HIV NURSING

— CARING FOR PEOPLE AFFECTED BY HIV —

Research

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Aims and Scope

HIV Nursing has been developed as a forum for those at the forefront of caring for people affected by HIV. The journal is supported by a highly respected Editorial Board drawn from a wide range of nursing specialties. This is further strengthened by an Advisory Panel who will be making regular contributions to the journal.

HIV Nursing is intended to provide a medium for communication on issues relating to HIV care, which will be run by the care professionals for those involved in the day-to-day matters affecting the lives of patients.

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Editorial Office

Research and HIV nursing

Carol Pellowe

Deputy Director, Faculty of Health and Human Sciences, Thames Valley University

Welcome to this edition of *HIV Nursing*, which for once is focused on you rather than your patients or clients. The theme in this edition is research: how to do it and how to disseminate it. It always strikes me at conferences how much good research is being done by those working in the HIV field yet how little we get to hear about it. Are we suffering from the shrinking violet syndrome or just too busy to put pen to paper? Whichever, NHIVNA has always held as its basic tenets, education, support and research and this edition attempts to address all three.

On 1st May 2008, the Nursing and Midwifery Council's new Code of Conduct [1] became operational and I draw your attention to two aspects:

- You must deliver care based on the best available evidence or best practice.
- You must take part in appropriate learning and practice activities that maintain and develop your competence and performance.

Evidence-based practice and the need to maintain competence means that continuing education is now integral to our continuing practice. As nurses increasingly register as graduates, demands for higher education grow. At one time, holding a Master's qualification was rare, now it is fairly commonplace and people are looking at studying at doctoral level. Although doctoral work is often associated with the phrase 'many are called but few are chosen', this is perhaps more accurately linked with people choosing the wrong research subject or doctoral pathway. To address this, Mark Hayter discusses the advantages and disadvantages of doctoral study through either a traditional PhD or a professional doctorate. He provides some helpful issues to consider before embarking, perhaps the most important of which is to choose something you are interested in.

To follow this we have two examples of research in progress. Rui Baptista-Gonçalves shares his experience of some of the practical issues facing a PhD student in getting started and choosing a suitable methodology. Simon Jones discusses the advantages of making research part of your working life and describes the challenges of undertaking evaluation research with voluntary organisations at home and overseas.

Regardless of whether you may wish to pursue further studies the opportunities to undertake research are many and in this field there are many funding opportunities, not least of which is the Boehringer Ingelheim research grant available to NHIVNA members. Having been a member of a selection panel I am all too aware how frequently applications fail to address the key requirements of a research call. Anyone considering submitting a proposal is well advised to read Peter Harper's five rules on writing a proposal and using them as a check list during their preparation.

Many on a master's course undertake a project for their dissertation. Although there is a temptation to see the award as the only goal, it is worth sharing what you did with others. With the NHIVNA conference not far away and the International AIDS Conference next year, it is time to start thinking about submitting an abstract. Abstract writing, like proposal writing, is not difficult if you follow some simple rules and they are included in an article in this edition. There are huge advantages in presenting at NHIVNA's national conference. First is its nursing focus, unlike other HIV conferences, and second, the opportunity to win one of the many awards for best practice, innovation or research. What have you to lose? So get your thinking caps on and start writing and while you are at it, how about an article for *HIV Nursing*?

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Correspondence to: Dr Carol Pellowe, Deputy Director, Faculty of Health and Human Sciences, Richard Wells Research Centre, Thames Valley University, Paragon House, Boston Manor Road, Brentford, Middlesex TW8 9GA, UK
(email: carol.pellowe@tvu.ac.uk)

Developing research skills through doctoral education: a traditional PhD or a professional doctorate?

Mark Hayter

Senior Lecturer, School of Nursing and Midwifery Care, University of Sheffield

The doctoral level qualification is one of the key ways by which nurses can develop their research skills [1]. This article intends to explore how doctoral level study can enable nurses to improve their career prospects and also engage in research that can inform evidence-based practice and make a significant contribution to the knowledge base of nursing. It will also explore the different types of doctoral education possible for nurses, exploring the advantages and disadvantages of these alternatives. The article will also discuss the issues that nurses should consider before embarking on this long, often lonely, but ultimately fulfilling research-training journey.

Doctorates and research

There is no doubt that a sound research training is important for clinicians wishing to advance their career – either within healthcare services or within the higher education sector [2,3]. For any clinician wishing to enter nurse education, particularly in some of the research-led universities, a doctoral qualification is an enormous asset, often a prerequisite for a lecturer post. However, doctoral level research training can also equip an individual to expand their clinical career into research areas. The traditional PhD or taught professional doctorate is basically a preparation process for becoming a rigorous and competent researcher. Unlike any research studies at master's level, the doctoral process takes several steps up the analytical ladder to engage the students in an endeavour that results in the production of 'new knowledge' [4]. Therefore, it is not a process embarked on lightly. However, it is a process that enables the type of detailed study someone will only do once in their career. The opportunity to become engrossed in an area of importance and interest is without academic compare.

Doctoral level study of any type immerses the learner in the philosophical background to research methodologies, demands an in-depth critique of research methods, and also requires that the learner develops an understanding of a particular area that would enable them to discuss this on a par with national and/or international leaders in that field [5]. A doctoral qualification is like an admission ticket to the research world as a doctorate is an internationally recognised symbol that one should be taken seriously as an academic and researcher.

Studying at this level, whatever the nature of the programme, requires commitment and persistence. A doctorate is not an extended master's thesis; it is on a totally different scale indeed. Doctoral students will be required to commit to detailed study over a number of years, usually between five and seven. A healthy interest in the research question is a necessity to sustain this and it is therefore important to be clear about the driving force behind studying at this level. If the prime motivation is to obtain the qualification rather then engage in an area of intense interest, proceed with caution!

Doctoral level education in the UK

Until the mid-1990s healthcare practitioners wishing to pursue doctoral level study would be required to register for what can be referred to as a 'traditional' PhD [6]. This would involve the student registering with a university and being allocated a supervisor to pursue a research study in a predetermined subject area. The student would submit a proposal outlining their research aims and a suitably qualified and experienced academic would then support them through the PhD process. This typically involves 3 years of full-time or 6–7 years of part-time study. There is no taught element to the traditional PhD and the student embarks on a lone process that sees the initial development of a research proposal, completion of an empirical research study and production of a thesis [7]. This thesis is then assessed by examiners who are expert in that particular field of study. This examination also includes an oral examination – the *viva voce* – that is a staple element of the PhD process.

Professional doctorates

As healthcare professionals have become integrated into the higher education sector there has been some criticism of the traditional PhD, particularly by nurses [8]. The main arguments being that the PhD 'was divorced from the realities of practice' and that the PhD was designed for producing academics, not skilled, knowledgeable practitioners, capable of transferring their research skills to the clinical environment [9]. This general dissatisfaction has led to the development of numerous doctoral-level programmes intending to provide an alternative, more clinically and professionally appropriate route to a doctoral award [10].

Although these programmes differ somewhat, the general theme is that they consist of clusters of taught modules that explore research from a broad perspective and also contain educational units pertinent to nursing and healthcare, for example, health economics, nursing philosophies and conceptual issues of care and health service delivery [11]. They usually offer interim exit awards along the way, enabling students to leave with a post-graduate diploma or master's degree. Professional doctorates usually incorporate an empirical research project where students are still required to collect and analyse data and present a 'shortened' thesis. However, not all professional doctorates include this and they consist entirely of individually taught and assessed modules of study [12].

Advantages of the professional doctorate

Embarking on a taught programme can be advantageous in a number of ways. A structured programme will often have set study days and predefined submission dates for written work along the way. This can be useful if an individual finds self-organisation problematic and prefers to be given deadlines. The use of set study days can be useful when negotiating study time with employers as well. Another strength of a taught doctorate is that it will cover a wide range of research methods. In a traditional PhD, the student pursues the programme of research using a certain methodology, often to the exclusion of other approaches. A traditional PhD utilising a qualitative design will not involve training on quantitative techniques, for example statistical data analysis. Taught professional doctorates will provide students with a grounding in all types of research methods and is an approach that could be argued as providing broader research training than the traditional PhD route [13]. In addition, unlike traditional PhDs, students often have the option to leave the programme with an intermediate award, such as a Master's degree.

Furthermore, one of the strongest attractions of taught doctorates is the opportunity to study with a group of like-minded fellow students. On some professional doctorate programmes these may be from across the health professional spectrum. This enables the sharing of ideas and discussion in the taught sessions, the cross cultivation of ideas for research, and of course, the opportunity for mutual support. Learning at doctoral level can be challenging and having other individuals to share in this can be very supportive. The professional doctorate is most suited to individuals who thrive on educational discussion and debate and also who like to work towards pre-defined deadlines and assessment schedules [14].

Disadvantages of the professional doctorate

In a way the disadvantages mirror the advantages. The structure of the programme may be too rigid to allow for work and family commitments. The extensive nature of the learning outcomes could provide a broad but superficial grounding in research methods, lacking the in-depth analysis and examination of a specific research methodology required at this level of academic study. There is also the manner of how the qualification is regarded by prospective employers and the wider academic community. It is often the case that taught professional doctorates are regarded as second class doctorates behind the traditional PhD [15]. This is perhaps unfair but should be taken into account when making a decision on which doctoral route to follow.

Advantages of the traditional PhD

A traditional PhD entails the in-depth study of a particular issue and the extremely rigorous application of a research methodology. It allows the student to become totally engrossed in the research question and does not involve the 'distractions' that study outside this area may entail. It is an internationally recognised qualification and the UK PhD in particular, is held in high regard – this aspect should not be dismissed lightly [16]. Prospective employers and research collaborators will know what the award means but it may be continually necessary to explain what a professional doctorate involves and means in many international, even national arenas [17].

A PhD enables a student to work with an international expert in their field of study. Universities often use supervisory teams that enable the student to have access to a group of highly skilled academics. A close working relationship between student and supervisor(s) can lead to a career-long research partnership. PhDs are really suited to individuals who can organise themselves and be self-motivated and to people who can set their own learning targets and enjoy periods of reflection and lone enquiry [18]. A further advantage of a traditional PhD is the flexibility it affords. Students are not linked to assessment schedules and deadlines, nor lectures or study days. This enables students to set their own pace and study at times and locations that suit them – for example around work and family commitments.

Disadvantages of the traditional PhD

Study this way can be a long and lonely experience. There may be times when emotional support from peers experiencing similar pressures of study would be extremely helpful. There is also a tremendous amount riding on the supervisory relationship. If this breaks down it can significantly

affect the process and outcome of the PhD [19]. Another disadvantage is that the PhD is, to a large, extent an 'all or nothing' process: there is no opportunity to step off and receive an intermediate award such as a post–graduate diploma. There is an awful lot riding on the final examination stage. Although the PhD enables an in-depth study focus, it may be too focused and may not enable the student to explore the wider contexts and tangentially related topics that a taught programme would offer. For healthcare professionals it may not enable clinical issues to be fully explored and the traditional research process may not reflect the varied educational needs of the modern healthcare worker. As stated earlier, professional doctorates exist to counter this argument.

Planning for doctoral education

The decision to undertake doctoral level study of any type is, of course, an individual decision but it needs to be an informed one. The following list of points may help a potential doctoral student in this regard. When thinking about doctoral study:

■ Take a close look at what is available. There may be funding from commissioners of continuing professional education for a professional doctorate programme.

■ What support would your employer offer? Would time off for specific study modules be given?

■ Talk to other students on both the professional doctorate and PhD routes and learn from their experiences.

■ If possible, seek the advice of a colleague in higher education with experience of PhD supervision for their guidance.

■ Be honest about your learning style: do you prefer group interaction or working alone? Do the more fixed assessment deadlines of the professional doctorate appeal to your motivation requirements or do you thrive on self-set goals?

■ Think carefully about why you want to do this type of study. How does it fit with your career plan? Have you a real interest in the in-depth study of a particular issue or does a broader set of learning outcomes appeal to you?

■ Be realistic about competing demands from work or home life, not just immediately but in the future.

Conclusion

Whichever route the student takes, doctoral level study requires a significant commitment over a long period of time and is not a decision that should be made impulsively. Professional doctorates offer numerous advantages and are certainly growing in number and credibility but the traditional PhD remains the internationally recognised measure of academic and research excellence. Students should think carefully about what type of study suits their style of learning and working. Both awards, however, place the student within the top 1% of the population educationally and although the relative merits of different types of doctoral education are contentious issues, the achievement of a doctoral-level award can be a life-affirming, career-changing event.

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Correspondence to: Mark Hayter, Senior Lecturer, School of Nursing and Midwifery Care, University of Sheffield, Samuel Fox House, Northern General Hospital, Herries Road, Sheffield S5 7AU, UK (m.hayter@sheffield.ac.uk)

Doing a PhD in HIV: practical issues and considerations

Rui Baptista-Gonçalves

PhD Candidate, Thomas Coram Research Unit, Institute of Education, University of London

Despite the major scientific advances that occur almost on a daily basis within the field of HIV medicine, living with HIV is still charged with a variety of negative factors, including stigma and discrimination. These can lead to other violations of human rights such as denied access to healthcare and work, which can greatly impair the health and wellbeing of people living with HIV. I have also worked closely with people who live with HIV for a number of years and while I have supported individuals through my clinical work, I have also witnessed some of the difficulties that they go through, whether at a social, personal or emotional level. In the past some of my research work has looked at the social needs identified by people living with HIV and the extent of the hardship faced after receiving an HIV-positive diagnosis [1]. Other studies in the UK have also looked at the challenges that HIV-positive people face at a wider societal level [2,3] and concluded that the changes in antiretroviral treatment did not translate into straightforward changes in the patterns of need. The complexity of changes in need has been compounded by the unpredictable relationship between needs and service use [3]. It is therefore imperative that studies should accompany and address this shift from the resolution of a medical challenge to the broader social impact.

I have also found it remarkable that not only are needs individually framed but also the advances in disease management continue to reveal new and significant needs. For example, those needs that derive from the fact that seven out of ten people with HIV are of reproductive age [4] and therefore more likely to claim back their reproductive and sexual rights.

This introduction sums up the beginning of my practical and theoretical journey when deciding to embark on a doctoral programme. Despite the general misconception that studying at doctoral level is merely a compulsory step in order to become an academic, the essence of a PhD is richer in that it often stems from the desire to further knowledge in a specific subject. In fact, doctoral degrees have become increasingly more attractive to nurse educators, clinicians and a new generation of nurse researchers [5].

A PhD is traditionally an advanced academic degree that is achieved though independent work and must deliver original information. In terms of duration, it can take from 3 to 4 years full-time, to 7 years part-time, and it can assume a variety of formats: traditional (short research, training and thesis), taught PhD (common in the US, with a greater number of lectures pre-thesis), practice-based (based in the student's professional environment) and by publication (the student submits a number of scientific articles to peer-reviewed journals and a final portfolio is submitted to the institution).

Most PhD programmes will require the candidate to prepare a research proposal that should accompany all the documentation to be submitted upon application. It is therefore imperative that the candidate is aware of the state of the art around the topic of choice, and the various literature sources from where this knowledge can be gained. This also applies if the candidate is applying for a PhD studentship, in which the topic can be pre-set according to the curriculum of the specific research unit. Whatever the case, one should bear in mind that undertaking a PhD can be a very lonely and isolated venture. Before anyone embarking on studying towards a PhD, there are a number of questions, mostly around motivational levels, funding and ability to devote so much time to one research topic that might emerge in the candidate's mind. These are critical aspects that need to be considered carefully.

In fact, the independence of the work involved throughout the PhD programme can be translated into students doing everything for themselves, in situations where established researchers might use assistants [5]. A PhD is very different from taught degrees (master's or undergraduate) for its flexibility and autonomy. However appealing these might be, students often miss the structured format of other degrees.

Choosing the right supervisor, especially if you know little about who's a recognised expert in the area you want to develop your studies, can be very tricky. Supervision plays a very important role, as the supervisor(s) not only offer academic and pastoral support but also alert the student to potential issues they might find and offer ways of minimising the overload and stress levels.

One other consideration relates to the financial burden that a PhD can cause. Thankfully there are a few studentship and scholarship programmes available, and these will not only cover the costs of fees but also offer the student a stipend for other costs (including living allowances, travel, etc.)

Alternatively, some universities offer part-time doctoral programmes, which allow candidates to work concomitantly. Before I secured funding for my PhD, I was working full-time and studying part-time, which I found quite difficult to manage. If you chose this path, make sure you can keep track of all the demands and constant input that both aspects require. It has been reported that students undertaking part-time PhDs can underestimate just what is truly required [6].

Interest in a subject or specific research problem can be, as mentioned above, what triggers the aspiration for studying towards a PhD. Some prospective students might wish to develop certain ideas around key concepts, whereas others are more aware of which methods and what research questions they would choose in their studies. When it comes to methodology, it is often thought amongst doctoral students that using both quantitative and qualitative methods is far more robust than simply using one of the paradigms. This also avoids over-familiarisation with one paradigm only, which can be criticised within the scientific community [5]. In my particular case, I envisaged my study would benefit from an ethnographic approach for data collection through field observation in clinical settings, in-depth interviews with people living with HIV and their carers, and analysis of documentation, such as local and governmental policies, acts, etc. In order to complement this qualitative part, two surveys would then be applied to patients and their carers. This, as I discovered later on, was not the most suitable option in order to enhance the real value of my research. Using multi-strategy research, in this case using qualitative and quantitative methods, is not always appropriate. The reason for this is that each methodology carries its own commitments and follows dissimilar paradigms [7]. This means that, if I had decided to go on with my initial choice, I would be adding to the incompatibility between paradigms rather than combining them; the paradigms were incommensurable [8].

Overall, having a PhD shows the world you're capable of putting in the disciplined effort, logical thought and leaps of insight required of people who will go on to innovate and lead innovators [9]. It can be a frustrating, stressful and onerous journey. However, it also provides candidates with the ability to further their knowledge and to contribute to the advancement of science in their chosen areas whether it is a *conceptual contribution* (stronger theory around the key subject), an *empirical contribution* (better understanding of the topic) or a *practical contribution* (for policy and professional development and practice).

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Correspondence to: Rui Baptista-Gonçalves, Thomas Coram Research Unit, Institute of Education, University of London, 27/28 Woburn Square, London WC1H 0AA, UK
(email: rbaptistagoncalves@ioe.ac.uk)

Getting involved in research: evaluating the Positive Self-Management Programme

Simon Jones

Senior Lecturer, Richard Wells Research Centre, Thames Valley University

Working as a university lecturer on a research methods course, the question I am most often asked by potential students is: 'How can I get involved in research when I also have a full-time job?' To which my reply is invariably the same: 'By making your research part of your job.' By this I mean choosing a question or a problem related to a particular aspect of your job that you find interesting and want to resolve. You may suspect that you already know the answer to that question, or the answer may even appear to be common sense. However, until you have subjected a problem to a rigorous and systematic investigation, your 'knowledge' of a solution remains little more than 'guesswork' based on past experience and instinct [1]. A structured approach to solving work-related issues allows us to make research a part of our work and gives the decisions we make a solid evidence-base. Taking such an approach has always been my advice to those who have the will and inclination to become involved in research, but lack the time or the money. It enables you to become involved in research while simultaneously helping you to improve your working practice and create new knowledge that can be shared with your peers. Sharing your research findings will allow others to learn from your experiences and gives you the opportunity to make a difference on a wider scale.

One of the easiest ways you can make research a part of your job is through the rigorous evaluation of a new or existing practice, service or policy. Such evaluation is not carried out often enough in the workplace, and when it is, it tends to be informal and too often the results are not written up for publication and dissemination, but kept private. This is a wasted opportunity. Evaluation research is a chance for you to make the most out of something that should already be a mandatory part of your role, and a chance for your employer to assess an important element of their organisation. Obviously each research project has to be developed to meet the needs of a particular question or problem, but a real-world example I frequently use to illustrate how easily work-related evaluation can be turned into research is the work I carried out as part of my involvement in the piloting of the Positive Self-Management Programme (PSMP) in Africa. What follows is a description of the background behind the PSMP pilot; an account of the methodological approach taken in the evaluation; a summary of the research findings; and an outline of how those findings are to be shared and disseminated.

The Positive Self-Management Programme (PSMP)

Greater access to antiretroviral drugs in developing countries is bringing with it an array of new challenges. As people diagnosed with HIV begin to live much longer, they must also begin to learn how to manage their symptoms and gain greater control of their daily lives. Increasingly the battle to live is becoming a battle to live well. Developed by Stanford University, the Positive Self-Management Programme (PSMP) is a 7-week course for people with HIV delivered for 2.5 hours, once a week. Generally, groups are made up of between eight and 16 participants who work together with two or three trained facilitators, at least one of whom is a person living with HIV. Throughout the course, the emphasis is on the members of the group identifying problems and finding solutions for themselves. The Programme is designed to provide participants with skills and techniques that allow them to improve and maintain their physical and mental health. For example participants learn problem-solving skills and then apply them to commonly experienced problems with medication such as poor adherence. They learn how to use simple relaxation and distraction techniques to alleviate problems such as fatigue, anxiety or the side-effects of medications. The programme aims to give participants the skills to coordinate all the things needed to manage their health, as well as to help them keep active and generally improve the quality of their lives. Subjects covered include:

- How to best integrate medication regimens into daily life so they can be taken consistently;
- Techniques to deal with problems such as frustration, fear, fatigue, pain and isolation;
- Appropriate exercise and nutrition for maintaining and improving strength and endurance;
- How to make short- and long-term plans ('action planning');
- Communicating effectively with family, friends, and health professionals;
- Disclosure.

The PSMP in the United Kingdom

In 2002 Living Well became the first organisation to be granted the licence to deliver the PSMP in the United Kingdom (UK). Funded by the NHS, Living Well has since become responsible for rolling out the Programme across the country, and today it

remains the largest provider of the PSMP in the UK, giving support and consultation to other organisations who wish to deliver it. The NHS and UK Government's commitment to self-management and self-care provision is reflected in several recent policy initiatives:

■ *The Expert Patient: A New Approach to Chronic Disease Management for the 21st Century.* September 2001;

■ *Supporting People with Long Term Conditions: An NHS and social care model to support local innovation and integration*, January 2005;

■ *Self Care – A Real Choice: Self care support – A practical option*, January 2005;

■ *Our Health, Our Care, Our Say, White Paper* January 2006.

Up until August 2007, Living Well had delivered the PSMP to over 350 participants and trained over 50 new facilitators. The results from the most recent evaluation of the PSMP found that [2]:

■ 98% of participants felt that the PSMP had been worthwhile;

■ 94% said the Programme had met their expectations and that they would recommend it to others;

■ 87% said the PSMP had helped them to feel more in control of their condition;

■ 63% felt that the Programme had empowered them to make informed choices about HIV medication and motivated them to take more responsibility for their health;

■ 76% reported that the skills they had developed on the PSMP had helped them to more effectively manage their condition;

■ 71% had gained greater confidence and felt that the PSMP had helped them to develop and improve their social and support networks;

■ 69% said that they were more confident in their ability to build personal strategies to support their sexual health, general health and wellbeing.

Having successfully incorporated the PSMP into the range of options it offers to people living with HIV in London, Living Well received funding from the Elton John AIDS Foundation (EJAF) in 2005 to pilot the Programme in Africa. This required the training of facilitators, the recruitment of participants and the co-ordination of the Programme's delivery. In partnership with ICA:UK, together with three non-governmental African organisations (ICA: Kenya, Society of Women and AIDS in Kenya, and Africare), Living Well established an initial cohort of 50 participants in Kenya (three groups) and Uganda (one group). On behalf of Thames Valley University, I was commissioned to evaluate the PSMP's impact on African participants by collecting evidence of the Programme's effects on the participants, facilitators and local organisations involved in the pilot.

Methodology

The pilots were evaluated both quantitatively and qualitatively using a three-stage methodology that included the use of before and after questionnaires, one-to-one interviews and focus groups.

Stage 1

All participants were asked to complete questionnaires pre- and immediately post-PSMP. These questionnaires included the WHOQOL-HIV BREF [3] and the Medication Adherence Scale (MARS) [4] instruments, together with a number of other items designed to examine participants' knowledge, plans for the future, medication adherence and overall perceptions of the Programme. Data collected from these questionnaires was analysed descriptively through the use of frequencies, percentages and means; and inferentially using a paired t-test.

Stage 2

Eighteen months after the completion of the PSMPs, the participants, facilitators and local organisations who were involved in the pilot were invited to attend a 1-day workshop in Nairobi, Kenya where they were asked to complete questionnaires and take part in a number of structured activities, i.e. focus groups, participant presentations. Participants' questionnaires included the same instruments as those they completed in Stage 1 together with a number of other items designed to examine the long-term effect the PSMP has had on them by allowing us to compare their responses with those collected from the same individuals pre- and post-pilot. Facilitators' questionnaires included items that allowed me to gather data on how their training and involvement in delivering the PSMP had impacted their lives, and how the support they received could have been improved. The questionnaires given to the representatives from the local organisations examined the issues surrounding the implementation of a PSMP, including the recruiting of participants and facilitators. These questionnaires also encouraged evaluation and discussion of any other effects the PSMP has had, the lessons learned, and possible future improvements to the Programme.

Whilst the main focus of Stage 2 of the evaluation was on the impact of the Programme on participants, I was also interested in any additional benefits the PSMP may have had for the facilitators and organisations involved. This was partially based on anecdotal evidence that some facilitators had experienced increased career opportunities with other agencies.

All who attended the workshop were asked to take part in group activities in which they were asked to:

■ Test a number of propositions based on the themes that emerged from the Stage 1 questionnaires;

■ Identify key aspects of the PSMP's impact on them over the past 18 months;

■ Explore the ways in which the Programme could possibly be improved; and

■ Discuss what additional support was needed once the Programme ended.

Panel 1. Most Significant Change technique

The Most Significant Change (MSC) technique is a form of participatory monitoring and evaluation. It is participatory because many project stakeholders are involved both in deciding the sorts of change to be recorded and in analysing the data. It is a form of monitoring because it occurs throughout the programme cycle and provides information to help people manage the programme. It contributes to evaluation because it provides data on impact and outcomes that can be used to help assess the performance of the program as a whole.

Essentially, the process involves the collection of significant change (SC) stories emanating from the field level, and the systematic selection of the most significant of these stories by panels of designated stakeholders or staff. The designated staff and stakeholders are initially involved by 'searching' for project impact. Once changes have been captured, various people sit down together, read the stories aloud and have regular and often in-depth discussions about the value of these reported changes. When the technique is implemented successfully, whole teams of people begin to focus their attention on programme impact. [5]

Stage 3

Using the questionnaires completed by participants during Stage 2, I identified those participants who benefited the most and those who had benefited the least from the PSMP, i.e. those participants whose reported perception of benefit was the highest and those whose was the lowest. A purposive sample of two participants (one who has benefited the most and one who has benefited the least) was selected from each of the four original pilot groups, giving a total of eight participants. I then recruited four local researchers through the Aga Khan University (Nairobi) to use a process based on Davies and Dart's 'Most Significant Change' technique [5] to interview each participant plus two people they nominated as best positioned to provide verification of the impact the PSMP has had on them, e.g. a member of the participant's family, a friend, colleague, employer etc. See Panel 1 for more details.

By including such an approach I hoped to gain an in-depth, objective understanding of how the PSMP has impacted on the lives of participants, their relationships and ultimately their community. I used local researchers for the interviews rather than conducting them myself in an attempt to overcome any potential language difficulties. English is the second or third language for most of the participants and I wanted them to be free to express themselves without limitation. Using local researchers also builds local research capacity and helps foster new international research networks. The interviews were structured, tape-recorded and transcribed into English by the four researchers, but all subsequent analysis was carried out by myself.

Research findings

Of the 50 participants who completed the pilot PSMP, 41 returned to play a part in the evaluation, as did all 11 facilitators and three organisational representatives. The evaluation looked at a variety of areas associated with participants' confidence levels; adherence to medication; quality of life; attitudes towards the programme; and whether they felt they had enough information and knowledge to make decisions regarding key issues relating to their general health, welfare and ability to support others. The evaluation of participants conducted immediately following their completion of the PSMP found that in the vast majority of these areas statistically significant improvements were made, and for the most part these improvements had been sustained 18 months later.

The PSMP was extremely well evaluated by participants, facilitators and organisational representatives alike. Participants reported that the Programme had given them back their self-esteem and helped them improve their quality of life by enabling them to take better care of themselves and their families. Participants said that they felt empowered and more able to make informed decisions regarding key issues such as diet and nutrition; exercise; getting advice and help; supporting others; developing personal goals for the future; problem solving; and disclosure. More participants started taking anti-HIV medication following their completion of the Programme and those that were taking antiretroviral medication reported improvements in their adherence to therapy. Participants reported that the PSMP had helped them to gain greater confidence in coping with HIV and felt it had enabled them to build personal strategies to support their general health and wellbeing. Over the last 18 months participants have established better relationships with their healthcare providers; set and achieved a variety of impressive goals; and used the techniques they learned from the PSMP to manage stress, fatigue and difficult emotions. Participants have attempted to improve their diets and take better care of their physical health through exercise. Many of them have re-established themselves in their

communities and now actively seek to help others through voluntary and educational work.

Participants now feel more able to disclose their status to those close to them (sexual partners, friends, family and colleagues) and have the communication skills to do so effectively. Those participants who were unemployed when they began the PSMP have been vigorously seeking paid employment, some even using their PSMP certificates to help them secure a new post. Others have been able to set up their own small businesses. Participants are generally much more open and able to share experiences with friends and family and more able to negotiate sexual situations – practising safer sex when appropriate.

Sharing the findings

On the basis of these research findings I was able to conclude that the PSMP can be successfully transferred to the African context. In addition, because I took a scientific, rigorous and structured approach to the evaluation it means that the experience, lessons and evidence gained from this pilot can be used to help introduce the PSMP to other similar countries in Africa. Based on these findings I was also able to make a number of key recommendations as to how the PSMP could be improved for the African setting, and give an indication of the type of further mechanisms that need to be put in place to support participants, facilitators and the organisations involved in delivery. My findings were shared in five main ways. First, a full report of the research findings was submitted to EJAF and published on the Living Well website. Second, an abridged two-page version of the findings was sent to all those who were involved in the pilots. Third, an account of the research and summary of the findings will be presented at the XVII International AIDS Conference 2008 in Mexico. Fourth, the findings are currently being written up for full publication in an appropriate, peer-reviewed journal. And finally, I wrote the article you have just finished reading in the hope that it might encourage at least one person to do some research of their own. If that one person is you, then this article has been worthwhile.

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Correspondence to: Simon Jones, Senior Lecturer (Research), Richard Wells Research Centre, Thames Valley University, Paragon House, Boston Manor Road, Brentford, Middlesex TW8 9GA, UK (email: simon.jones@tvu.ac.uk)

Writing research proposals: five rules

Peter J Harper

Senior Lecturer, Faculty of Health and Human Sciences, Thames Valley University

Writing a research proposal is quite a challenge; especially writing a good research proposal. What is a 'good' proposal? Punch proposes the following three 'overarching' questions in relation to the proposal writing process [1] and says that a good proposal would succinctly and clearly answer these questions.

- *What* is this research trying to find out; what questions is it trying to answer?
- *How* will the proposed research answer these questions?
- *Why* is this research worth doing?

The process of describing the what, the how, and the why in a proposal frequently involves the process of summary and it is not unusual to have to write within a word limit, regardless of the specific nature or purpose of the proposal. Any form of writing that involves summarising always raises the tricky issue of what to include and what to leave out. You may have spent a great deal of time planning your research project in considerable detail. You can be so close to your project that it is frequently difficult to objectively and concisely describe what you intend to do. As a result the proposal writing process can be quite emotional, especially for novice researchers working alone, and it is easy to take critical questions about the proposed research too personally. Many proposal writers are frustrated by the questions raised by the readers of their proposals who, as far as they are concerned, have either failed to read it properly or are too stupid to understand it! Unfortunately, in some instances, this judgement may be correct but more often than not the readers are not stupid but rather are genuinely seeking to understand your intentions.

Proposals are written for a variety of reasons but two are particularly significant. The first is the proposal written for educational purposes [1]; in this case the proposed research may never actually take place and the proposal becomes an end in itself, that is, an assessment tool. For research students the proposal is a required prelude to their research written to show what is intended and to convince others of its academic potential. The second type of proposal is that written to secure research funding [2]. A fundamental difference here is the origin of the focus of the research. Whereas the student frequently has a fair amount of choice with regard to the focus, the focus of commissioned research is largely predetermined by others. Another significant difference is that the student generally works alone under academic support but commissioned research is often undertaken by teams of researchers working collaboratively.

Regardless of the purpose of the research there are some common principles in developing a proposal. This article will not attempt to describe a step-by-step approach to developing a research proposal; there are plenty of good publications that do this in far more detail than is possible here [1,3]. What follows are five rules to guide you in creating your proposal. These five rules focus on the essence of a good proposal and are drawn from the experiences of a variety of people ranging from professional researchers working in teams to practitioners and students working largely by themselves with minimal support.

Rule one: read and understand the guidance

Rule one is absolutely critical. It doesn't matter whether you are a lone research student or a member of a large research team; ignore the guidance you have been given at your peril. If there is something in the guidance you don't understand, ask for clarification before you proceed. There is almost invariably some kind of guidance available to the proposal writer; in addition to word limits the guidance may include specific areas to be covered, the format of the proposal, and to whom, when and how it should be submitted. In the case of proposals that have been written in response to commissioned, funded, research it is vital that any guidance on the background context is studied carefully and it may even be necessary to undertake a little additional research into the nature and preferences of the organisation and/or individuals commissioning the research. Do they have any preferences with regard to specific topics/issues or research methodology; have they ever commissioned any qualitative research for instance? Guidance can be brief or extensive but you must make sure you follow it. Do not, for example, apply to an organisation for funding for a project in Africa if their guidelines clearly state that they only fund projects in the UK. This might sound ridiculous but proposal writers sometimes make this sort of mistake.

If you are a student and you are writing your proposal as an assessment task there will be assignment guidelines, usually written but sometimes verbal. If you haven't been given any guidance you should ask for it and if it is still not forthcoming then you almost certainly have grounds for a formal complaint. If the guidance

is only given verbally ask for it in writing. As a student undertaking research you may be asked to submit your proposal to a formal ethics committee. This process often involves completing a form as well and good practice would be to provide guidance notes for completing it. In this sort of situation be careful about simply copying sections from your proposal into sections of the form; what is perfectly clear in the context of the proposal can become ambiguous when viewed as an isolated paragraph in a form.

Rule two: seek advice and support

Even if you are very sure of your own abilities there is nothing like letting at least one independent reader look at your proposal before you submit it for review. Apart from anything else they will often spot simple things like typographical errors. Sometimes academic organisations will require you to submit your proposal for peer review prior to formal submission but not always. Choose who you ask for advice and support carefully. Just as it would be pointless to ask someone who is notoriously poor at spelling themselves to check your work for errors it is no good asking for comment on complex controversial methodologies from people who know less about the method than you do. You obviously need to leave time for this process; it is unrealistic to expect someone to drop other commitments in order to read your proposal. For a document of 2–3000 words you should allow at least a week for quality feedback. You can choose different people for different purposes. If you know someone who is a good proofreader ask them to do just that. To save time all round you can direct someone toward a specific section or issue. If you are a novice researcher get some advice on methodology early on with regard to what is appropriate, realistic, and achievable in the time available.

Rule three: don't forget about presentation

You don't have to use professional printing techniques when writing your proposal but it is in your interests to pay attention to presentation in terms of logical sequencing, accuracy and consistency. Use headings to give structure to your proposal; exactly what headings to use will depend on the context of the research but again, we can draw on Punch [1] for a basic structure that can be adapted as required (see Figure 1).

A quick internet search would give you many variations on proposal structure but the important thing is to take the reader through the proposed research logically from the context of the research (the why) through the purpose of the research (the what) to what will actually happen (the how). When you write your proposal imagine if you lost it in the street or left it on a bus; would someone who

Figure 1. Checklist of headings for research proposals. Modified from [1].

Title and title page

Abstract

Introduction: area, topic and statement of purpose

Research questions

- General
- Specific

Conceptual framework, theory, hypotheses

The literature

Methods

- Design: strategy and framework
- Sample
- Data collection: instruments and procedures
- Data analysis

Significance

Limitations and delimitations

Ethical issues: consent, access and participants' protection

References

Appendices

Notes

In some types of research, the research questions would come after the literature section. In some situations, sections on costs (budget), risk management and timetable are also required. A table of contents coming immediately after the title page is helpful to readers.

picks it up be able to clearly understand what it is proposing and why?

Simple things can greatly improve the integrity of your proposal; choose three or, at the most, four heading level styles and use them consistently throughout the document. The same goes for spacing between paragraphs and sections. Don't forget page numbering and give your proposal a version number in the footer as this is often required in accompanying forms. If you can't be bothered to check your spelling and grammar then get someone else to do it for you but don't expect readers of your proposal to take you seriously if you give them a document with many typographical errors.

Use visual aids in the form of figures and tables to clarify your proposal. A good diagrammatic overview of your study is worth its weight in gold and visual timelines make the progression of the research much clearer for the reader. At the same time, having to put something complex into

diagrammatic form can clarify your own understanding about what you are proposing.

Rule four: recognise any ethical dimensions to your research

For healthcare practitioners, probably the most common reason for writing a research proposal is to get ethical approval. This applies both to academic and commissioned research. This undertaking has become increasingly complex over recent years as health providers have become increasingly sensitive to potential ethical issues and now also involves the parallel process of research governance approval. It is important for health professionals to realise that, even though there may not be any obvious ethical issue associated with the proposed research, some form of ethical approval will be required for the majority of research projects that involves the participation of patients and/or staff in NHS environments or use NHS resources. It is equally important to realise that the concept of ethics now extends beyond issues such as voluntary participation, informed consent and the right to withdraw etc. to include the quality of the proposed research methods. In other words a poorly designed study, or even a poorly described study, would be considered unethical. This can be quite a problem when writing a proposal if you intend to use unusual or innovative research methods as the systems and people involved in healthcare ethics are orientated, in general, to linear, pre-defined quantitative approaches and experimental research in particular. Iterative research (research that evolves in stages based on the outcomes of previous stages) may be perfectly acceptable and unproblematic to university ethics committees but be particularly difficult to 'sell' to NHS research committees. Much qualitative research is iterative and there are specific issues related to the writing of proposals for this type of research but they are beyond the scope of this article [4, 5]. The time required for ethical approval can be surprisingly long so any time spent identifying potential problems and pre-empting questions about your proposal is time well spent. You can, for instance, use published examples showing how the type of research you are proposing has been used elsewhere.

Rule five: expect questions

Expect your proposal to be challenged. If it is not then all is well and good but usually it will be and if you have prepared yourself you will be better able to deal with any criticism that comes your way. Often the process of being challenged leads to a better research project and as such it can be a very positive experience. Unfortunately not every reader is positive and you may find yourself on the receiving end of some negative and potentially hurtful comments if you take them personally. Some people take the opportunity to exercise their own particular hobby-horses in this situation and there is little you can do other than to respond professionally to criticism using an evidence-based approach. You won't be able to anticipate every eventuality so expect to be surprised. If, as suggested in Rule Two you have sought the advice of others then (a) collectively you will have anticipated most potential problems and (b) you can at least share the burden of the criticism.

Conclusion

Proposal writing is demanding not so much from a descriptive perspective but in terms of adjusting the proposal to fit its specific purpose. It is relatively easy to find a framework of headings to guide you through the writing process but not so easy to choose the right words and phrases that will trigger a positive response from individual readers with their own personal, sometimes complex, agendas. In this respect probably the most important of the rules is the first; reading and understanding the guidance. The rules presented here are intended to highlight some of the issues in proposal writing but they are only broad guidelines. Your research proposal is unique; you need to find out who will read it and try to anticipate and pre-empt their response as best you can. Good luck!

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Correspondence to: Peter J Harper, Senior Lecturer, Faculty of Health and Human Sciences, Thames Valley University, Richard Wells Research Centre, Paragon House, Boston Manor Road, Brentford, Middlesex TW8 9GA, UK
(email: peter.harper@tvu.ac.uk)

How to write an abstract

Carol Pellowe

Deputy Director, Faculty of Health and Human Sciences, Thames Valley University

At this time of year we seem to enter the conference season, including of course the 10th NHIVNA National Conference in Glasgow. Although securing the funding to attend may be the first priority, it is also an opportunity to think about what you may be able to contribute to the proceedings. Too often nurses fail to share their good practice because they either do not feel it is sufficiently noteworthy or are unsure how to write an abstract. This article covers all you need to know.

What is an abstract?

An abstract is a short summary of your work with the aim of enticing selectors to invite you to present your work. Abstracts are also used in publications where they summarise the key points of the article. As these also appear in web searches the intention of an abstract is to entice the reader to obtain and read the full article. Therefore abstracts should be an accurate and full summary written in such a way as to 'sell' your work.

Getting started

First look at the *call for abstracts* and the areas in which papers are being requested. Think about what you may have done differently over the last year or changes that have taken place in your workplace Have there been any innovations, changes in practice as a result of audit or research undertaken that relate to these subject headings? It is useful at this stage to talk to colleagues about their perspectives. Talking to colleagues may also give you someone to collaborate with.

Check the last date for submission and how the submission should be made, for example, some conferences will only receive abstracts online, others require an online form to be used that may limit the number of words or characters. In this case, draft your abstract in a Word or other word-processed document and only when happy with it, cut and paste it on to the form. Although some conferences will extend the deadline do not assume this will be the case. Large conferences like the International AIDS Conference have in addition to their standard deadline a 'late breaker' that allows submission of new work after the official deadline. However, this is generally restricted to research completed after the deadline or significant new results recently released. Make sure you have all this information before you start work and ensure you have enough time to plan and redraft you work before the deadline.

Decide whether you would like to present your work orally or as a poster. If you are nervous about public speaking then a poster may appear a more attractive option; however, do bear in mind that a good poster takes a lot of work to prepare and the printing can be expensive. Many trusts now have media services or an audio-visual aids department that can advise and help design your poster, so do establish what services are available locally before deciding.

Writing an abstract

An abstract should include a title, why and what you did, how you did it, what you found and what it means. Think carefully about the title particularly if it is to be included in a searchable database. Whilst it may seem attractive to have a catchy title, it needs to include key words otherwise a database search will not pick it up. For example, if your work is about 'adherence', make sure 'adherence' or a synonym appears in the title. If you are writing an abstract about research there are standard formats you should follow (Table 1). Instead of a hypothesis you may state a problem. The methods describe the key data collection methods, for example, questionnaire or in-depth interview. In the results section, report the key findings only and, if using statistics, their significance. The discussion should include the findings' similarities or not to other equivalent research and the limitations of the study. The conclusion should be the key message from your study and whether it can be generalised or is specific to a particular group.

NHIVNA and other conferences invite abstracts on work that is not based on research. There is no

Table 1. A standard research abstract

| Hypothesis |
| Methods |
| Results |
| Discussion |
| Conclusion |

Table 2. Template for non-research abstract

| Problem statement |
| Motivation |
| Approach |
| Results/recommendations |
| Conclusion |

formal structure for such submissions but you could try using the template in Table 2. The problem statement should be the answer to the question 'what was the problem/issue?' whereas the motivation section should cover why what is being written about is important. The approach should describe how you dealt with the problem/issue and the results should outline what happened as a result. You may have recommendations to make about, for example, changes in practice and the conclusion should reinforce your key message.

The key points in writing an abstract are to keep it focused, only include essential information, make it interesting and keep within the word count. Abstract writing requires practice and drafts always benefit from feedback from others. Look for people who are practised in abstract writing or failing that ask colleagues who know the subject.

Post submission

Once you have submitted your abstract start thinking and planning the presentation. Ensure you have booked your place at the conference and have travel arrangements in place. If accepted you should stick to the original abstract and not introduce new or different work. Remember there are prizes for presentations at the NHIVNA conference so you may find yourself able to attend another conference as a result. As both oral and poster presentations require significant work you might consider writing an article on the subject for *HIV Nursing*, that way you get two means of spreading the word. Good luck and now get writing!

Correspondence to: Dr Carol Pellowe, Deputy Director, Faculty of Health and Human Sciences, Richard Wells Research Centre, Thames Valley University, Paragon House, Boston Manor Road, Brentford, Middlesex TW8 9GA, UK (email: carol.pellowe@tvu.ac.uk)

Call for Papers
2008

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The themes for this year's issues include:

Issue 8.3 Focus on the Competencies: Health Promotion
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NHIVNA update

Plans are well underway for the 10th Annual Conference. You should have recently received the Second Announcement for the conference in Glasgow on June 26th and 27th. There is still plenty of time to both register and to let colleagues know of the exciting and packed programme. Full details of the pre-conference study day supported by Abbott will be announced soon. Keep your eye on the website for that.

Talking of the website, the members-only area is almost ready to launch. To help make it a success, we need your contributions and any documentation you are willing to share with colleagues, for example, protocols or policies, can be included.

Sadly, Kieran Sharkey has decided to resign from the Executive Committee. After many years of active contribution, latterly as Newsletter editor he has decided to step down at the conference in June. I would like to take this opportunity to thank Kieran for all his efforts and contributions over the years; he will undoubtedly be missed. However, this of course leaves a vacancy on the committee and if you would be interested in joining the committee, full details are on the website. We hope to announce the new member at the AGM at the June conference.

The first two of this year's study days have taken place and the feedback has been overwhelmingly positive. The London day focused on Caring for Inpatients and the Liverpool day was related to Outpatients and Community Care. The next two days are planned for London and Birmingham later in the year.

Full information on all NHIVNA events is available on the website (www.nhivna.org).

We hope to see you in Glasgow for the conference in June.

Sheila Morris, Chair, NHIVNA

National HIV Nurses Association

10th Annual Conference of the
National HIV Nurses Association (NHIVNA)

26–27 June 2008 ▌ Glasgow Marriott Hotel ▌ Scotland

Dear Colleague

It gives me great pleasure to announce our **10th Annual Conference**.

The plenary programme is taking shape and we are delighted to confirm that a number of eminent speakers have agreed to participate. One of the many highlights of the conference will be the presentation of the very latest research, education and clinical practice initiatives in HIV nursing during the oral presentation sessions. I would like to encourage as many delegates as possible to submit abstracts for review – especially those nurses who have undertaken their own original nursing research.

Please note that NHIVNA is also inviting applications for a number of scholarships and awards. Some are related to the submission of abstracts but there are also awards directed at junior and student nurses, designed to assist them to attend the conference. Full details can be found on the NHIVNA website (www.nhivna.org).

As is customary, there will be a Gala Dinner. This year it is to be held at Òran Mór, a converted church, which is now a cultural centre hosting a varying programme of events. We anticipate an evening of good food, fine wine and after-dinner entertainment.

I look forward to welcoming you to Glasgow.

Best wishes

Sheila Morris
Chair, NHIVNA

Sessions to include:

Modernising nursing careers in HIV nursing

Developing roles in HIV nursing

HIV as a chronic illness: models of chronic disease management

Managing adolescents and transitional care

Current health policy in relation to HIV

Treatment of HIV co-infection

HIV NURSING

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3. **References:** References in the text should be cited consecutively, including tables or figure legends, as they fall in the text. Each reference should be numbered in square parentheses and listed at the end of the article in numerical order, according to the following style:

   Wu AW, Rubin HR, Mathews WC *et al*. Functional status and well-being in a placebo-controlled trial of zidovudine in early symptomatic HIV infection. *J Acquir Immune Defic Syndr*, 1993, **6**, 452–456.

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4. **Illustrations and tables:** These should be provided wherever appropriate. All figures sent with the hard copy of the manuscript should be clear and supplied at larger than the final printed size. In general, figures supplied by the author are redrawn to the Journal style. Where this is not possible, the illustration supplied should be of sufficiently high quality to ensure good reproduction. Colour reproduction is available at the author's expense (cost available on request). All hard copies of illustrations should be clearly labelled with the author's name, figure number and orientation. Where appropriate, magnification figures or scale bars should be supplied. Illustrations and tables must be cited in the text in numerical order. Figure captions should provide an adequate description of the figure without discussing it. When required, it is the author's responsibility to obtain permission to reproduce illustrations or tables, and to include the appropriate credit in the figure or table legend. All photographs are returned to authors on publication.

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