# Declaration of Interests

| Speaker Name | Statement |
| --- | --- |
| **Eileen Nixon** | None |
| **Date :** | **June 2018** |

# Challenges in Care

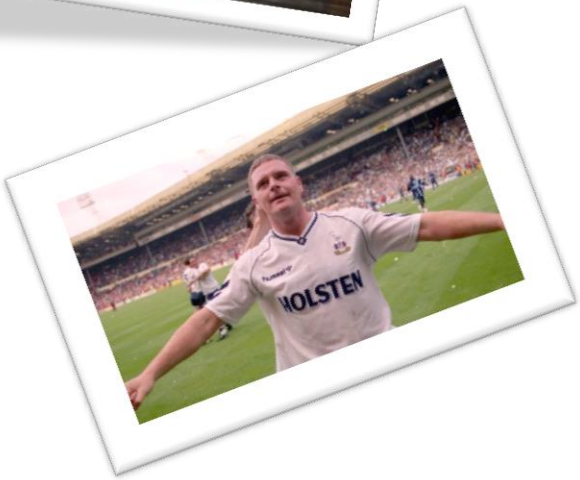
**Eileen Nixon and Pauline Jelliman**


Dear Past,
THANK YOU FOR WHAT YOU TAUGHT ME.
Dear Present,
I'M SMARTER AND STRONGER NOW.
Dear Future,
I PLAN TO KICK SOME SERIOUS BUTT.
Love,
ME
@ENCOURAGEDINHEART

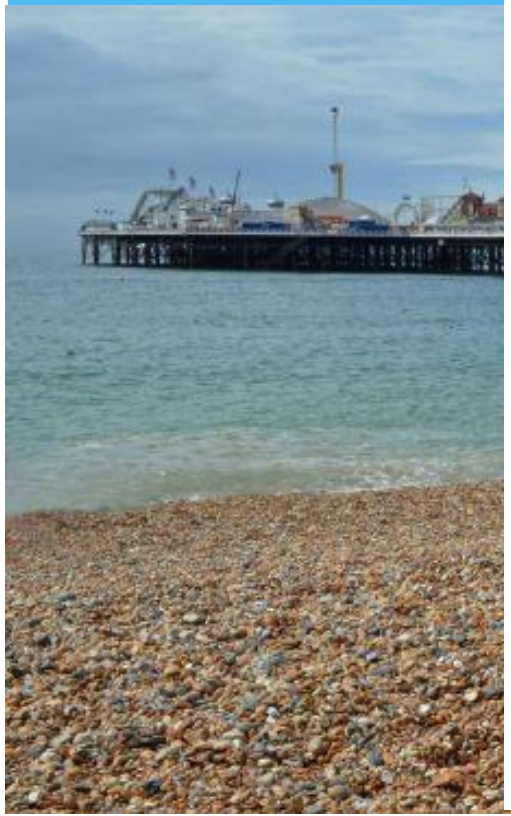
# Challenges in Care

# 1988

COMIC RELIEF


# 1988 in Brighton



**THE SUN SAYS**

## Town of shame

**FOUR years after the IRA bomb, the Tories bravely return to Brighton.**

But in a local newspaper poll, 73 per cent of Brighton people say the Tories are no longer welcome.

Many claim that the extra security infringes civil liberties.

What liberty do they prefer?

*The liberty to plant a bomb unhindered?*

Brighton has become a nasty town of drugs, gays, AIDS and drunks. With a Left-dominated council whose mayoress once refused to curtsy for Royalty.

**If they took a poll in Brighton about the Second Coming of Christ, that would probably get a No vote, too.**

# What the papers were saying


*http://www.gayinthe80s.com/2013/01/1984-85-media-aids-and-the-british-press/aids-press-collage/*

# Uncharted Territory

The Province Monday, April 3, 1988

# Embalmers fear AIDS risk

## 'HAPPENING ALL OVER'

News Services

A Toronto AIDS support group says the discriminatory attitude of most B.C. funeral homes is true across Canada.

"It's happening all over," said Phil Shaw, spokesman for the AIDS Committee of Toronto.

"There's only a small number of funeral homes that we can refer people to, even here in Toronto."

In St. Catharines, Ont., one funeral director quit his job to lobby against area doctors who don't warn embalmers about diseases like AIDS in bodies they prepare for burial or cremation.

In Halifax, the Nova Scotia Embalmers Association wants bodies of people who have died of infectious diseases to bear labels with bold, five-centimetre-high lettering spelling out the nature of the illness.

The Ontario Funeral Directors' Association has expanded its code of ethics to eliminate discrimination against AIDS victims.

But it said funeral directors can adapt services to protect employees and the public, which means some funeral homes may refuse to embalm AIDS victims.

There have been 907 confirmed cases of AIDS deaths in Canada.

By JOHN TRETHEWEY
Staff Reporter

Fear of AIDS has gripped B.C. funeral homes.

Spokesmen say almost all funeral homes are refusing to embalm those who died of acquired immune deficiency syndrome.

Only three Vancouver funeral homes take victims of AIDS.

Funeral-home workers fear infection through exposure to blood and other bodily fluids.

Vancouver funeral director Bert Landriault put it bluntly: "I wouldn't touch them with a 10-foot pole."

It's a fear based on fact, say experts.

They say bodily fluids from recently deceased AIDS sufferers are infectious. Jim Houseman, a director of the B.C. Funeral Association which represents all but a handful of the province's nearly 70 homes, told The Province fewer and fewer embalmers will touch the bodies of AIDS victims.

"The majority of operators would not like to deal with an AIDS victim — actually do the embalming," he said. "And I know people who have and don't want to any more."

Said Landriault: "They don't pay us enough money. I've got a family and I'm not willing to take the chance."

Landriault, who works for Roselawn Funeral Home on East Broadway, said in an interview he once had to be treated for blood poisoning after pricking himself with a suture needle.

It scared him for life.

"They can fire me tomorrow if they force me to do an AIDS case. I would gladly go," he says.

Others feel the same way despi federal and provincial guidelines.

Embalmers working on AID cadavers must don disposab paper jump-suits, two to three pai of rubber gloves, goggles and eve helmets. The extra equipment, di infectant and other costs can ad between $150 to $500 to the bill.

Labor and Consumer Service Minister Lyall Hanson said he w soon form an advisory board t rewrite funeral-home legislation.

Hanson told The Province yeste day ministry officials and the boar will discuss legislation — similar t Ontario's — to prohibit funera homes from discriminating against AIDS victims.

# Palliative care in advanced HIV disease: presentation, problems and palliation

**Veronica Moss**

AIDS 1990, **4** (suppl 1):S235–S242

**Keywords: Palliation, psychological issues, multisystem disease, coexisting diagnoses, polypharmacy, pain, symptom control, syringe driver.**

## Introduction

It could be said that all care in AIDS is necessarily palliative, since no specific cure has yet been found. However, some types of medical intervention can clearly prolong life in HIV- or AIDS-infected people. Because the disease is new and those most commonly affected are relatively young, it is natural that medical research and care has been aimed at prolonging life at (almost) all costs. In Westernized countries at least, most of the care has taken place either in hospitals or on an outpatient basis from hospitals that have the resources and expertise to develop the services required.

However, by the late 1980s a demand had emerged for services that place an emphasis on palliation, on good symptom control, on quality rather than quantity of life, and on bereavement support and pastoral care. Increasing expertise in the treatment of common opportunistic infections and cancers associated with AIDS, as well as the research into and use of antiretroviral drugs such as zidovudine (AZT), has led to a growing population of young clients requiring a continuum of care and support at home or in the community outside the acute hospitals. Many of these have chronic physical, mental or psychological disabilities, which place a great strain on their carers and on the community services. Primary care providers such as general and family practitioners are increasingly becoming involved, and hospices are preparing for a new and younger client group than their traditional one. Because many hospices were initially reluctant to become involved, a small number of voluntary specialist hospices, and National Health Service and voluntary community support teams have developed in the United Kingdom. As the mystique and fear or prejudice surrounding AIDS fades, more hospice teams are becoming directly involved.

Mildmay Mission Hospital in the East End of London opened in February 1988 and was the first specialist hospice and continuing-care unit to open in Europe for people with AIDS. It is a voluntary independent charity, and its philosophy and palliative care approach are based on that of the traditional hospice movement, but also on the considerable amount of consumer research that had taken place, both in the United Kingdom and in San Francisco, before opening. The London Lighthouse, also voluntary, opened a residential unit 6 months later in the West End of London. A hospice in Edinburgh is planned to open in 1990. In the United Kingdom several National Health Service hospital-based community-care teams, notably the St Mary's Hospital team and the Bloomsbury Community Care Team, led the way in providing care at home. Before these developments, the Coming Home Hospice in San Francisco, which opened in 1987, and other similar experiments had begun in North America and Canada in response to the growing, sometimes overwhelming, needs that were becoming evident [1].

The hospice movement and palliative medicine have emphasized the need for comfort and a good quality of life for the person facing a terminal illness. Death need not always be seen as a failure. Sometimes it may even be an achievement; it may well be a relief or a release not only for the patient but also for those around him or her. It is possible to enable a person to die with dignity, still retaining a sense of control, and in comfort. The memories that the relatives and partners will have to live with inevitably include a sense of loss and grief, but they do not have to include severe pain, distress and a sense of failure. The emphasis on the needs of the whole person also includes the importance of provision for meeting spiritual, social and emotional as well as physical needs.

In most respects palliative care in AIDS is very similar to that in any terminal illness. However, there are some important specific differences which are briefly discussed below.

## The patient with advanced AIDS

Most patients with AIDS in the West are young men, mostly homosexual or bisexual. Most are in what should be the prime of life. Many are successful business people used to being in control, and are highly creative. Others

# Defining palliative care in HIV/AIDS

* Was inhaled pentamadine palliation?
* Was gancyclovir and foscarnet palliation?
* What pain control or symptom control would people with HIV need?
* How much morphine would it take to control the profuse diarrhoea that patients experienced?

Am J Clin Oncol. 1990 Aug;13(4):315-9.

# Treatment of advanced Kaposi's sarcoma using a combination of bleomycin and vincristine.

Gill P[1], Rarick M, Bernstein-Singer M, Harb M, Espina BM, Shaw V, Levine A.

Author information

**Abstract**

Eighteen patients with disseminated AIDS-related Kaposi's sarcoma (KS) and compromised bone marrow function were treated with a relatively non-myelosuppressive regimen of bleomycin and vincristine (BV). At study entry, the patients presented with the following median laboratory values: hemoglobin of 9.5 g/dl, granulocyte counts of 1,173/mm3, platelet counts of 218,000/mm3, and CD4 lymphocyte counts of 58/mm3. All patients had extensive Kaposi's sarcoma. Nine patients had visceral involvement: four with pulmonary involvement, two with gastrointestinal involvement, and three with both. Following a median number of seven cycles of biweekly chemotherapy, complete or partial tumor responses were achieved in 13 patients (72%). Two patients experienced bleomycin-induced skin toxicities, whereas 10 others (55%) experienced peripheral sensory neuropathy requiring vincristine dose reductions. Opportunistic infections had occurred in 11 patients prior to initiation of chemotherapy and in 16 after initiation of chemotherapy. Despite the frequent development of opportunistic infections, BV chemotherapy was relatively well tolerated and resulted in a high response rate in this patient population that presented with suboptimal marrow function and extremely low CD4 lymphocyte counts.

PMID: 1696066

[Indexed for MEDLINE]

MeSH terms, Substances

News

# TB outbreak at hospital sparks alert

CELIA HALL Medical Editor | Thursday 17 August 1995 00:02 | 0 comments

Like

CELIA HALL

Medical Editor

A London hospital has changed its procedures following an outbreak of multi-drug-resistant tuberculosis in which one patient may have infected four others on an Aids ward.

# IV access options for AIDS patients with cytomegalovirus disease

Juliet Sargent, Eileen Nixon

+AFFILIATIONS

https://doi.org/10.12968/bjon.1997.6.10.543
Published Online: December 27, 2014



ABSTRACT CITED BY PDF PDF PLUS

In view of changes over the past 2 years in the intravenous (IV) management of patients with AIDS and cytomegalovirus (CMV) disease, a small study was carried out at the Kobler Clinic, an HIV treatment centre in London, to examine optimal IV access for CMV induction treatment. Thirty lines were analysed over a period of 4 months: 18 were peripherally inserted central catheter. (PICCs) and

# What have we learnt from past challenges

* Impact of fear, stigma and discrimination
* Putting the patient at the centre of care
* Respecting patient choice and control
* To fight the patient's corner
* A whole raft of new clinical skills
* Thinking outside the box

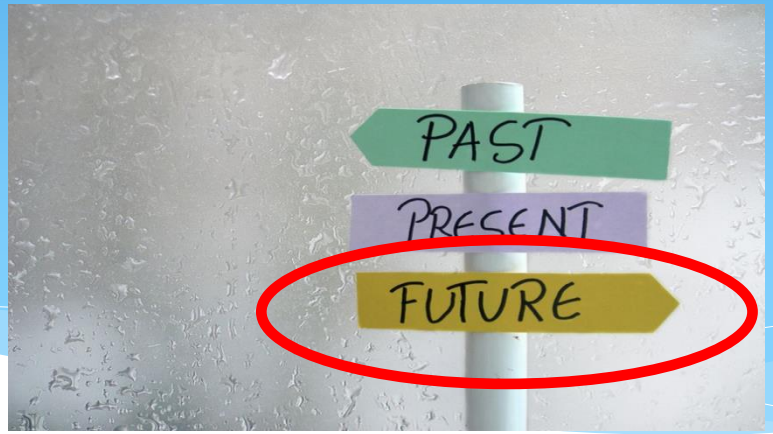
# Conclusion

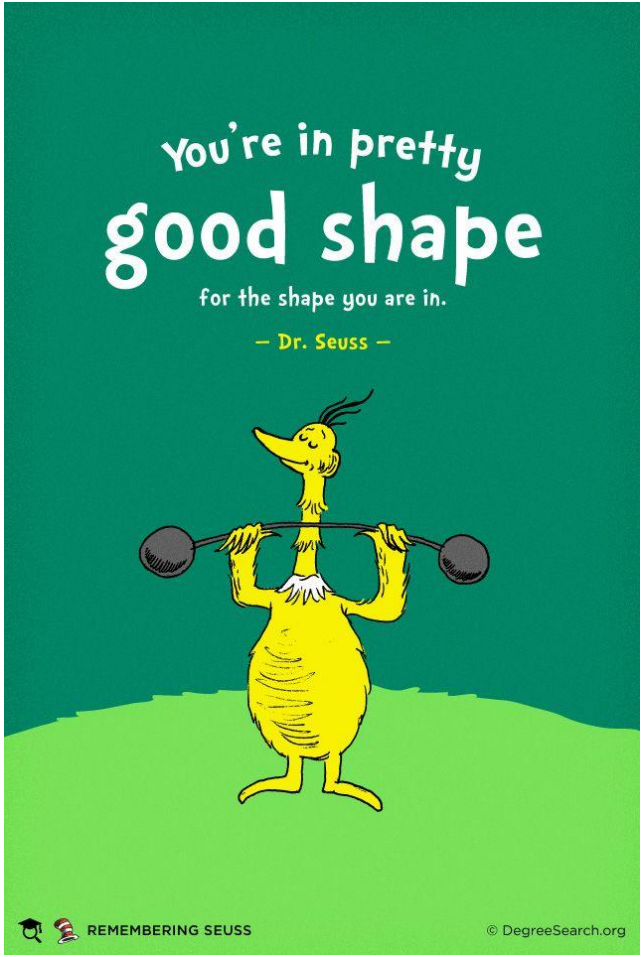
* Remarkable experience caring for people with HIV/AIDS in the 80s and 90s
* It was an honour and a priviledge to be part of this history
* Working in uncharted territory taught us to deal with uncertainty and to navigate new obstacles in the best interests of patients
* This is my lesson from the past

# With thanks to the following for their contribution to this presentation and this experience

* The many patients who enriched our lives and taught us so much
* Ann Wood, Clinical Nurse Manager, Mildmay Mission Hospital 1980 onwards
* Colleagues, family and friends who were part of this experience

# Challenges in Care






- ❑ BHIVA Standards
- ❑ BHIVA Guidelines
- ❑ National data reporting
- ❑ Enviable cascade of care
- ❑ HIV Clinical Reference Group
- ❑ HIV Service Specification
- ❑ NHIVNA/ STIF Competencies
- ❑ Advanced Practice Guidelines
- ❑ Annual Health Check Document
- ❑ Research Strategy
- ❑ HIV Community Nursing Model

# Threats

* Underfunding of health and social care services
* Fragmented healthcare system
* Increasing homelessness, drug and alcohol use
* Potential devolvement to Primary Care
* Cuts to support services and voluntary organisations
* Cuts to education for healthcare workers
* Tendering of services

# At the short end of the stick

* Paul, age 62, diagnosed in 1998
* Multimorbidities
* Poor GP care
* Drug interactions
* Lack of care co-ordination
* Impact on mental health and cognition
* Lives alone
* Established relationship with HIV clinic

* Doesn't meet threshold for social care
* Doesn't meet threshold for local mental health services
* No access to community nurse specialist
* Feels abandoned by services

# How do we provide care for people with HIV in the future?

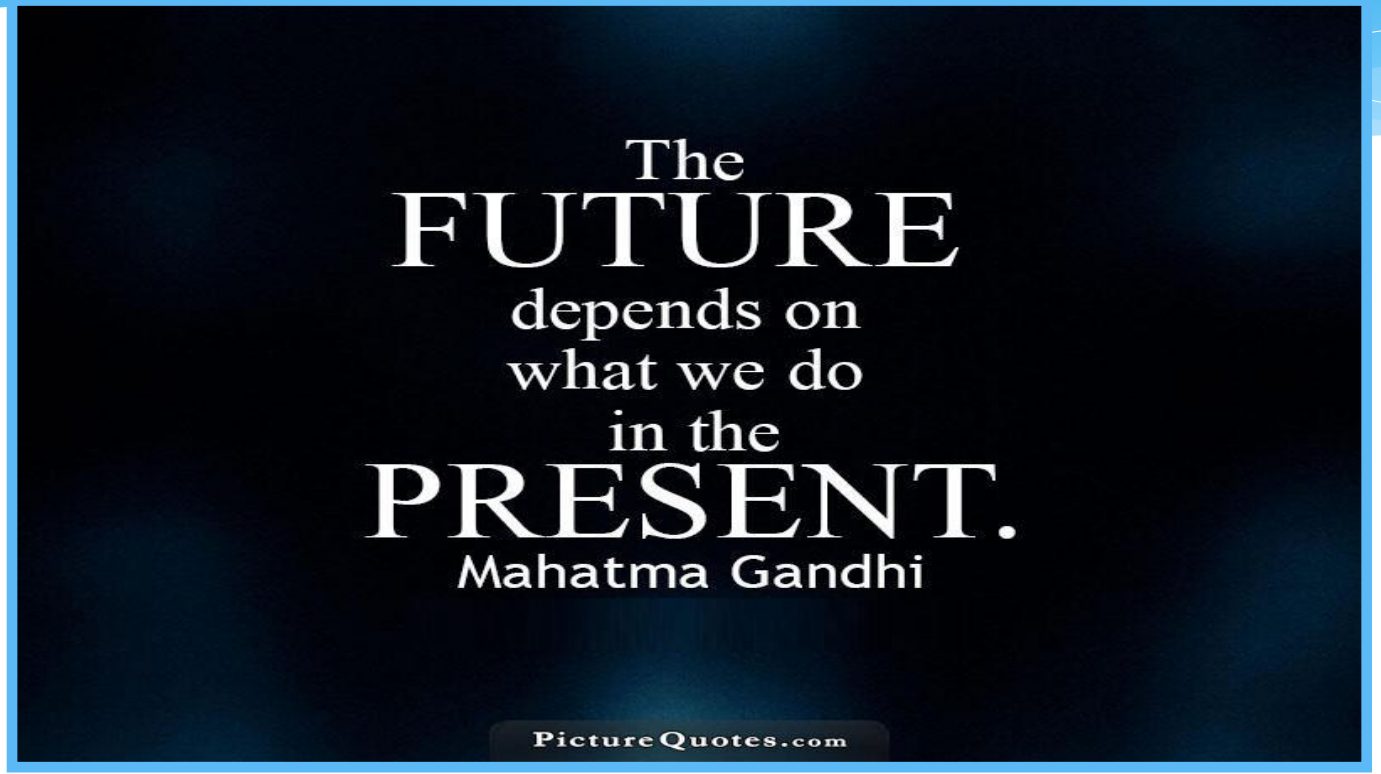
## What we know

* Quality of life is affected by multi-morbidity[1]
* Co-morbidities are significantly more prevalent in HIV[2-5]
* What patients value about their HIV care
* Current model of specialist care results in excellent clinical outcomes
* Lack of GP knowledge[6]
* Frequency of drug interactions[7,8]
* Avoidance of care due to stigma[9,10]

## What we don't know

* How the treatment cascade will be affected outside of the specialist setting
* How new generic models of multi-morbidity will apply to PLWHIV
* What is the evidence base for the role of clinic based HIV nurses

*1. Langebeek N, et al. AIDS. 2017;31(10):1471-81. 2. Kooij KW, et al. J Infect Dis. 2015;211(4):539-48. 3. Schouten J, Clin Infect Dis. 2014;59(12) :1787-97. 4. Petoumenos K. et al. PLoS One. 2017;12(9):e0184583. 5. Levett TJ, et al. J Am Geriatr Soc. 2016;64(5):1006-14. 6.Defty H, et al. Br J Gen Pract. 2010;60(574):348-51. 7. Holtzman C, et al. J Gen Intern Med. 2013;28(10):1302-10. 8.BHIVA Position Statement The future role of primary and community care in HIV. 2013. 9. 2015. TPLWHSS. HIV in the UK: Changes and Challenges; Actions and Answers National findings.; 2015. 10.Namiba A, et al. Primary care access: How general practice can better respond to the needs of people living with HIV 2011*


The
FUTURE
depends on
what we do
in the
PRESENT.
Mahatma Gandhi
PictureQuotes.com

# Core principles of HIV care


# Articulate what is different about HIV

* Long-term HIV care is still a new concept
* HIV affects a diverse range of population groups
* Effective treatment is required at an individual and population level
* Premature ageing and multi-morbidity
* High levels of mental health
* Stigma

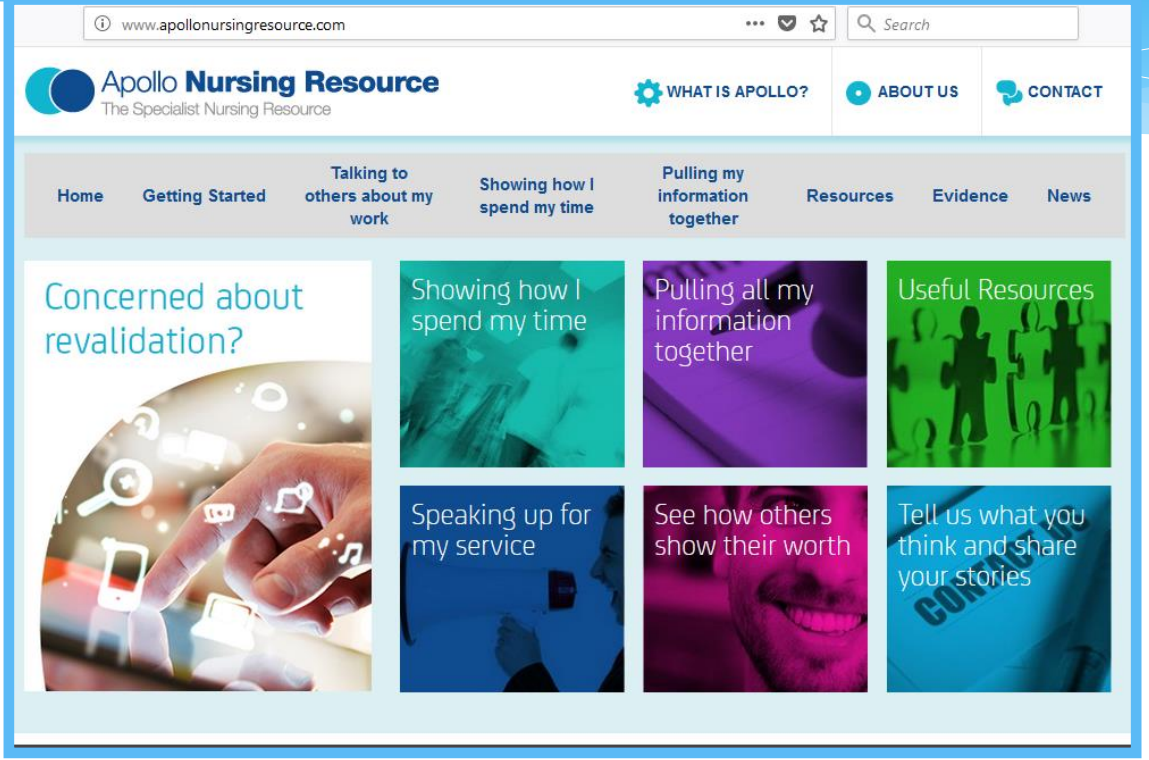

*The future of HIV Services in England: Shaping the response to changing needs. Kings Fund. April 2017*

# Co-design services with patients

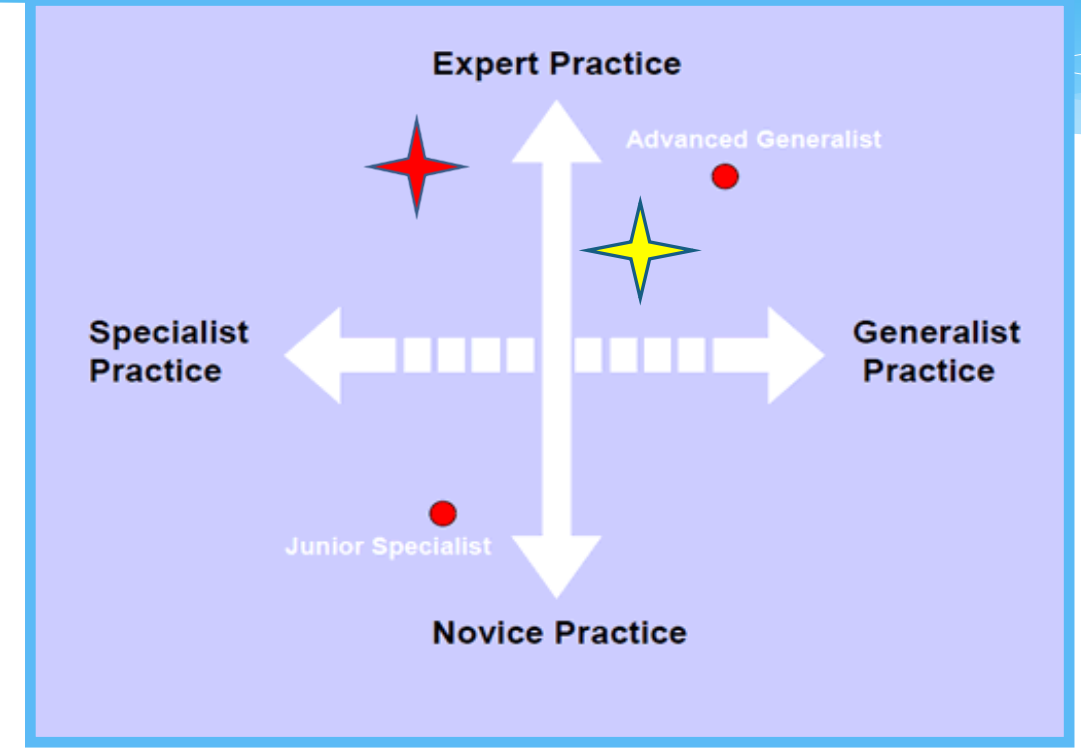
# Gather evidence for what nurses do

* Audit standards you have in place
* Define the detail of what nurses do
* Participate in defining research questions and conducting nursing research

# Proving your worth



# Keep developing skills




*Framework for Advanced Nursing, Midwifery and Allied Health Professional Practice in Wales*

# Challenge the can’t do responses

# Is the future uncharted territory?

# What you going to do today to change tomorrow?

* Continue to work in partnership with patients
  * Use peer mentors
  * Involve patient feedback and patient advocates in service planning
* Provide evidence for what you do
* Turn your threats into opportunities if possible
* Use the available frameworks and guidelines
* Educate others
* Share learning across the HIV nursing community

# Conclusion

* The past has taught us what we can all achieve
* The future awaits our present response