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This Data will be available for as long as your network continues to meet and will then be taken down from the internet and either stored securely at the Superhub or deleted.

Your ongoing participation in this ECHO session is assumed to imply your agreement to the use of your data in this way.

If you are NOT willing for your data to be used in this way, please LEAVE the session at this point.

www.hospiceuk.org
WELCOME TO CLINICAL ECHO May 2022
Evidence Update Max Watson

Palliative Care Research

Kate Flemming

APM Update

Matt Dore

The development of Nurse Consultant Role
Amanda Mayo and Nigel Dodds St. Christopher’s

Experience of remote consultant support
Emily Collis

Chat Box

- Your Questions
- Resources
- Information/innovations
- Email clinical@hospiceuk.org

Please share resources, powerpoint, links etc. with those who would benefit.
Last Month 73,000 deaths (138,000)
18 million cases (40 million)
UK: coronavirus deaths per day

UK: people in hospital with coronavirus each day
World Covid Impact
Nearly 15 million excess deaths worldwide

Almost three times more excess deaths than officially reported Covid deaths

- Officially reported Covid deaths: 5.4 m
- Excess deaths during pandemic: 14.9 m

Global excess death toll was higher for men

- 57% male
- 43% female

Lower-middle income countries had most excess deaths

- High-income countries: 15%
- Upper-middle income countries: 28%
- Lower-middle income countries: 53%
- Low-income countries: 4%

Source: World Health Organization
Disputed figures

The report has caused controversy in India, where the government has challenged WHO’s figures. It disputes the methodology behind WHO’s assessments, which estimated 4.7 million covid-19 deaths in India—around three times the country’s official figure and around a third of the global total. India also contested a study published in the *Lancet* in April that estimated the country to have recorded more than four million excess deaths during the pandemic.

WHO officials emphasised large confidence intervals for some nations: the lower range for excess deaths in India was 3,308,100, and the upper range was 6,479,698. They called for better health monitoring to be better able to respond to future pandemics.
Different countries, different pandemics

Excess deaths per 100,000 in 2020 & 2021, selected countries

Peru: 437
Russia: 367
South Africa: 200
India: 171
Brazil: 160
Turkey: 156
US: 140
Italy: 133
Germany: 116
Spain: 111
UK: 109
Argentina: 99
Global average: 96
France: 63
Sweden: 56
China: -2
Japan: -8
Australia: -28

Note: Excess death rates are calculated as an average of the rates for 2020 & 2021
Source: World Health Organization
Covid-19: US passes one million deaths as mask mandates return

Janice Hopkins Tanne

The US passed one million deaths from covid-19 on 4 May 2022, data from NBC News showed.1 This is the world's highest reported death toll, although deaths are thought to be undercounted. Per capita, Peru has the highest death toll.

Reports of US deaths were slightly lower from other sources: Johns Hopkins University reported 996 541,2 the New York Times 995 715, and the Centers for Disease Control and Prevention (CDC) 994 187.3-4

The CDC said that more than 80% of US deaths had been among unvaccinated people. However, during the omicron surge in January and February this year some 42% of deaths were among vaccinated people. Most were over 75s who had been vaccinated but had not received boosters.5

In the past two weeks cases of covid-19 have increased by 54% and hospital admissions by 59%, but deaths have dropped by 3%.6 The rise in cases is thought to be caused by the omicron subvariants BA.2.12.1 and BA.2.12.

On 3 May the CDC reinstated its recommendation for people to wear masks on planes, trains, and buses despite a ruling on 18 April by a Trump appointed judge that struck down the CDC's mask mandate.7

From 5 May the Food and Drug Administration has also introduced limits on use of the Janssen (Johnson & Johnson) vaccine because of “the risk of thrombosis with thrombocytopenia syndrome, a syndrome of rare and potentially life-threatening blood clots in combination with low levels of blood platelets with onset of symptoms approximately one to two weeks” after vaccine administration. Sixty such cases have been confirmed in the US, including nine deaths.8

The FDA now recommends that the Johnson & Johnson vaccine should be used only by people who have had an anaphylactic reaction to the mRNA vaccine, those with “personal concerns” about mRNA vaccines, and people who would otherwise remain unvaccinated because of difficulty getting mRNA vaccines.

Although 70% of the US population aged over 5 is fully vaccinated, vaccines for young children are still not available. Both Moderna and Pfizer-BioNTech have asked the FDA for approval of vaccines for children under 5. An FDA panel will consider children’s vaccines next month.

References

2 Johns Hopkins University. Coronavirus resource center. 5 May 2022. https://coronavirus.jhu.edu/
6 Tanne JH. Covid-19: Mask mandate is struck down in cases is thought to be caused by the omicron subvariants BA.2.12.1 and BA.2.12.
8 pmid:35440431

In the past two weeks cases of covid-19 have increased by 54% and hospital admissions by 19%, but deaths have dropped by 3%. The rise in cases is thought to be caused by the omicron subvariants BA.2.12.1 and BA.2.12.
Deaths by place of occurrence
England and Wales, deaths registered between 7 March 2020 and 28 May 2021

- Covid-19 deaths
- Excess deaths from other causes compared with 2015-19 average

Source: ONS • Excludes deaths in ‘other’ settings such as hospices
Palliative and end of life care profiles: May 2022 data update

The profiles provide an overview of palliative and end of life care in England at various geographies.

From: Office for Health Improvement and Disparities
Published: 4 May 2022

Related content
Collection: Palliative and end of life care

Documents
- Palliative and end of life care profiles: May 2022 data update
  - https://fingertips.phe.org.uk/profile/end-of-life
Palliative and End of Life Care Profiles

These profiles have been developed by the National End of Life Care Intelligence Network (NEoLCIN) to improve the availability and accessibility of information and intelligence around palliative and end of life care. They provide an overview across multiple geographies in England, to support commissioning and planning of local services.

The data in the profiles are grouped into topics. These include:

- place of death
- underlying cause of death
- mortality
- death in usual place of residence (DiUPR)
- care homes and community
- hospital care
- dementia

Classification of place of death is a guide that supports the methods used for all place of death indicators on these profiles.
Map 19: Variation in the number of patients in need of palliative care/support, as recorded on GP disease registers per 100 deaths by CCG.
Table 1 shows the annual number and percentage of people who have died for five place of death settings (hospital, home, care home, hospice and other places) in 2019, 2020 and 2021.
Figure 2: Monthly trend (%) in deaths (all ages) by place of death: NHS Barnsley CCG (2019 to 2022)

NHS Barnsley

Figure 2 shows the number of monthly deaths by place of death (hospital, care home, hospice, home, and other places) from 2019 to 2022. The graph illustrates the percentage of deaths occurring in each category, with a notable trend observed over the years.
Since the start of the Covid-19 pandemic the number of people dying at home has increased significantly. However, financial and staff resources, have not shifted out of hospital at the same rate. This project, funded by The Department of Health and Social Care, will explore whether and how NHS and local authority commissioners in England measure and assure the quality of the end-of-life care and support provided to patients who die at home, their families and unpaid carers. As part of this, we are interested in how commissioners identify and address inequalities when they are commissioning services.

Report to be delivered Autumn 2022
Enhanced health in care homes is realistically achievable in any area of England. A history of joint working between relevant organisations – NHS, care homes and local authorities – is useful but not essential and, in some cases, significant results can be visible within a few months.

This report is based on interviews with people in 15 areas around England that could demonstrate progress in developing enhanced health in care homes.

Better ways of measuring impact, including effects on care quality and quality of life, are needed. Care home residents should be involved in defining what 'good' co-ordination of care looks like.

Those in leadership roles need to constantly reinforce equal partnerships and avoid historical patterns of making decisions without consulting care homes, accepting lower access to health care for care home residents, or assuming that care home staff need additional training to enable co-ordinated care, but NHS staff do not.

Enhanced health in care homes requires skilled leadership. Networks and communities of practice are essential to support leaders at all levels and share learning.

More clarity is needed on expectations for access to health care for care home residents; resourcing enhanced health in care homes and understanding return on investment; and appropriate use of public funds to support training and information systems in independent care homes.
Compulsory for staff twice a week
Booked admissions PCR 72 hours before and a LFT on day of transfer
Advised but not compulsory for visitors unless providing close personal care LFT
NHS England  IPC changes for hospitals and General practices

• Relaxation, - replace physical distance measures with risk assessments

• Isolation periods from 10- 7 days if two negative lat flo tests 24 hours apart

• “Should return to pre pandemic physical distancing in all areas, and to pre pandemic cleaning protcols..”
Virus
How will the pandemic end?
We’re not expecting that this virus is going to be eliminated or eradicated. It’s going to stay with us, clearly. It’s spread too widely and, unfortunately, infects many animal species.
The best case scenario is that with increasing levels of population immunity, both because of exposure to the virus and because of vaccination, by the end of 2022 the severity of the disease declines even though people may still be getting infected.

The worst case scenario is that the next variant is not only more transmissible but more virulent than omicron and is able to evade the immune responses that we’ve generated thanks to vaccination. And then basically, we start all over again.

The in-between scenario is the virus becomes endemic, you get waves of infection and you may then see an increasing number of deaths as well. This could occur at different time periods in different countries, and it would depend on how quickly immunity wanes and how many susceptible people there are in the population—not just the elderly and those with underlying illnesses and who are immunocompromised, but new birth cohorts who don’t have immunity.
From 5 May the Food and Drug Administration introduced limits on use of the Janssen (Johnson & Johnson) vaccine because of “the risk of thrombosis with thrombocytopenia syndrome, a syndrome of rare and potentially life-threatening blood clots in combination with low levels of blood platelets with onset of symptoms approximately one to two weeks” after vaccine administration. Sixty such cases have been confirmed in the US, including nine deaths.

The FDA now recommends that the Johnson & Johnson vaccine should be used only by people who have had an anaphylactic reaction to the mRNA vaccine, those with “personal concerns” about mRNA vaccines, and people who would otherwise remain unvaccinated because of difficulty getting mRNA vaccines.
CLINICAL
Omicron and impacts on antibody treatments

Because most antibody treatments are focussing on spike protein, with the change from Omicron BA.1 to BA.2 a change from 37 spike mutations to 31, leaving some antibody treatments ineffective.

Sotrovimab no longer deemed effective and under review by MHRA after FDA removed authorisation

REGEN COV now not authorised

Industry working on antibodies that will work more generally on the virus. Bebtelovimab retains activity against BA.1 and BA.2
Hepatitis in children: What’s behind the outbreaks?

Cases of idiopathic hepatitis in children have been reported around the world. Elisabeth Mahase looks at what we know so far

Elisabeth Mahase

How many children have been affected?

The World Health Organization has so far reported 169 cases of acute hepatitis of unknown origin from 11 countries in Europe and the US, as of 21 April 2022.1

In the UK, where the increase in cases was first noted at the start of 2022, 114 cases have been confirmed, followed by 13 in Spain, 12 in Israel, nine in the US, six in Denmark, five in Ireland, four in the Netherlands and in Italy, two in Norway and in France, and one in Romania and in Belgium. Ages of the affected children range from 1 month to 16 years. Japan’s health ministry (25 April) has reported its first possible case in a child under the age of 17 who has been admitted to hospital.2

Is this higher than normal?

It seems to be. Will Irving, professor of virology at the University of Nottingham, told The BMJ that there had always been a background but low incidence of severe hepatitis in young children without a known cause but that now the numbers had risen fivefold to 10-fold. These cases are referred to as non-A-E hepatitis, because although the patients are known to have hepatitis, all the markers for the usual suspects—hepatitis A, B, C, and E—are negative.

Irving said, “Normally a paediatric haematologist in, say, Birmingham, at one of the big UK centres, might see one or two cases a month. For many years we’ve wondered whether there was another virus that’s causing non-A-E hepatitis. There’s always a background level there, but now Birmingham, for example, has seen 40 cases in three months.”

How serious is it?

Most children seem to be recovering well. However, WHO has confirmed that at least one child has died so far, while 17 children (around 15% of the total known cases) have needed a liver transplantation.3

Simon Taylor-Robinson, consultant hepatologist at Imperial College London, said, “Treatment is usually supportive, with hydration and management of temperature, because the problem normally resolves. The liver has an amazing ability to regenerate itself after an insult. Generally, within a few days or weeks, things settle back down with this supportive treatment. If blood tests are significantly abnormal, treatment would be in a specialised hospital, as in rare cases the liver injury can require more specialised medical intervention.”

Why is it happening?

While there is no certain cause, the current hypothesis relates to adenovirus type 41, because many of the children with hepatitis have tested positive for this virus. Adenovirus 41 is known to infect children and cause symptoms such as diarrhea, vomiting, and fever, although it has not previously been linked to hepatitis.

In its latest report the UK Health Security Agency said it believed that there was a “cofactor affecting young children which is rendering normal adenovirus infections more severe or causing them to trigger immunopathology.”4 The report listed several possible cofactors, including susceptibility arising from lack of prior exposure during the pandemic; a prior infection with SARS-CoV-2 or another infection; a coinfection with SARS-CoV-2 or another infection; or a toxin, drug, or environmental exposure.

The agency suggested some other possible causes, although it noted that these did not fit as well with the current evidence. These included a novel variant of adenovirus, with or without a contribution from a cofactor as listed above; a drug, toxin, or environmental exposure; a novel pathogen either acting alone or as a coinfection; or a new variant of SARS-CoV-2.

Commenting on the current theories, Zania Stamataki, associate professor in viral immunology at the University of Birmingham, said, “The rising incidence of children with sudden onset hepatitis is unusual and worrying. If an adenovirus is to blame, this could be a new variant of adenovirus that may cause liver injury in children with naive or immature immune systems. But we need to know more to be sure.

Alternatively, if adenovirus is the culprit for hepatitis in children who are otherwise well, we ought to look for other infections and environmental causes that could exacerbate adenoviral inflammation.”

Might the pandemic have played a role?

Irving said that the covid pandemic could have had an effect, notably through the reduction in social mixing and virus spreading. “It is conceivable that whatever it was that was causing the odd case before is now, like all of the other viruses, simply circulating more widely because of the effects of lockdown and then the release from lockdown.”

“That’s an alternative hypothesis: that there’s always been a non-native virus that we haven’t yet identified and that’s simply circulating at greater levels

Unknown. ?? Cofactor increasing susceptibility to adenovirus? `

?new variant??

??lockdown effect

The World Health Organization has reported 169 cases of acute hepatitis of unknown origin from 11 countries in Europe and the US, as of 21 April 2022.1

In the UK, where the increase in cases was first noted at the start of 2022, 114 cases have been confirmed, followed by 13 in Spain, 12 in Israel, nine in the US, six in Denmark, five in Ireland, four in the Netherlands and in Italy, two in Norway and in France, and one in Romania and in Belgium. Ages of the affected children range from 1 month to 16 years. 10% need transplant

non-A-E hepatitis, because although the patients are known to have hepatitis, all the markers for the usual suspects—hepatitis A, B, C, and E—are negative.
Covid-19: Only a quarter of patients admitted to hospital feel fully recovered after a year, study finds

Elisabeth Mahase

Only around one in four people who had covid-19 reported feeling fully recovered within a year of being discharged from hospital, a study has found.1

The research, presented at the 2022 European Congress of Clinical Microbiology and Infectious Diseases held in Lisbon, Portugal, included 2320 patients discharged from NHS hospitals in the UK from March 2020 to April 2021. They were assessed at five months and at one year after discharge, with 807 (32.7%) completing both visits.

The study found that the proportion of patients reporting full recovery was practically unchanged between the two visits: 26% at five months (501 of 1965) and 25% at one year (232 of 964).

Recovery was assessed using patient reported outcome measures, physical performance, and organ function at five months and at one year after hospital discharge. Blood samples were also taken at five months to check for the presence of various inflammatory proteins.

Factors associated with being less likely to report full recovery at one year were being female (odds ratio 0.68 (95% confidence interval 0.46 to 0.99)), being obese (0.50 (0.33 to 0.75)), and having had invasive mechanical ventilation (0.42 (0.23 to 0.76)).

**Symptom severity**

The research paper, published in the *Lancet Respiratory Medicine*, is part of the Post-Hospitalisation Covid-19 study, a national consortium led by experts at the University of Leicester and University Hospitals of Leicester NHS Trust to investigate the long term effects of covid-19 on health outcomes in patients who were admitted to hospital.

In an earlier paper from the same group the authors identified four clusters of symptom severity at five months, which have subsequently been confirmed at the one year mark by this latest study. Just over 1600 patients had sufficient data to allocate them to five months to check for the presence of various inflammatory proteins.

The researchers found that being obese, having reduced exercise capacity, a greater number of symptoms, and increased levels of the inflammatory biomarker C reactive protein were all associated with the more severe clusters. Levels of the inflammatory biomarker interleukin 6 (IL 6) were also found to be higher in the “very severe” and the “moderate with cognitive impairment” clusters than in the “mild” cluster.

Louise Wain, one of the study authors who is an epidemiologist and GSK/British Lung Foundation chair in respiratory research at the University of Leicester, said, “No specific therapeutics exist for long covid, and our data highlight that effective interventions are urgently required. Our findings of persistent systemic inflammation, particularly in those in the very severe and moderate with cognitive impairment clusters, suggest that these groups might respond to anti-inflammatory strategies . . . ”

“The finding also suggests the need for complex interventions that target both physical and mental health impairments to alleviate symptoms. However, specific therapeutic approaches to manage post-traumatic stress disorder might also be needed.”

A paper describing the longest known covid-19 infection—a patient who tested positive for 305 days before dying—was also presented at the conference. The previous longest confirmed case was believed to be 335 days.1


3 King’s College. London. UK patient had COVID for 305 days. 22 Apr 2022. https://www.kcl.ac.uk/news/uk-patient-had-covid-for-305-days
As of December 2021, 1.3 million people in the United Kingdom and an estimated >100 million worldwide are currently living with long covid or post-covid-19 syndrome;

Studies have shown that long covid is a novel, multisystem condition with considerable symptom burden and negative impacts on work capability and QoL.

Owing to a lack of patient reported outcome measures specific to long covid, researchers and clinicians are using bespoke surveys, generic patient reported outcome measures, or symptom burden measures validated in other disease groups to assess the symptom burden from long covid.

With extensive patient involvement, this mixed methods study developed and validated the symptom burden questionnaire for long covid. This novel questionnaire has the potential to benefit international clinical trials and inform best practice in clinical management.
Conceptual framework showing scales (domains) of symptom burden questionnaire for long covid (SBQ-LC, version 1.0).

SBQ-LC (version 1.0)

8 Interference items
- Breathing
- Pain
- Circulation
- Fatigue
- Memory, thinking, and communication
- Movement
- Sleep
- Ears, nose, and throat

123 Symptom items
- Stomach and digestion
- Muscles and joints
- Mental health and wellbeing
- Skin and hair
- Vision
- Female reproductive and sexual health
- Male reproductive and sexual health
- Other symptoms


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WORKFORCE
NHS workforce shortages and staff burnout are taking a toll

“...It’s no surprise that all of this has dented morale and day-to-day costs which their workers face and worry million people, trust leaders know the spiralling government this year. As collective employers of 1.4 staff must see a meaningful pay rise from the too. In the face of the mounting cost of living crisis, Staff satisfaction with pay is at its lowest in five years…'

Almost all respondents who replied to a recent NHS Providers survey said that staff shortages are having a serious and detrimental impact on services and will hinder efforts to deal with those major care backlogs. Trusts need more staff to be able to reduce delays and to treat patients as quickly as possible. It’s tough too to see a sharp drop in public satisfaction with the NHS, although given the impact of the pandemic it isn’t completely surprising. We want the public and politicians to understand the pressures which the whole of our health service is under, with huge strain on exhausted staff. They need to see that the government will offer support to help boost morale and retention. NHS Providers, along with more than a hundred health and social care organisations, have supported the inclusion of measures in the Health and Care Bill going through parliament requiring ministers to publish regular independent assessments of the number of health and care workers needed to make workloads sustainable. This has so far been resisted by the government. As workers and employers start paying for the welcome extra investment from the Health and Care Levy it’s vital too that the government comes up with a fully costed and funded long term plan to ensure that we have the workforce we need to meet increased demand for NHS and social care services today and in the future.
The UK economy has a problem with its over 50s: following the COVID pandemic, they have been leaving the labour force en masse, causing headaches for businesses and the government. Roughly 300,000 more workers aged between 50 and 65 are now “economically inactive” than before the pandemic, leading a tabloid paper to dub the problem the “silver exodus”.

The largest rise in inactivity post-pandemic is coming from workers in the lower-middle income bracket (earning roughly £18,000 to £25,000 per year) in their most recent job.
Workforce

- Health and Care Bill
- Shape of Training
- Demographics
- Geographic variation
- Last person standing phenomenon

Interest in nursing as a career increased

300,000 unemployed 55-65 year olds...

Health and Care Bill & Workforce planning
NI Health: Cancer patient numbers may rise by 40% by 2030

By Marie-Louise Connolly
BBC News NI Health Correspondent

The number of people living with cancer in Northern Ireland is expected to rise by 40% by 2030, according to Macmillan Cancer Support.

There are an estimated 82,000 people living with the disease but this could go up to 114,000 in eight years.

The charity called for urgent investment to mitigate "against a deepening workforce crisis".

It said a functioning Stormont executive was crucial to ensure workforce planning happens.

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### Estimated number of people living with cancer by nation, at the end of 2020, 2025, 2030 and 2040

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<thead>
<tr>
<th></th>
<th>2020</th>
<th>2025</th>
<th>2030</th>
<th>2040</th>
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<tr>
<td>England</td>
<td>2,400,000</td>
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<tr>
<td>Wales</td>
<td>170,000</td>
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<td>300,000</td>
<td>350,000</td>
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<tr>
<td>Northern Ireland</td>
<td>82,000</td>
<td>97,000</td>
<td>114,000</td>
<td>150,000</td>
</tr>
<tr>
<td>UK</td>
<td>2,900,000  (&quot;almost 3 million&quot;)</td>
<td>3,400,000  (&quot;almost 3.5 million&quot;)</td>
<td>4,000,000  (&quot;almost 4 million&quot;)</td>
<td>5,300,000  (&quot;almost 5.3 million&quot;)</td>
</tr>
</tbody>
</table>
Workforce

How to have the most impact?

Gathering better data on Hospice workforce
Call for papers closes 16 May!

There’s still time to submit an abstract about your work for our national conference.

https://www.hospiceuk.org/professionals/courses-conferences/national-conference/call-for-papers
Research objectives:

• To determine whether there are statistically or clinically significant differences in receiving pain medication by racial and/or ethnic group for people with advanced diseases.

• To explore issues and themes in pain management for people with advanced diseases from different racial and ethnic groups.

What they did

• Systematic review of both quantitative and qualitative research
• Literature from countries with ‘very high’ Human Development Index
• Pain related to disease or treatment
• English language only

Two different types of synthesis

• One of purely quantitative papers to explore the ‘differences’ (n=18)
• One of qualitative and quantitative to explore the ‘issues’ and ‘themes’ (n=46)
• Papers were predominantly from USA, UK - 3, New Zealand - 1
What they found – quantitative review

Overall there was not enough high quality quantitative evidence to draw a conclusion on the differences in receiving pain medication for people with advanced disease of different racial and ethnic groups.

What was observed was that:

• 5/8 papers reported Hispanic patients were significantly less likely to receive pain medication as compared to White patients or other groups.

• 3/8 studies, Black and African American patients were significantly less likely to receive pain medication compared to the patients in the White group.

• 3/8 (38%) studies, Asian patients were significantly less likely to receive medication compared to White patients, or other groups.

• In no study were white patients less likely to receive pain medication.
What they found – mixed methods review

Patients from different ethnically diverse groups had concerns about tolerance, addiction and side effects. These fears may have different foundations and are differently prioritised according to culture, faith, educational and social factors.

Also that:
- Cultural and social doctor/patient communication issues, including non-verbal
- Many patients with unmet pain management needs and fewer pain assessments for Hispanic, Black and African American groups
- When pain was explicitly reported by people from ethnically diverse groups, it was not always recognised the same way as pain reported by people from White groups

Findings were discussed with PPI representatives from ethnically diverse...
Implications for policy and research

There is need for:
• Greater policy and research engagement with issues of ethnicity, race and racism within palliative care
• Research on pain management, race and ethnicity based outside of the USA
• Community partnership working with racially and ethnically diverse groups to develop culturally competent pain management

There is still a significant amount of undertreatment for pain across different conditions for many people from different ethnic groups.

It is also indicative that those from racial and ethnically diverse groups may face other barriers to pain management.
FAMCARE 2022

The Association for Palliative Medicine welcomes ALL services providing specialist palliative care to patients in the UK and Ireland to register and participate in FAMCARE 2022.

What is FAMCARE?
An annual audit run by the APM, consisting of a survey sent out to recently bereaved relatives.

The survey consists of 17 questions covering several different aspects of care. Upon completion this is returned to the APM for analysis.

Participating services are either a hospital based palliative care team, hospice inpatient unit or a home care team specialising in providing end of life care.

FAMCARE is GDPR compliant

What information do you get?
Participating services receive individual feedback, (including their own data) and also comparable (anonymous) data from other services.

An annual report detailing trends, discussions and suggestions will be available on the APM’s website.

Benefits
- Obtain a powerful insight into what has and hasn’t gone so well this year.
- Direct involvement of your service in a national audit for the purpose of service improvement.
- An opportunity to enhance the experience of care for dying persons and their relatives.
- Useful to support appraisal and revalidation.

Cost
You will need to be an APM member. The cost of the audit is £125 per service per year, to be paid at registration.

This cost includes envelopes, and stamps.

Register
Registration opens 20 April 2022
Registration closes 17 June 2022

Don't miss out!
Click the links below to visit the APM website or email the APM secretariat
PALLIATIVE CARE ON THE RESPIRATORY WARD

PART 5 OF A 6 PART SERIES

For Jr Docs & med students pre specialist training

https://apmeducationhub.org/events/palliative-care-respiratory/

Speakers: Dr Ian Clifton, Consultant in Respiratory Medicine and Dr Suzie Gillon,
Aspiring Nurse Consultant (Palliative Care) Programme
Hospice UK ECHO
11th May 2022

Nigel Dodds (Nurse Consultant)
Amanda Mayo (Care Director)
Overview

- We are developing a programme to support the training and development of nurses who are aspiring to become nurse consultants.
- We have 3 people in Associate Nurse Consultant posts, who over the next 2-3 years we will take on a work-based programme to develop their clinical, leadership, educational, research and audit skills AND their consultancy skills.
- Alongside the ‘on the job’ training, we are building an interactive programme of learning, alongside a competency framework.
Why are we doing this?

- Experience of working with a group of Nurse Consultants
- Shared clinical leadership with medical consultants, rehabilitation consultant
- Succession planning
- No clear pathway or route to becoming a nurse consultant
- The value we have seen in the nurse consultant role, allows us to attend to some challenges we are facing, e.g.:
  - High numbers of vacancies across medical workforce
  - Ageing nursing workforce;
  - Lack of ‘ready made’ NC available for recruitment;
  - Increasing complexity of patients being referred for specialist palliative care
What is a Nurse Consultant, and what defines advanced practice?

• A clinician with a verified portfolio of evidence at a Masters level of practice across all four pillars of practice (Leadership, Clinical, Education and Research) who has a minimum of 5 years post graduate experience.
• Others have argued (Manley, 2019) Consultancy requires a ‘5th pillar’
• All four (five) pillars of practice are integral and influence every intervention
• They are multi-professional, cross organisational and cross boundary clinicians
• Leaders opposed to managers
Working towards advanced level practice

**Expert Clinical Practice**
- Senior and widely experienced
- High level of knowledge and skill
- Person-centred, safe and effective

**Education**
- Teach others, and set curriculum
- Supervise and mentor others
- Create a learning environment

**Nurse Consultants**

**Professional leaders**
- Self-leadership
- Develop others
- Local/regional/national
- Set strategy
- Role model good practice

**Service improvement**
- Lead strategic QI projects
- Implement evidence based practice
- Masters or Doctoral level study

**Research**
- Engender a confidence in audit and research
- Masters or Doctoral level study
Being a consultant

**Our values**

**CORPORATE RESPONSIBILITY**
- St Christopher’s CARE
- Population health
- User engagement
- Risk benefit and reputation
- Data and clinical performance?

**LEADERSHIP BY EXAMPLE**
- Responsibility
- Legitimate authority
- Distinct from management

**TECHNICAL SKILLS**

**LEVELS OF COMPETENCE**
- ✓ Clinical / Practical Reasoning
- ✓ Communication
- ✓ Expert knowledge

**DOMAINS:**
- ✓ Assessment
- ✓ Interventions
- ✓ Presence vs action

None of us has all of these in equal measure, but without a view of the ideal, we have no reference point for:
- • our own development to be the best we can be, nor
- • an understanding of each other or what we are and should be together.

**THE ATTITUDES & CHARACTERISTICS OF A TEAMPLAYER**
- Confident
- Collaborative
- Trustworthy
- Consistent
- Visible
- Available
- Approachable
- Accountable
- Flexible
- Coach, not Critic
- Insightful & self-aware
<table>
<thead>
<tr>
<th>Our training for St Christopher’s Associate Nurse Consultant posts</th>
<th>Our road map</th>
</tr>
</thead>
<tbody>
<tr>
<td>• 1-3 years</td>
<td>• Work experience across all our (3) clinical settings</td>
</tr>
<tr>
<td>• Salary, with all training costs covered and a study budget of £5K</td>
<td>• Work experience with partner providers (e.g. Acute Trusts, Frailty teams, GPs)</td>
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<tr>
<td>• Learning contract based on own needs and using competencies as a supporting framework</td>
<td>• Experienced practice supervisor</td>
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<tr>
<td>• Yearly portfolio and reflective diary</td>
<td>• Advanced academic modules (Assessment/NMP)</td>
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<tr>
<td></td>
<td>• QI and leadership training</td>
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<tr>
<td></td>
<td>• Exposure to all areas of consultant practice</td>
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<tr>
<td></td>
<td>• 60% clinical time each week</td>
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<tr>
<td></td>
<td>• 20% QI</td>
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<td></td>
<td>• 20% Study</td>
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<td></td>
<td>• Monthly study day, working with others on programme (specific topics, and action learning)</td>
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Aims and objectives of the programme

• Development of aspiring Nurse Consultants in palliative care:
  • During the programme individuals will work across organisations and different care settings (include ICS, and education) to develop capabilities across the whole patient pathway
  • The approach taken will support the aspiring NC to role model consultant behaviours, namely, responsibility, legitimate authority, and leadership which is distinct from management
  • The programme will support development of the attitudes and characteristics of a leader, including approachability, visibility, collaboration, self awareness, and confidence
  • Participants will be exposed to contemporary demands and opportunities to enable them to develop new skills and capabilities
  • providing a blend of “in-role” and “classroom” learning
  • with flexibility within the programme to allow aspiring NC to tailor their learning to reflect previous experience and aspirations for their role
  • using a community of practice approach to support learning (learning needs self created – then experts brought in to meet needs)
Aims and objectives of the taught programme

• Support for hospices and other organisations as hosts of aspiring NC
• To learn about the potential for these new roles, for the postholder and organisation, and opportunities for working in new ways
  • Supporting the individual practitioners through coaching, assessors, practice supervisors
  • Succession planning
• To reposition hospices as strong training institutions for all important roles in the emerging PEOLC workforce,
• Maximising on the opportunities afforded by St Christopher’s CARE to support the development of these individuals
  • A pedagogical framework co-created by participants
  • Multi-dimensional competency framework to support practice
  • The Lantern Model
  • Palliative Discovery
  • Pioneering nurse community
  • Enrichment programme and conferences
  • Engagement with community action and related research (to help focus on addressing inequalities in own place of work)
<table>
<thead>
<tr>
<th>Year 1: Moving into advanced practice (Principles of advanced practice, influence)</th>
<th>Year 2: Towards Consultant practice (Organisational and system leadership)</th>
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</thead>
<tbody>
<tr>
<td>Introduction, overview of programme</td>
<td>Consultancy: Your role as a consultant nurse in relation to others</td>
</tr>
<tr>
<td>Action learning and reflection</td>
<td>Action learning and reflection</td>
</tr>
<tr>
<td>Developing advanced clinical practice</td>
<td>Quality improvement</td>
</tr>
<tr>
<td>Action learning and reflection</td>
<td>Action learning and reflection</td>
</tr>
<tr>
<td>Your role in the local and national system</td>
<td>Developing leadership</td>
</tr>
<tr>
<td>Action learning and reflection</td>
<td>Action learning and reflection</td>
</tr>
<tr>
<td>Developing education skills</td>
<td>Developing research and audit</td>
</tr>
<tr>
<td>Action learning and reflection</td>
<td>Action learning and reflection</td>
</tr>
<tr>
<td>Self-leadership and leading teams</td>
<td>QI Project presentation and peer review</td>
</tr>
<tr>
<td>Review of first year</td>
<td>Programme review</td>
</tr>
</tbody>
</table>
## Annual costs of programme (approx.)

<table>
<thead>
<tr>
<th>Course/study day/ Learning</th>
<th>Costs</th>
<th>Mode of delivery</th>
</tr>
</thead>
<tbody>
<tr>
<td>Salary (including ‘on costs’)</td>
<td>Agenda for Change 8a equivalent (circa £55-70k)</td>
<td>Employing organisation</td>
</tr>
<tr>
<td>Advanced assessment skills course</td>
<td>£2500 (Hospice UK grant support)</td>
<td>University</td>
</tr>
<tr>
<td>Non-medical prescribing course</td>
<td>£2500 (Hospice UK grant support)</td>
<td>University</td>
</tr>
<tr>
<td>Hospice UK Leadership Programme</td>
<td></td>
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<tr>
<td>St Christopher’s monthly study day</td>
<td>£200 a day x 12 days  = £2400 (internal costs plus costs of 6 external speakers)</td>
<td>St Christopher’s CARE</td>
</tr>
<tr>
<td>St Christopher’s CARE enrichment and education programme (Communities of Practice, study days)</td>
<td>No charge</td>
<td>St Christopher’s CARE</td>
</tr>
<tr>
<td>Introductory session for supervisors and managers</td>
<td>Included in costs</td>
<td>St Christopher’s CARE</td>
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What will success look like?

- Nurse Consultants demonstrate competencies and consultant level attributes, as proposed by St Christopher’s CARE
- A new career pathway in palliative care, tried and tested, for nurses who love their clinical role and who want to continue to build their expertise and impact
- A cohort of NCs confident and capable to support the multi-disciplinary palliative care team in their roles
- A new generation of NCs in palliative care who are excited and take responsibility for system wide improvement of palliative and EOLC services as clinical leaders
- Tested and refined set of competencies that aspiring NCs can work towards in the future
- New partnerships that connect this work to wider national programmes including credentialing, e.g. Health Education England, the National End of Life Care Programme, and the support this element of workforce development – with HEE, team focused on credentials (Vanessa), end of life care programme (Sheree F), SEL PEOLC partnership
Nigel Dodds: n.dodds@stchristophers.org.uk
Amanda Mayo: a.mayo@stchristophers.org.uk
Supportive, Palliative and Care in the last days of life for all:
working in partnership with NHS providers and UK Hospices to provide
reliable, responsive and cost-effective 24/7 consultant support.
Who are we?
Ambition

Bespoke and holistic solutions

- A new remote-based model
- Led by specialist consultants
- Robust governance system

- 200 hospices
- 200 trusts
- 1200 hospitals
Outcomes

- Over 25 organisations using our services
- Strong evidence base of rapid response times (average 6 minutes)
- Enhanced confidence and autonomy with clinical decision-making
- Improved team dynamics
- Reopening of units or prevention of unit closure
My Role:

• Join weekly Hospice IOM MDT (remotely via zoom)
  – Inpatient & Community SBAR uploaded prior on Sharepoint

• Weekly Hospice IOM board round with medical, nursing & pharmacy input
  – all Hospice inpatients plus complex Community/Hospital/Hospice at Home

• Write up notes (summary/recommendations) on Sharepoint
  – these are added to patient record

• Daytime advice 9-5pm (weekly, on a Tues)

• Out of hours on call rota (1 in 8 approx)

• Monthly supervision for pall med specialty doctor
Areas of Input:

• Suggesting new drugs eg naloxegol
• Suggesting new routes eg sc keppra/levetiracetam, po ketamine
• Sharing EBM eg long acting opioids for breathlessness
• Complex case discussions eg multiple neuropathic agents, opioid induced hyperalgesia, role of interventional analgesia
• Use of Outcome measures eg OACC suite
Challenges

• Do not get to review patients face to face nor meet relatives

• Once weekly consistent input only – at other times other SCUK consultants may input & have access to limited notes, those on Sharepoint, plus verbal handover

• Training needs not met in same way without face to face consultant presence
How does it feel?

• True sense of a virtual team (remote working normalised by pandemic) – professional & emotional connection
• Dependent on eyes/ears on the ground – never in doubt
• Professional satisfaction – shared learning across roles
• On call more onerous than my UCLH on call as more admin – reflective of tighter governance!
• Sense of teamwork within SCUK (annual away day & quarterly evening consultant meetings)
• Remote input (boardround/supervision) allows greater objectivity
Questions??
THANK YOU
Workforce Ideas?

Evidence Update Max Watson
Palliative Care Research

APM Update Matt Dore

The development of Nurse Consultant Role Amanda Mayo and Nigel Dodds St. Christopher’s

Experience of remote consultant support Emily Collis

Discussion and Close Max, Kate and Matt

Chat Box
• Your Questions
• Resources
• Information /innovations
• Email clinical@hospiceuk.org

Please share resources, powerpoint, links etc. with those who would benefit
Next session: June 8 2022

15:30 – 17:00
Kindness and effective care depend on close observation: reflections from a deathbed

Richard Smith chair

Much of good care is little things, things that are not heroic and are not measured, but make all the difference between good and poor care. Unintended lack of kindness might be something like giving a dying person tea with milk when they drink only black coffee. This happened to my mother, and something similar, but a bit more serious is happening now with my mother.

My mother is close to death. Indeed, she looks more like a corpse than a living person. I sat with her for some four hours yesterday, and mostly she was calm, sleeping, and just occasionally groaning. But as time passed she became more uncomfortable. The nurse and I debated whether she should have a small dose of morphine. The obvious discomfort she felt when turned decided me that she definitely needed an injection. The nurse agreed, but the whole process took time because they have to get two qualified nurses to inject morphine.

I wondered if even a small dose of morphine might kill her, but it didn’t. She became calmer, but the effect began to fade. I suggested that they might give her another injection, but they said that they would have to wait for four hours. I expected that they would give the injections regularly during the night.

When I arrived this morning my mother was clearly distressed. They were planning to wash her. I said that I thought that they ought to give her an injection before they did so and asked if she had had an injection during the night. The nurse didn’t know and said she would check the system and added that she would have had an injection “only if the nurse thought she needed it.” The nurse came back a few minutes later and said how she hadn’t had an injection. I pointed out that it’s better to prevent pain than try and treat it when it’s arrived.

They agree that they will give her an injection and suspend the washing until she’s comfortable. Unfortunately, it takes about 30 minutes to assemble two nurses. During that time I suggest that they might give her twice the dose they gave her yesterday. The nurse says she’d have to get a doctor’s permission to do that, and, as this is a care home there is no doctor available.

As it happens, it appears that the nurse hadn’t read the instructions left by the palliative care team. They can give twice the dose she had yesterday, and she can have it every hour if necessary. They gave her the injection 10 minutes ago, and the morphine is having its sweet effect.

Nobody here is unkind. The nurses and carers want to do their best, and they show their kindness by offering me tea every few minutes. But to be effective kindness needs close observation and a thoughtfulness that probably eludes most of us. The nurses and carers live as well in terror of the “rules, the system,” especially when it comes to opiates. Lack of close observation and the need to follow the rules have unnecessarily led to suffering for my mother.

A week later: That last dose of morphine was enough. My mother didn’t need any more and died peacefully 15 hours after that injection. My brothers and I prepared to celebrate a rich life filled with love and caring, and her death has led me to reflect on the world’s most difficult job, being a mother. https://richardsmith.wordpress.com/2022/04/13/the-good-enough-mother-the-greatest-invention-of-the-20th-century-reflections-after-a-mothers-death/
WHAT WILL MATTER by Michael Josephson (c) 2003

Ready or not, some day it will all come to an end.
There will be no more sunrises, no minutes, hours, or days.
All the things you collected, whether treasured or forgotten, will pass to someone else.
Your wealth, fame, and temporal power will shrivel to irrelevance.
It will not matter what you owned or what you were owed.
Your grudges, resentments, frustrations, and jealousies will finally disappear.
So, too, your hopes, ambitions, plans, and to-do lists will expire.
The wins and losses that once seemed so important will fade away.
It won’t matter where you came from or what side of the tracks you lived on at the end.
It won’t matter whether you were beautiful or brilliant.
Even your gender and skin color will be irrelevant.
So what will matter? How will the value of your days be measured?
What will matter is not what you bought but what you built; not what you got but what you gave.
What will matter is not your success but your significance.

What will matter is not what you learned but what you taught.
What will matter is every act of integrity, compassion, courage,
or sacrifice that enriched, empowered, or encouraged others to emulate your example.
What will matter is not your competence but your character.
What will matter is not how many people you knew but how many will feel a lasting loss when you’re gone.
What will matter is not your memories but the memories of those who loved you.
What will matter is how long you will be remembered, by whom, and for what.

Living a life that matters doesn’t happen by accident.
It’s not a matter of circumstance but of choice.
Choose to live a life that matters.