National Research and Development Strategy for HIV nurses





Introduction

This research and development (R&D) strategy which has been developed by the National HIV Nurses Association represents an important milestone for HIV nursing in the UK. It is the first document to promote audit, evaluation and research with the aim of informing the direction of HIV nursing. This strategy is intended to inform the HIV Nursing research and development agenda for the next five years (2018–2023).

In this first section of the document we present the strategy and outline the context within which it has been developed. In the second section we focus on operational aspects. We introduce the NHIVNA research and development framework and explain how it can be used. We then offer wider guidance on how to engage with the strategy through a series of frequently asked questions.

We anticipate that it will be useful for the following groups:

- Nurses working in HIV care
- Academics working—or supporting students—in the HIV field
- Audit and evaluation/quality improvement departments at NHS Trusts
- Other professional HIV organisations (e.g. BHIVA)
- HIV-related Community and key patient groups (e.g. UK-CAB)

Part one: Strategy and research themes

Background

This document reflects NHIVNA's commitment to research. It builds on previous work undertaken to support research activity and develop a research and audit portfolio. Most notably, the following NHIVNA-led initiatives have helped to create a foundation for this strategy work.

2013 – A national evaluation of HIV nurses' knowledge, attitudes and practices towards Treatment as Prevention (TasP)

2014 – A Qualitative Systematic Review (Meta-Synthesis) of the Provision and Management of HIV Testing from a Health Professional Perspective

2015 – The first National Nurse-led Audit of the Standards for Psychological Support for Adults Living with HIV

2016 – A qualitative study exploring shared decision making in HIV nursing care



Developing the strategy

This strategy was developed through consultation with the whole membership. The process was led by the NHIVNA research subcommittee in collaboration with an independent consultation. It involved the following activities, conducted in 2017–18:

An initial workshop – involving a purposive sample of clinical and academic NHIVNA members (n = 14) which provided overall strategic direction and resulted in the identification of a set of three provisional research priority areas.

An online survey – of the whole NHIVNA membership to canvass views and opinions on the value of a R&D strategy and the proposed research priority areas. The survey also gathered valuable information on the extent of research expertise within the workforce and how that might be used to support research capacity development in the wider membership.

Ongoing consultation – with the workshop members to define the focus and scope of three research themes that reflect our three research priority areas and to refine the strategy document.

The overall aims of this strategy are to:

- Increase the amount of high-quality HIV nursing research, evaluation and audit aligned to current health priorities.
- Develop the capacity and capability of the NHIVNA membership to undertake and engage with research activities for the benefit of high-quality patient care.
- Establish a framework within which nurses working in the field of HIV can shape the future of care delivery based on a culture of continuous quality improvement in patient care and experience, innovation, and promotion of evidence based practice.

The objectives are to:

- Establish networks aligned to the three research themes in order to support the development of informal mentorship arrangements, foster research collaborations, and promote engagement in research activities across the whole membership.
- Embrace Patient and Public Involvement and Engagement (PPIE) in all HIV nursing research; working together to shape and develop research that aims to improve the provision of care and management.
- Raise awareness of and improve access to research funding opportunities in order to increase the amount of research activity.
- Develop a database of research project titles, suitable for dissertations and aligned to our priority areas, to promote engagement of a wider nursing community in HIV research and build a stronger body of evidence based knowledge.
- Support and promote dissemination of research and audit activity and outputs to inform continuous quality improvement in care and treatment of people living with HIV.

The research themes

1. Healthcare delivery

The healthcare needs of the HIV population are changing and national policy is directed towards greater community based care delivery and increased involvement of primary care to manage long terms conditions. This indicates a need for changes in the way that HIV services are delivered. This theme explores the ways in which services are responding to the changing requirements around HIV health care delivery and seeks to generate an evidence base to inform developments in this area. Areas of interest include the emergence of new models of HIV service delivery and the development of new and innovative ways of delivering care and the questions related to these developments. For example, how can services work proactively to manage an ageing population to equip them to age well with HIV and continue to live full and meaningful independent lives? What models work best for what populations and in what contexts and settings? What models of care are able to produce best patient outcomes? Who is providing care in these new models and what is the evidence base around the role of the HIV nurse in different models of care?

2. Patient experience

Understanding how people living with HIV experience the different aspects of care delivery is vital to inform meaningful engagement with patients, to improve ongoing care and treatment, and to foster ongoing therapeutic relationships. The specific focus in this theme is on challenging assumptions and stereotypes by developing detailed insights into the specific issues that arise for different populations living with HIV, particularly marginalised populations and those who are vulnerable. A key area of interest is stigma which remains an issue for many people living with HIV despite advances in treatment. Other areas of interest include the ways in which specific behaviours, for example, the use of chemsex, are impacting on those living with HIV. Also, the psychosocial aspects of growing older with HIV and the ways in which this impacts, for example in changing social circumstances including the need for residential care.

3. Developing the workforce

This theme is concerned with developing a nursing workforce equipped to operate effectively within the context of HIV service provision that is increasingly delivered across different settings, using different approaches and involving different multidisciplinary teams. It recognises that the HIV specialist nursing workforce have increasing roles in managing HIV care delivery and the increasing involvement of those working in a range of health care settings. This includes an increased involvement of those in informal and formal carer roles including those providing residential and domiciliary health and social care as the long term health and social care needs of the ageing HIV population become increasingly apparent. Areas of interest include the education and training needs of the established and the emerging nursing workforce including those on pre-registration programmes. Also workforce development issues related to those working in HIV specialist settings including advanced clinical roles and those caring for HIV populations in hospital and community settings.

Key outcomes

Our research strategy will be delivered through the following five key outcomes:

- A range of development opportunities to support R&D capacity among the HIV Nursing workforce
- 2 The development of productive collaborations involved in shaping and developing research, development and audit activity
- **3** A demonstrable impact of our work on the ways in which HIV services are delivered
- A demonstrable contribution to understanding of patient experience and promotion of patient and public involvement and engagement in HIV Research and Development
- 5 A demonstrable influence on developments to ensure that the nursing workforce is equipped to deliver high quality HIV care

Assessment of progress

We will monitor progress against these outcomes annually through a series of specific indicators including:

- Level of engagement with the research networks
- Indications of research collaborations
- Applications for and uptake of research funding opportunities
- Completion of funded projects
- Research outputs



Part two: Making it happen

In this section, we focus on operational aspects. We explain how our strategy fits with the wider health and social care agenda. We then introduce the NHIVNA research and development framework and offer a number of examples to explain how it can be used. Finally, we offer wider information on how to engage with the strategy through a series of frequently asked questions.

The strategy and the wider health and social care agenda

NHIVNA have aligned this research and development strategy to the wider NHS quality agenda^{1, 2, 3} and the British HIV Association Standards of Care⁴. By aligning the strategy in this way will ensure that our research and development is built on the principles of quality (defined as effectiveness, experience and safety) and guarantee that the results from our work will contribute towards both continuous quality improvement in practice and the strategic direction of the NHS. In addition, our commitment to involving and engaging patients and the public within our research fits in with the National Institute of Health Research (NIHR) PPIE Strategy.

Figure 1 (below) demonstrates how we have triangulated the BHIVA Standards of Care with the elements of quality and the principles of research, development and audit. In practice, this means that we can align activities from any one of our three research themes to quality indicators and standards of care. Aligning our activities in this way makes this a more robust and advantageous approach to writing bids, undertaking research, audit and evaluation, interpreting results and translating findings into care settings.

The NHIVNA research and development framework

The NHIVNA research and development framework in *Table 1* (overleaf) brings together the three domains of quality (effectiveness, experience and safety) with the three areas of R&D (audit, evaluation and research).

The framework is designed this way to help you develop your project ideas and formulate them into questions. The UK Policy Framework for Health and Social Care Research⁵ in *Appendix 1* helps you to decide the correct approach to take.

We have provided some example questions for study in the tables overleaf. These initial ideas may sit correctly in one cell of the table but after further exploration and development of the project idea it may turn out to be more appropriately placed elsewhere. These examples are intended only as a guide to demonstrate the differences between audit, research and evaluation.

Figure 1: NHIVNA R&D Strategy and wider NHS context



Table 1: The NHIVNA research and development framework

	Effectiveness of care and improving quality of life	Positive experiences of care	Safety and protection from avoidable harm
Audit			
Evaluation			
Research			

Using the framework

The following examples populate the framework to indicate how it can be used.

Theme: Healthcare delivery. BHIVA standard of care. 7d – Palliative care				
Audit	Are BHIVA standards for palliative care being met in clinical practice?			
Evaluation	How effective are communication processes between HIV services and specialist palliative care teams?	To what extent do patient centred outcomes determine treatment and management of PLHIV with life limiting conditions?	Is pain control and symptom management effective for those with life limiting conditions?	
Research	What are the support needs of family carers for PLHIV with life limiting conditions?			
Theme: Pati	i ent experience . BHIVA standar	d of care. 2 – Person-centred ca	re	
Audit		Are the BPS psychological standards of care for PLHIV (2011) being met within clinical practice?		
Evaluation	Are remote consultations an effective way of delivering routine HIV care?	Do electronic patient held records improve integrated care?		
Research	How does menopause impact on women living with HIV?	What are the experiences of MSM who access support for chemsex use?		
Theme: Developing the workforce. BHIVA standard of care. 8 – Developing and maintaining excellent care				
Audit	Prescribing of ARTs in nurse- led clinics.		Is HIV training provided within mandatory training programmes for social care staff?	
Evaluation	What works to enable residential care staff to care effectively for PLHIV?	Uptake and outcomes of a new peer support service.		
Research	What are the barriers to offering HIV testing in primary care?		What are the training needs of those caring for PLHIV in residential care settings?	

Frequently asked questions

1. What are the research networks groups?

A network group has been set up for each of the three research themes. Their purpose is to encourage development of the NHIVNA research community and support research related activities. They do this by acting as a forum for discussing areas of interest, generating project ideas, exploring and developing research collaborations and providing general research related support and guidance. Many of the NHIVNA membership have research experience and have indicated that they are keen to support those with less experience in a range of different ways. The networks will provide a mechanism by which to provide that support.

2. Am I eligible to join a research network?

Yes. We hope that all NHIVNA members and others who are interested in HIV nursing research will join a network. You can join more than one but you might want to think about how much time you are likely to have to actively engage in discussions.

3. What is the commitment to joining a network?

There is no commitment but we hope that all those who join will engage regularly with their network and contribute to discussions.

4. How do I join a network?

The networks are managed through the NHIVNA website. To join, you simply need to sign up via the instructions on the website.

5. I want to get involved in doing some research but I don't know where to start.

Sharing your ideas with the members of your network group is a very good place to start.

6. How can I decide if my project is research, evaluation or audit?

Consult the UK Policy Framework for Health and Social Care Research (*Table 1*, previous page) which details the key characteristics of research, evaluation and audit. Sharing your project ideas within your research network will also help you to clarify what sort of project it is likely to be.

7. Are there any funding opportunities linked to the strategy?

NHIVNA has created some small funding opportunities linked to the strategy which will be awarded through a competitive process. We will also raise awareness of other funding opportunities, through the NHIVNA website and through the research networks.

Appendix 1

Appendix 1. The difference between audit, evaluation and research

Audit	 Designed and conducted to produce information to inform delivery of best care. Designed to answer: 'Does this service reach a predetermined standard?' Measures against a standard 		
Evaluation	 Designed and conducted solely to define or judge current care. Designed to answer: 'What standard does this service achieve?' Measures current service without reference to a standard. 		
Research	 Defined as the attempt to derive generalisable or transferable new knowledge to answer or refine relevant questions with scientifically sound methods. This excludes audits of practice and service evaluations. It includes studies that aim to generate hypotheses as well as studies that aim to test them, in addition to simply descriptive studies. 		

Definitions are taken from the UK Policy Framework for Health and Social Care Research⁵.

References

- ¹ https://www.gov.uk/government/statistics/nhs-outcomes-framework-indicators-may-2017-release
- ² https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/216159/dh_132362.pdf
- ³ https://services.parliament.uk/bills/2010-11/healthandsocialcare.html
- ⁴ http://www.bhiva.org/documents/Standards-of-care/2018/BHIVA-Standards-of-Care-2018.pdf
- ⁵ http://www.hra-decisiontools.org.uk/research/docs/DefiningResearchTable_Oct2017-1.pdf

Acknowledgements

This research and development strategy was developed by members of The National HIV Nurses Association (NHIVNA). The initiative was conceived by Hilary Piercy from NHIVNA and supported by a grant from the M•A•C AIDS Fund.

The development of this strategy would not have been possible without the expertise and commitment of: Hilary Piercy, Michelle Croston, John McLuskey, Matthew Grundy-Bowers, Gary Barker, Jane Bruton, Lars Eriksson, Catrin Evans, David Evans, Pauline Jelliman, Eileen Nixon, Linda Panton, Breda Patterson and Shaun Watson.

We would also like to thank and acknowledge the support of Mediscript (Secretariat for NHIVNA) and to Andrew Cornes, Graphic Designer. The project was facilitated by Stephen Callaghan, Principal Consultant EQE Health and Clinical Lead for Care Aware International.



Developed in conjunction with EQE Health Ltd.