tomorrow, working on research projects concerned with issues of serious social significance. For more information see: http://www.nuffieldfoundation.org/

Parkinson's UK

Parkinson's UK funds research projects, in the form of research grants, for research directly related to Parkinson's. For more information see website: www.parkinsons.org.uk

Stroke Association Scotland

The Stroke Association has funded various research into the prevention and treatment of stroke and better methods of rehabilitation. For more information about grants that may be currently available see website: www.stroke.org.uk

The Wellcome Trust

The Wellcome Trust offers a variety of funding schemes in support of biomedical research and the medical humanities. For more information see website: http://www.wellcome.ac.uk/index.htm

11.2 Possible sources of funding (Allied Health Professions)

Stroke Association, UK

Stroke Association UK currently funds two AHP research bursaries each year. For more information see website: http://www.stroke.org.uk/

11.3 Possible sources of funding (Medical)

Medical Research Council

The Medical Research Council funds research through a range of grant schemes. For more information see website: www.mrc.ac.uk

11.4 Possible sources of funding (Nursing)

Royal College of Nursing (RCN)

The RCN website includes a section designed to provide assistance in sourcing and successfully applying for funding: http://www.rcn.org.uk/development/researchanddevelopment/funding

11.5 Possible sources of funding (Pharmacy)

Royal Pharmaceutical Society of Great Britain

The RPSGB administers a small number of awards and scholarships, some of which are relevant to pharmacists looking to undertake research. See the Royal Pharmaceutical Society website for up-to-date information about these awards: www.rpharms.com

Pharmaceutical Companies

Pharmaceutical research is often funded by pharmaceutical companies. Liaising with pharmaceutical companies to undertake research is possible, though this may have the potential to introduce bias which may affect how the research is graded in terms of the quality of the evidence it provides.

Pharmaceutical Care Research Groups

Some NHS Boards may have pharmaceutical care research groups that may provide small project grants to assist in the early stages of research.

Other useful websites

The National Institute for Healthcare Research has a section of its website dedicated to health-care research funding. For more information see website:
http://rdfunding.org.uk/

Section 12: Analysing Results

12.1 Qualitative Analysis

Analysis of qualitative data often starts very early in the research process, since analysing data whilst new data is still being gathered can allow a researcher to develop questions and refine the research as data collection progresses. Analysis continues well after all the data has been gathered, and there are various techniques for undertaking this, usually involving content analysis to generate categories and explanations. Qualitative research is likely to deliver large amounts of data and the whole analysis process can be slow and involve much work. Some software packages have been designed to help in this process, and one commonly used package is NUDIST. The quality of final analysis is always dependent on the proficiency of the researcher, and if you are inexperienced it is a good idea to seek someone with more experience to help (if you want help but don't know who to speak to, you could contact one of the key palliative care research collaboratives or academic centres listed in section 5.2).

> **Further resources on qualitative data analysis**
>
> Miles, M.B. and Huberman, M. (1994) *Qualitative Data Analysis: An Expanded Sourcebook* Sage Publications
>
> Mays, N. and Pope, C. (2000) Qualitative research in health care. Assessing quality in qualitative research. *BMJ* 2000;320:50

12.2 Quantitative Analysis

Analysis of quantitative data can be a complex and demanding process. Some guidelines to successful analysis are set out below.

12.2.1 Design data collection mechanisms

It is essential to design data collection forms appropriately or, in a clinical trial, case report forms. It can be helpful to design these forms having sought the advice of the statistician who will be undertaking the data analysis. This ensures that forms capture the right data.

12.2.2 Code data

Coding data makes it easier to analyse. Free text is very difficult to analyse so when forms are designed it is best to offer several options from a set list.

12.2.3 Design database appropriately

Once the data has been collected then it is best entered into a database to make it easier to manage. Microsoft Excel can be difficult to use for this purpose and often assistance from someone experienced in database design is necessary. This will make data analysis easier for the statistician.

12.2.4 Ask a statistician to review your results

Review by a statistician is essential. Not only will this lead to the most reliable results, but most peer-reviewed journals will be very wary of a manuscript which reports statistics and does not have a statistician on the authorship or as an acknowledgement. The statistician will produce a report which can be included in the results section of any report or paper.

Section 13: Writing up your research

Writing up your research can take longer than you expect, so it is a good idea to start early and write your literature review before you begin collecting data. It may be possible to write up certain aspects of your research as you go, and if you can, it is wise to avoid leaving everything to the end.

When writing up your work it is important to provide details of the sources that helped you to form your ideas or that you wish to refer to within the text. Sources are generally cited briefly within the text and then detailed in full in a reference list at the end of the work. You need to include details such as author, title, page number, publisher and date of publication. If referencing a web-based resource it is helpful to make a note of the date it was accessed. There are several established referencing systems, and it is important to pick one and apply it consistently. Two commonly used referencing systems are Harvard and Vancouver – see 'further resources' box below for more information.

It may be that interim reports are required by your funding body, and that other types of updates will be required by relevant stakeholders while the research is underway. For example it is likely that the Ethics Committee will wish to see an annual report, and you should certainly submit a final copy of your research to the Ethics Committee and to the Research and Development (R&D) Committee. You should therefore check what reports are required of you so that you can ensure you meet deadlines and make notes of the appropriate information as you go along.

How you present your findings will depend on your intended audience, and the language and style you use is likely to vary depending on whether you are presenting your findings to participants, to your funding body, or to professionals through a journal. Various courses are available which provide information about how to write up research, and the organisations listed in section 5.2 should be able to direct you to current courses in this area. More information on presenting your research findings is given in Section 14.

Further resources on writing up research

Albert, T. (2000) *Winning the Publications Game: How to write a scientific paper without neglecting your patients.* Oxford: Radcliffe Medical Press Ltd.

Library, Imperial College London and Library, University of Southampton (2009) *Citing & Referencing Guide: BMJ Vancouver Style* (WWW) University of Southampton (Available from: http://www.soton.ac.uk/library/infoskills/references/index.html)

Department of Library Services, De Montfort University (n.d) *The Harvard system of referencing* (WWW) De Montfort University Leicester (Available from: http://www.library.dmu.ac.uk/Images/Selfstudy/Harvard.pdf)

Section 14: Disseminating research findings

Once you have completed your research you will want to share your findings with others. The most common ways of doing this are to publish your findings in a journal and/or to present your findings as a poster at a conference. This section aims to help you to find appropriate ways of disseminating your research findings.

14.1 Publishing in a journal

Most researchers are keen to get their work published in a peer reviewed journal. A list of key journals that publish palliative care research is available at Appendix 1. There are various aspects to take into account when choosing in which journal to seek publication.

14.1.1 Impact factor

The impact factor (IF) is a measurement invented by *Thomson Scientific.* It is a measure of the frequency with which the 'average article' in a journal has been cited in a particular year or period, (Garfield, 1994) and is often used as a measure of the importance of a journal to its field. Impact factors are calculated each year by Thomson Scientific for those journals which it indexes, and the factors and indices are published in Journal Citation Reports. Impact factor is not the only aspect to consider when assessing the usefulness of a journal, publishing in a journal with a high impact factor is likely to increase the academic kudos of your article. Most journals publish their impact factor on their websites, and palliative care journals with a high IF include the *British Medical Journal, British Journal of Cancer*, and *Palliative Medicine.* Generally speaking, it is harder to get an article published in a high IF journal than in a low IF journal.

14.1.2 Readership

Consider the readership of your article. For instance is your article aimed at a single disciplinary group (eg nurses or doctors only) or a multi-disciplinary group? Consider if the usual readership of the journal matches your target audience.

14.1.3 Previous content

The best way of assessing whether your article is suitable for the journal is to look to see whether similar articles have been published in that journal in the past.

14.1.4 Quality of your research

Aim for a journal appropriate for the quality of your research. For example, it is unlikely that an audit of ten patients will be published in the Journal of Clinical Oncology. However it will hurt no more than your pride to submit to a high quality journal and be rejected, and you may be surprised that your manuscript is accepted. You can also write to the editor to see whether they would consider publishing your article.

> **Practical tip:**
>
> You should not submit to more than one journal at a time.

14.2 Presenting findings at a conference

Presenting research findings at a conference is often the first step researchers take towards sharing their work more widely. Study abstracts are submitted to the conference organisers, resulting in an invitation to present orally or bring a poster presentation to the conference, usually with the proviso that this work has not been published or presented before.

In the field of palliative care the following conferences may be of interest:

European Association of Palliative Care: the EAPC holds an event each year, alternating between a Congress one year and a Research Forum the next. Prizes are awarded for posters presented at the conference. See www.eapcnet.org for more details.

Palliative Care Congress: this biennial conference is co-hosted by the Association for Palliative Medicine (APM), the Palliative Care Research Society (PCRS) and the Royal College of Nursing Palliative Nursing Forum. See www.pccongress.org.uk for more details.

Palliative Care Research Society: the PCRS holds an annual conference. See www.pcrs.org.uk for more information.

Scottish Partnership for Palliative Care: the Partnership holds an annual conference and each year invites applications for poster presentations. For more information see: www.palliativecarescotland.org.uk

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Practical tip:

Though it is not an absolute rule, it is generally expected that only unpublished work will be presented at conferences, and that the same piece of work will not be presented at several conferences.

Section 15: Authorship

15.1 Agreeing co-authorship rights

One important consideration when undertaking a piece of research is deciding who has the right to be credited as an 'author' of the piece of work and to have 'ownership' of the ideas and intellectual material contained within.

Co-authorship can be a complicated and sensitive issue. Ideas vary about the kind of contribution that merits a co-authorship credit to its contributor. Mishandling of this important issue can lead to tensions with colleagues, and to accusations of plagiarism. It is therefore advisable to think about authorship issues early on in the conception of your research, and to keep a note of the contributions of each member of the research group as you go along. Having a steering committee for your research can help to establish agreement on authorship issues.

Since views on this can vary greatly between different departments and institutions, it is wise to find out what authorship conventions are currently used in your area. Universities are likely to have their own guidelines on authorship rights, and journals generally have stated conventions of authorship which the researcher is expected to know before a piece of work is submitted for publication.

It is worth consulting the International Committee of Medical Journal Editors' (ICMJE) *Uniform Requirements for Manuscripts Submitted to Biomedical Journals*. The ICMJE uniform requirements are designed to assist authors and editors to produce and disseminate good reports of biomedical studies, and cover many areas relating to preparing, editing and submitting manuscripts, one of which is authorship. Hundreds of journals worldwide have contacted the ICMJE to request being listed on their website as a journal that follows the *Uniform Requirements for Manuscripts Submitted to Biomedical Journals*. For more information, see: www.icmje.org

The *Uniform Requirements for Manuscripts Submitted to Biomedical Journals* provide a useful reference point when thinking about authorship issues. However, it is still advisable to contact a journal directly if you have questions about its policies concerning authorship.

15.2 Authors' responsibilities

As an author you have various responsibilities. For example, it is essential to respect the rights and privacy of the participants in your research. It is also important to appropriately credit any previously published material that you quote, replicate or make reference to – there are various rules about copyright and you should make sure that you follow them. You should also declare any potential conflicts of interest that may be relevant to your research, and some journals require the completion of a formal declaration of interests by a submitting author.

It is advisable to ensure you are aware of the responsibilities you have as an author. For example, you should not submit the same manuscript to two journals at the same time, and you need to keep the original data from your research for a period of time after publication of your research in case your publishing journal requires access to it (Gustanii, 2008). Some resources to help you familiarise yourself with the issues and rules involved are listed below.

> ### Further resources on authorship issues
>
> Gustanii, B. (2008) *How to write and illustrate a scientific paper* Cambridge: Cambridge University Press
>
> For information about copyright see the website of the Intellectual Property Office: http://www.ipo.gov.uk/copy.htm
>
> The SAGE publications website provides some good information about declaring conflicting interests: http://www.uk.sagepub.com/authors/journal/conflicting.sp

Section 16: Practical hints and tips

Ensure that your research has a steering committee

A steering committee is a group of people who have experience in the subject being researched and who are interested in the project. A steering committee can provide helpful advice and direction, contacts to help the project along, and an unbiased view on issues that may be causing problems.

Ensure you have the right backing before you begin

Only take on a piece of research if you have good peer and academic support.

Don't over-estimate your ability to recruit

A common mistake made by researchers is to over-estimate how many participants they will be able to recruit to their study. Over-estimating in this way is likely to cause a study to fail.

Check that you fulfil the obligations set out within your funding agreement

Many funding bodies automatically have intellectual property of your research as a condition of this agreement and will therefore wish to see your research before it is published.

Use research tools that have been tried and tested

Using credible tools makes it more likely that your research can be included in meta-analysis in the future, thus adding to the quality of the body of palliative care research evidence available.

Acknowledge the funders of your research

It is good practice to acknowledge the body that funded your research, and you will be glad you did so if you wish to apply to the same body for funding again in the future.

Speak to someone

Speaking to an expert in your chosen field will give you insights you can't gain from books. If you don't know who to speak to, you could begin by contacting one of the key palliative care research collaboratives or academic centres, for example:

- *Cancer Care Research Centre* University of Stirling: www.cancercare.stir.ac.uk
- *The Cancer Experience Collaborative*: www.ceco.org.uk/
- *The Compass Collaborative*: www.compasscollaborative.com/
- *Edinburgh Cancer Research Centre*: www.ecrc.ed.ac.uk/
- *Palliative Care Research Society*: www.pcrs.org.uk
- *Primary Palliative Care Research Group* University of Edinburgh: www.homepages.ed.ac.uk/smurray1/
- *Scottish Primary Care Research Network*: http://www.sspc.ac.uk/spcrn/
- *University of Glasgow Centre for Oncology and Applied Pharmacology*: www.gla.ac.uk/departments/cancerpathology/oncology/

Plan for all costs

When costing research it is important to include all costs, including the time of the primary researcher. If time is not made available and paid for, the research is likely to fail. Research is time consuming and tiring and will always take second place to clinical work. It therefore needs the proper support if it is to stand a chance. Secretarial support is another area which can frequently be overlooked.

Work collaboratively

For several reasons, it is a good idea to work collaboratively when undertaking research. If you are inexperienced, it can help to work with someone more experienced than yourself. There have also been many palliative care studies which have been locally based or small in scale, and the results of such studies may not be valid in other settings and are therefore often less useful (Johnston et al, 2005). Multi-disciplinary and multi-centre collaboration is therefore particularly helpful in providing useful palliative care evidence. If you are unsure of who to collaborate with, you may wish to contact one of the research centres listed in section 5.2.

Section 17: Additional Resources

Some additional resources are listed within the relevant chapters of this guide. Further useful resources are listed below.

Research Governance Framework for Health and Community Care

Before you begin a piece of research, it is good idea to look at the Scottish Government's *Research Governance Framework for Health and Community Care* (Chief Scientist Office, 2006). This document is available on the website of the Chief Scientist Office:
http://www.cso.scot.nhs.uk/Publications/ResGov/ResGov.htm

Medical Research Council (MRC)

The MRC website includes a section on *Ethics and Research Governance* designed to assist scientists to implement good practice and meet legal and ethical requirements. For more information see website: http://www.mrc.ac.uk

Medicines and Healthcare Products Regulatory Agency (MHRA)

Researchers must apply to the MHRA for permission to test drugs through clinical trials if these trials are to be conducted in the UK. For more information see website: www.mhra.gov.uk

NHS Education for Scotland Pharmacy Clinical Trials/Research web based educational package

This package has been developed by a multi-disciplinary reference group, to primarily facilitate the education of pharmacy staff within secondary care. This need was identified after the introduction of the EU Directive relating to research involving investigational medicinal products in 2001.
The educational package can be accessed at: http://www.nes.scot.nhs.uk/ct/index.htm

Patient Information

It is important that potential participants in a clinical trial have enough information to enable them to make an informed decision on whether or not to take part.

When considering what information patients may be interested in, or when directing patients towards appropriate information, you may find the following website helpful: www.cancerhelp.org.uk
(particularly: http://www.cancerhelp.org.uk/trials/understanding/default.asp?page=51)

Scottish Dementia Clinical Research Network

The SDCRN promotes clinical research in dementia across Scotland. It runs a register of potential research participants from both urban and rural areas to help recruitment to high quality studies. For more information see website: www.sdcrn.org.uk

Useful contacts:

- *Cancer Care Research Centre* Stirling University: www.cancercare.stir.ac.uk
- *The Compass Collaborative:* www.compasscollaborative.com/
- *Edinburgh Cancer Research Centre*: www.ecrc.ed.ac.uk/
- *Palliative Care Research Society:* www.pcrs.org.uk
- *Primary Palliative Care Research Group* University of Edinburgh: www.homepages.ed.ac.uk/smurray1/
- *Robert Gordon University School of Pharmacy:* www4.rgu.ac.uk/pharmacy/
- *Scottish Primary Care Research Network:* http://www.sspc.ac.uk/spcrn/
- *Strathclyde Institute of Pharmacy and Biomedical Sciences, Strathclyde University:* http://spider.pharmacy.strath.ac.uk/school/

- **University of Glasgow Centre for Oncology and Applied Pharmacology:**
www.gla.ac.uk/departments/cancerpathology/oncology/

Wellcome Trust Clinical Research Facility (WTCRF)

The WTCRF education programme runs varied courses to help you with your research. They also host regular seminars covering a variety of research and healthcare topics. For more information see website: www.wtcrf.ed.ac.uk

Appendix 1: Glossary

Abstract

Research articles published in journals usually begin with a very short summary of the research article which follows. This is called an 'abstract'. Components of an abstract vary according to discipline, but abstracts are always self-contained, and normally include the aims, methods, results and conclusions of the research.

Attrition

Given that participants in palliative care research are living with advanced illness, it is not unusual for participants to withdraw from research due to death or impairment due to progressive disease. This is known as 'patient attrition'.

Conflicts of interest

A conflict of interest occurs when an individual or organisation funding, sponsoring or collaborating in research would be in some way advantaged by the research having a particular outcome. The presence of a conflict of interest does not mean that any impropriety has or will take place.

Control Group

A control group is a group of research participants that is treated in exactly the same way as another group of research participants *except* for the one aspect of the situation being studied. For example, in a study examining the effects of a sleeping pill, an 'experimental' group could meditate, go to bed, read a while then take a sleeping pill, while the 'control' group would meditate, go to bed, read a while then take a placebo. Each group would be judged on how well it had slept, and any significant differences in sleep patterns could be attributed to the sleeping pill.

Clinical Audit

Clinical audit is 'designed and conducted to produce information to inform delivery of best care'. (NRES Ethics Consultation e-group, 2007)

Deductive Theory

Deductive reasoning is concerned with testing or confirming hypotheses. It works from the more general to the more specific. Sometimes this is informally called a 'top-down' approach. A deductive approach might begin with a *theory* about the topic of interest. This is then narrowed down into more specific *hypotheses* that can be tested. It is then narrowed down even further as *observations* are collected to address the hypotheses. This ultimately leads us to a test of the hypotheses with specific data.

Impact Factor

The impact factor is a measurement invented and used by *Thomson Scientific*. It is a measure of the frequency with which the 'average article' in a journal has been cited in a particular year or period. The annual *JCR* impact factor is a ratio between citations and recent citable items published. Thus, the impact factor of a journal is calculated by dividing the number of current year citations to the source items published in that journal during the previous two years. (Garfield, 1994)

Inductive Theory

Inductive reasoning works from specific observations to broader generalisations and theories. This is sometimes called a 'bottom up' approach. Inductive reasoning begins with specific observations and measures, then starts to detect patterns and regularities, formulates some tentative hypotheses that can be explored, and finally ends up developing some general conclusions or theories. It is the nature of inductive reasoning to be open-ended and exploratory, especially at the beginning.

Informed Consent

'Informed consent is an ongoing agreement by a person to receive treatment, undergo procedures or participate in research, after risks, benefits and alternatives have been adequately explained to them.' (Royal College of Nursing, 2005) Informed consent should be revisited throughout a study, particularly if it is scheduled to take place over a longer period of time, since patients may change their mind regarding participation.

Intellectual Property

Intellectual property refers to creations of the mind, for example inventions, literary and artistic works, and symbols, names, images, and designs used in commerce. Under intellectual property law, someone who possesses a piece of intellectual property has certain exclusive rights to the creative work, commercial symbol, or invention it applies to. For more information see the UK Intellectual Property Office website: http://www.ipo.gov.uk/

Outcome measures

'Outcome measures' specify how the effect of an intervention will be evaluated. The 'primary outcome measure' is the one of greatest importance, and other outcomes of interest are 'secondary outcome measures'. Trials can have more than one primary outcome measure.

Qualitative research

Qualitative research is concerned with exploring and understanding qualities such as people's views, attitudes, experiences and behaviours. Evidence is usually gathered by speaking to people and/or observing what people do and say. See section 7.2 for more information.

Quantitative research

Quantitative research concerns that which can be measured by quantity – 'how much', 'how many', 'how long' etc. See section 7.1 for more information.

Randomise

If a trial is 'randomised', then participants are allocated to different arms of the study completely at random. For example, the 'randomised control trial' is the most common type of clinical trial, and is designed to compare two treatments by randomly allocating a treatment to participants in the trial and then monitoring the effects of each.

Research

Research is: 'the attempt to derive generalisable new knowledge, including studies that aim to generate hypotheses as well as studies that aim to test them.' (NRES Ethics Consultation e-group, 2007)

Research Qualifications:

MSc

A Masters of Science (MSc) qualification usually takes one year to complete on a full-time basis, or two years to complete on a part-time basis. Most of the year can be spent undertaking various taught modules, but some MSc's are entirely research-based. Specific courses are run in different ways so that full-time work may be possible while completing an MSc.

M.Phil

The Master of Philosophy (M.Phil) is a research degree which requires the candidate to complete a thesis. The exact nature of a M.Phil will depend on the university in which it is undertaken, but is generally seen as a more advanced level of research degree than the MSc, but not as advanced as a PhD.

MD

Doctor of Medicine (MD) qualifications are available only for doctors and take the form of a research based study that usually takes around two or three years to complete. A registration and examination fee is paid to the university and someone is selected to guide the study. MDs generally involve less supervision than a PhD.

PhD

A Doctor of Philosophy (PhD) usually takes around 3 years to complete on a full-time basis, or longer on a part-time basis. Funding can be sought from various sources, for example the Scottish Government or MRC, and an application is made to a university with an outline proposal and a request to identify supervisors.

Reliable

A research tool is described as 'reliable' if it produces the same results time after time (see section 8.1 for more information).

Sample size

The 'sample size' of your study is the number of subjects taking part in the research. If there is only one sample the letter N is used to denote the total number in the sample. If there are two samples the lower case letter n is used for each.

Service Evaluation

Service evaluation is: 'designed and conducted solely to define or judge current care'. (NRES Ethics Consultation e-group, 2007)

Sponsor

A sponsor is an individual, organisation or group taking on responsibility for securing the arrangements to initiate, manage and finance a study. (A group of individuals and/or organisations may take on sponsorship responsibilities providing that they make arrangements to allocate appropriately all relevant responsibilities.) (Chief Scientist Office, 2006)

Statistically significant

A result is 'statistically significant' when it is unlikely to have been caused by chance. Statisticians have methods for determining whether or not a result is statistically significant, and how big a sample size is required in order to ensure that it is possible for the research to yield statistically significant results.

Sources of bias

A source of bias is: 'a source of error that cannot be reduced by increasing sample size. It is a systematic as opposed to random error.

Sources of bias include (a) *bias in sampling*, when members of the sample are not fully representative of the population being studied; (b) *nonresponse bias* in sample surveys, when an appreciable proportion of those questioned fail to reply; (c) *question bias*, a tendency for the wording of the question to invite an incorrect reply; (d) *interviewer bias*, a problem of personal interviewing when respondents try to reply in the way the interviewer is thought to expect.' (Encyclopedia.com, n.d.)

Supervisor

A research supervisor (often referred to as simply 'supervisor') is responsible for the general oversight of an academic research project.

Valid

A research tool is described as 'valid' if it actually measures that which it was designed to measure (see section 8.1 for more information).

Appendix 2: Key Journals

(This is not intended to be a comprehensive list, but does cover some of the key journals which publish palliative care research. The summaries below have been taken directly from, or adapted from, information provided on the websites of the publishers of these journals, and were correct at January 2011.)

British Journal of Cancer

The *British Journal of Cancer* BJC publishes significant original papers and reviews that:

- increase understanding of the causes of cancer
- inform timely detection and accurate diagnosis
- investigate molecular pathways relevant to cancer therapy
- contribute to the discovery of novel therapies
- help develop personalised therapy
- drive improvements in the treatment and survival of patients.

British Medical Journal

The *British Medical Journal* (BMJ) is an international peer reviewed medical journal and a fully 'online first' publication. The BMJ seeks to lead the debate on health and to engage, inform, and stimulate doctors, researchers, and other health professionals in ways that will improve outcomes for patients. The BMJ publishes original research articles, review and educational articles, news, letters, investigative journalism, and articles commenting on the clinical, scientific, social, political, and economic factors affecting health. The circulation of the BMJ totals approximately 122 000 copies, of which 10 000 are distributed outside Britain. In addition, international editions reach another 55 000 readers.

BMJ Supportive and Palliative Care

BMJ Supportive & Palliative Care is an international peer review journal for clinicians, researchers and other healthcare workers in all clinical services where supportive and palliative care is practised. The journal aims to link many disciplines and specialties throughout the world, promoting an exchange of research evidence and innovative practice by presenting high quality scientific reports, reviews, comment, information and news of international importance.

End of Life Care

This journal is designed to provide nurses working in hospitals, care homes and community settings with evidence-based articles and information so that they can give more effective care to dying patients and their families/friends.

European Journal of Cancer

The *European Journal of Cancer (including EJC Supplements),* is an international comprehensive oncology journal that publishes original research, editorial comments, review articles and news on experimental oncology, clinical oncology (medical, paediatric, radiation, surgical), and on cancer epidemiology and prevention. The *European Journal of Cancer (including EJC Supplements)* is the official Journal of the European Organisation for Research and Treatment of Cancer (EORTC), the European CanCer Organisation (ECCO), the European Association for Cancer Research (EACR), the European Society of Breast Cancer Specialists (EUSOMA) and the European School of Oncology (ESO).

European Journal of Palliative Care

The *European Journal of Palliative Care* is designed to be of direct and practical relevance to palliative care specialists, GPs, nurses (whether home- or hospital/hospice-based), medical and clinical oncologists, anaesthetists and pain specialists, geriatricians, AIDS specialists, psychiatrists/psychologists, social workers and site specialists (eg gastroenterologists, chest physicians, gynaecologists). EJPC is

mainly a review-based journal; but does accept relevant original research papers depending on their length and the topic. Commissioned review articles cover all aspects of the care of patients with advanced, incurable diseases, and contributions are welcomed from members of every discipline involved in palliative care.

International Journal of Palliative Nursing

The *International Journal of Palliative Nursing* (IJPN) is now established as the leading journal for nurses working in palliative care. It aims to provide nurses with essential information to help them deliver the best possible care and support for their patients. Each issue contains a range of peer-reviewed clinical, professional and educational articles, as well as information on practical, legal and policy issues of importance to all palliative nurses. The journal has a strong international focus and articles are commissioned internationally to encourage the sharing of practices and innovations worldwide, and to raise awareness of the different cultural influences on palliative care.

The Journal of Pain

The Journal of Pain publishes original articles related to all aspects of pain, including clinical and basic research, patient care, education, and health policy. Articles published in the Journal are most commonly reports of original clinical research or reports of original basic research. In addition, invited critical reviews, including meta analyses of drugs for pain management, invited commentaries on reviews, and exceptional case studies are published in the Journal. The Journal aims to improve the care of patients in pain by providing a forum for clinical researchers, basic scientists, clinicians and other health professionals to publish original research.

Journal of Pain and Symptom Management

The *Journal of Pain and Symptom Management* is an internationally respected, peer-reviewed journal and serves an inter-disciplinary audience of professionals by providing a forum for the publication of the latest clinical research and best practices related to the relief of illness burden among patients with serious or life-threatening illness. The Journal has strongly supported both quantitative and qualitative research underpinning the evolving discipline of palliative care, including clinical trials of pain or symptom control therapies, epidemiology of phenomena related to life-threatening disease and end-of-life care, instrument development to enhance clinical assessment and facilitate investigation, and health services studies evaluating the outcomes of diverse therapeutic models. It also offers extensive coverage of clinical practice issues, publishing both systematic and narrative reviews, case series and case reports, and both special articles and columns that present important updates on topics as varied as the international diversity of palliative medicine, the economics of palliative care, and bioethics in end-of-life care.

Journal of Palliative Care

The *Journal of Palliative Care*, published by the Centre de Recherche Institut Universitaire de Gériatrie de Montreal, is a Canadian-based, peer-reviewed, international and inter-disciplinary forum for practical, critical thought on palliative care and palliative medicine. The Journal, first published in the Autumn of 1985, is a quarterly publication now in its 25th year. The Journal's Editorial Board, authorship, readership and panel of manuscript reviewers is international. The Journal publishes 12 types of papers including reports of original research, opinion papers, current reviews, case reports, book reviews and reports on international activities. Each manuscript is submitted for evaluation to at least three reviewers.

Pain

This journal is the official publication of the International Association for the Study of Pain and publishes original research on the nature, mechanisms and treatment of pain. The journal provides a forum for the dissemination of research in the basic and clinical sciences of multi-disciplinary interest.

Palliative Medicine

Palliative Medicine is a peer reviewed, scholarly journal dedicated to improving knowledge and clinical practice in the palliative care of patients with far advanced disease. It reflects the multi-disciplinary approach that is the hallmark of effective palliative care. It is aimed at all members of the palliative

care team, including doctors, nurses, physiotherapists, psychologists, social workers, chaplains and occupational therapists. It is designed to be a practical journal to assist with the palliative care of patients.

The Pharmaceutical Journal

The Pharmaceutical Journal is the official weekly journal of the Royal Pharmaceutical Society. As well as providing comprehensive news coverage of all aspects of pharmacy in Britain and developments in other parts of the world of relevance, *The Pharmaceutical Journal* publishes technical articles and reviews on medicines and medicines use. Also included are letters, book reviews, reports of international conferences, and a continuing professional development section.

Scottish Journal of Healthcare Chaplaincy

The *Scottish Journal of Healthcare Chaplaincy* aims to assist healthcare chaplains and healthcare workers as they strive to provide effective spiritual, religious and pastoral care within the contemporary healthcare setting. The journal provides a multi-disciplinary forum for the discussion of a wide range of issues pertaining to health care and health care chaplaincy in all of its diverse forms. It focuses on the practice of chaplaincy in healthcare within Scotland and beyond, seeking to bring together practitioners and academics, ordained and lay people, in a way which will enable chaplains and carers to have invaluable access to new and innovative thinking and practice. As well as being multi-disciplinary, the journal also aims to explore inter-cultural and inter-religious issues which are an important focus for chaplaincy and healthcare within contemporary Britain.

Social Science and Medicine

Social Science & Medicine provides an international and inter-disciplinary forum for the dissemination of social science research on health. It publishes original research articles (both empirical and theoretical), reviews, position papers and commentaries on health issues, to inform current research, policy and practice in all areas of common interest to social scientists, health practitioners, and policy makers. The journal publishes material relevant to any aspect of health from a wide range of social science disciplines (anthropology, economics, epidemiology, geography, policy, psychology, and sociology), and material relevant to the social sciences from any of the professions concerned with physical and mental health, health care, clinical practice, and health policy and organisation.

Supportive Care in Cancer

Supportive Care in Cancer (SCC), is the official journal of the Multinational Association of Supportive Care in Cancer (MASCC). It aims to provide its members as well as all other interested individuals, groups and institutions with the most recent scientific and social information on all aspects of medical, surgical, nursing and psycho-social supportive care in cancer patients in all stages of their disease, supplementing or substituting basic cancer treatment. This journal publishes invited concise reviews, original work, guidelines, consensus papers and short communications, as well as letters relevant to its aims and scope.

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Appendix 4: Membership

Research Guidance Advisory Group:

Professor John Welsh
(Chairman)

Professor of Palliative Medicine,
St Margaret of Scotland Hospice

Mark Hazelwood
(from December 2009)

Director,
Scottish Partnership for Palliative Care

Dr Bridget Johnston

Senior Research Fellow,
University of Dundee

Dr Barry Laird

Research Fellow,
University of Edinburgh

Prof Scott Murray
(until January 2009)

St Columba's Hospice Chair of
Primary Palliative Care

Rebecca Patterson

Policy Manager,
Scottish Partnership for Palliative Care

Dr Deirdra Sives

Consultant in Palliative Medicine,
Strathcarron Hospice

Elaine Stevens
(until September 2009)

Education Manager/ Lecturer in Palliative Care,
RCN Palliative Nursing Group

Janet Trundle

Macmillan Specialist Pharmacist in Palliative Care,
NHS Greater Glasgow and Clyde

Patricia Wallace
(until December 2009)

Director,
Scottish Partnership for Palliative Care

Research Guidance Reference Group:

Professor John Atkinson   Associate Dean Research & Commercialism,
                           University of Paisley

Dr Paul Baughan   Macmillan Cancer Lead GP,
                           NHS Forth Valley

Dr Duncan Brown   Medical Director,
                           St Columba's Hospice

Dr Patricia Cantley   Consultant in Medicine for the Elderly,
                           NHS Lothian

Rev Stuart Coates   Chaplain,
                           Strathcarron Hospice

Caroline Cochrane   Clinical Psychologist,
                           Edinburgh Cancer Centre

Julie Graham   Macmillan Palliative Care Nurse Specialist,
                           Wishaw General Hospital

Dr Marilyn Kendall   Research Fellow,
                           University of Edinburgh

Paula McCormack   Director of Clinical and Education Services,
                           Highland Hospice

Suzanne Nimmo   Palliative Care Nurse Specialist,
                           NHS Forth Valley

Elaine Peace   Associate Director of Nursing – Primary and
                           Community Services, NHS Borders

Margaret Thomson   Head Occupational Therapist,
                           The Beatson West of Scotland Cancer Centre

Dr John Walley   Consultant in Palliative Medicine,
                           Accord Hospice

Prof Craig White   Associate Clinical Director,
                           NHS Ayrshire and Arran

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