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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.

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www.hospiceuk.org
WELCOME TO
CLINICAL ECHO
October 2022
Truss rejects ‘handouts’ in favour of tax cuts to help households

Conservative leadership frontrunner dismisses the ‘abacus economics’ of the Treasury

this week. On Thursday, he warned of a 15-month recession, rising unemployment and inflation peaking above 13 per cent later this year.

Truss’s answer is to prioritise longer-term reforms to boost growth — including the reversal of Sunak’s planned rise in corporation tax from 19 per cent to 25 per cent — rather than short-term palliative solutions.

“I think it’s completely counter-productive to be raising corporation tax,” she said. “I think that will stymie growth and make it harder to pay down debt.”
A penny for your thoughts….

Chat BOX

What plans does your organisation have to mitigate issues that are arising and will get worse over the coming months because of the cost of living crisis and its impact on patients, families and staff?
The cause of Queen prompted a good deal of discussion in the media for its confirmation that she died of 'old age'.

In a medicalised age, we are more used to seeing a specific condition – and frequently more just one – listed by a medical practitioner.
Queen Elizabeth II

Listing old age as a cause of death for the Queen is misleading

NEWS

Home | Cost of Living | War in Ukraine | Coronavirus | Caribbean | UK | World | Business | Politics | Year | Local

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Queen's cause of death given as 'old age' on death certificate

Published: September 30, 2022 5.20am BST

Published: 29 September
“A broad coalition of gerontologists and ageing and human rights groups strongly object to the use of old age or ageing as a diagnostic factor because it legitimises and magnifies ageism, bolsters the false claims of the anti-ageing industry, obscures the multiple causes of later-life ill health, and detracts from treatment and prevention.”

“In contrast, frailty is more homogeneous, evidence-based and clearly defined, and derives from multiple factors, socio-economic and biological. Frailty is not an inevitable consequence of old age and can be both prevented and treated.”
“Old age” was a leading cause of death in the 19th century, alongside the vague description of “found dead”.

In the 19th-20th century, registering death moved from clerical to secular, with the Births and Deaths Registration Act 1836 (UK).

Then this was published in 1909
Ian Hacking wrote that dying of anything other than what was on the official list was “illegal, for example, to die of old age”. Thus, “Old age” became a last resort phrase to describe an unknown cause of death.
Cause of death list

June 2020
Author: Dr Suzy Lishman, Chair of the RCPath Medical Examiners Committee.

“It is not intended to be an exhaustive list of all possible causes of death, but deals with conditions that have previously prompted discussion between certifying doctors, registrars and coroners.”
<table>
<thead>
<tr>
<th>Condition</th>
<th>Details</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hepatitis B</td>
<td>Refer to coroner if deceased was a health or care worker; otherwise acceptable</td>
</tr>
<tr>
<td>Hepatitis viral</td>
<td>Refer to coroner if deceased was a health or care worker; otherwise acceptable</td>
</tr>
<tr>
<td>Hepatorenal failure</td>
<td>Refer to coroner if not supported by another acceptable condition</td>
</tr>
<tr>
<td>Hernia</td>
<td>Acceptable, if described anatomically and supporting another acceptable cause of death (e.g. intestinal obstruction/peritonitis); refer to coroner if incisional/parastomal (may be related to surgical procedure)</td>
</tr>
<tr>
<td>Huntington’s chorea/disease</td>
<td>Acceptable</td>
</tr>
<tr>
<td>Hydrocephalus</td>
<td>Refer to corner unless supported by an acceptable cause of death (or state congenital)</td>
</tr>
<tr>
<td>Hypertension</td>
<td>Not acceptable as a standalone cause of death but acceptable if supporting, e.g. intracerebral haemorrhage</td>
</tr>
<tr>
<td>Hyperthermia</td>
<td>Refer to coroner</td>
</tr>
<tr>
<td>Cause of death</td>
<td>Action</td>
</tr>
<tr>
<td>-----------------------------------</td>
<td>------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Occipital lobe infarction</td>
<td>Acceptable</td>
</tr>
<tr>
<td>Old age</td>
<td>Acceptable provided the deceased is 80 or over, otherwise refer to coroner</td>
</tr>
<tr>
<td>On chronic renal fail</td>
<td></td>
</tr>
<tr>
<td>Osteomyelitis</td>
<td></td>
</tr>
<tr>
<td>Osteonecrosis</td>
<td></td>
</tr>
<tr>
<td><strong>Cause of death</strong></td>
<td><strong>Action</strong></td>
</tr>
<tr>
<td>Farmer's lung</td>
<td>Acceptable</td>
</tr>
<tr>
<td>Fibrosing alveolitis</td>
<td>Refer to coroner if deceased's occupation brought them in to contact with dust; otherwise acceptable</td>
</tr>
<tr>
<td>Fracture</td>
<td>Refer to coroner unless doctor states that it was caused by a disease (e.g. osteoporosis)</td>
</tr>
<tr>
<td>Fracture – pathological</td>
<td>Acceptable if underlying disease stated</td>
</tr>
<tr>
<td>Frailty of old age</td>
<td>Acceptable provided the deceased is 80 or over, otherwise refer to coroner</td>
</tr>
<tr>
<td>Frailty syndrome</td>
<td>Refer to coroner unless supported by an acceptable cause of death</td>
</tr>
</tbody>
</table>
Can ‘old age’ be given as a cause of death?

Old age can be used if a more specific cause of death cannot be given, in the absence of any factors that require a Coroner to be informed of the death and the deceased is aged 80 years or over.

‘Old age’ can be used where an individual was 80 years or older, but only if:

- You have personally or your clinical team have cared for the deceased over a long period (years, or many months)
- You have observed a gradual decline in your patient's general health and functioning
- You are not aware of any identifiable disease or injury that contributed to the death
- You are certain that there is no other reason that the death should be reported to the Coroner / PF [Procurator Fiscal]
Verification of life extinct (VOLE) is really quite important!

WA authorities deny claims palliative care patient was alive when taken to morgue

Allegations relate to 55-year-old man who was moved from a ward to the morgue on 5 September without his time of death recorded

Australian Associated Press
Thu 6 Oct 2022 22.06 BST

The WA coroner's court is examining allegations a 55-year-old patient at Rockingham General Hospital was still alive when he was transferred to the morgue. Photograph: monkeybusinessimages/Getty Images/iStockphoto
COVID (and flu) Update
Statistics
COVID-19 Dashboard by the Center for Systems Science and Engineering (CSSE) at Johns Hopkins University (JHU)

Last Updated at (MM/DD/YYYY) 11/10/2022, 20:22

Total Cases 622,360,704
Total Deaths 6,559,800
Total Vaccine Doses Administered 9,063,791,250

28-Day Cases 12,823,740
28-Day Deaths 41,500
28-Day Vaccine Doses Administered 58,830,340

Last Month 41,500 deaths
12.8 million cases

Germany
28-Day: 1,613,988 | 2,331
Totals: 34,121,168 | 150,720

US
28-Day: 1,383,744 | 11,615
Totals: 96,757,833 | 1,063,077

Japan
28-Day: 1,354,090 | 2,833
Totals: 21,593,704 | 45,667

Taiwan*
28-Day: 1,195,922 | 1,272
Totals: 6,945,018 | 11,620

Eszri, FAO, NOAA, USGS

Powered by Esri
Recent increases in COVID-19 cases and hospitalisation rates were described as "concerning" by the UK Health Security Agency (UKHSA).

In the week ending October 6, the number of people admitted to hospital because of COVID was up by 45% compared with the previous week, according to the Agency's latest surveillance data, published on Thursday.

Meanwhile, the most recent weekly figures from the Office for National Statistics (ONS) suggested a 25.2% jump in the estimated UK infection rate, although some countries and regions were affected more than others. Overall, around 1.3 million people in private households were likely to have tested positive for COVID in the week to September 26, compared with 1.1 million in the previous week, it said.

Estimates for the percentage of people who would have tested positive for COVID at the end of the first week of October had continued to increase in England and Northern Ireland, but trends from the Coronavirus Infection Survey were "uncertain" in Wales and Scotland, statisticians said.
COVID-19 cases in UK leap by 25% with big rise among over-70s in England

Although the total is now the highest since mid-August - probably caused by fading immunity - it is still some way below the 3.8 million in July.

COVID-19: 'Concerning' increases in COVID hospitalisations - with 250% rise in one region

There were 9,631 people in hospital with coronavirus as of 8am on 5 October - a 37% increase on last week's 7,024.

Covid data shows one in 50 people infected in England

ONS says 1.1 million people had virus in most recent week, with increases in all parts of England.
Infections continued to increase
Percentage testing positive for COVID-19, England
Office for National Statistics

Hospital admissions continued to increase
Hospital admissions involving COVID-19 per 100,000 people, England
UK Health Security Agency

ICU/HDU admissions remained low
ICU and HDU admissions involving COVID-19 per 100,000 people, England
UK Health Security Agency

Deaths decreased
Deaths registered by week involving COVID-19, England
Office for National Statistics

Antibody levels in adults remain high
Percentage testing positive for antibodies to COVID-19, England
Office for National Statistics

Over 4.7 million people have received an autumn booster
People aged 50 years and over who have had an autumn booster, England
GOV.UK Coronavirus Dashboard
Sept. 30, 2022 -- COVID-19 causes DNA damage to the heart, affecting the body in a completely different way than the flu does, according to a recent study published in *Immunology*. The study looked at the hearts of patients who died from COVID-19, the flu, and other causes. The findings could provide clues about why coronavirus has led to complications such as ongoing heart issues.

“We found a lot of DNA damage that was unique to the COVID-19 patients, which wasn’t present in the flu patients,”

**Transcriptomic profiling of cardiac tissues from SARS-CoV-2 patients identifies DNA damage**

Arutha Kulasinghe, Ning Liu, Chin Wee Tan, James Monkman, Jane E. Sinclair, Dharmesh D. Bhuva, David Godbolt, Liuli Pan, Andy Nam, Habib Sadeghirad, Kei Sato, Gianluigi Li Bassi... See all authors

First published: 15 September 2022 | [https://doi.org/10.1111/imm.13577](https://doi.org/10.1111/imm.13577)

Arutha Kulasinghe and Ning Liu are co-first authors.

Fernando Souza-Fonseca Guimaraes and John F. Fraser are co-senior authors.

**Funding information:** Australian Academy of Sciences; NHMRC, Grant/Award Numbers: 1157741, 2007919, 1135898, 2008542; The Prince Charles Hospital Foundation (The Common Good)
What about variants?
While BA.5 – one of the Covid Omicron sub-variants behind the last wave – *now makes up the majority of infections, there are new kids on the block too*. This includes a form of BA.5 known as BQ.1.1 which, while low in numbers, is growing rapidly in the UK.

The new sub-variants are not currently thought to be any more severe than other forms of Omicron.

The XBB strain is causing a small surge in cases in countries like Bangladesh and Singapore. The latter has recorded a daily average of about 5,500 cases over the past week, compared to a daily average of 2,000 cases a month ago.
Why are these variants on the rise?
Two words: immune evasion.

All the variants that researchers are tracking contain multiple overlapping changes to a portion of the spike protein called the receptor binding domain, which is targeted by potent infection-blocking, or neutralizing, antibodies. That numerous viruses are independently developing the same spike mutations suggests that these changes provide a big advantage to the viruses’ ability to spread, says Yunlong Richard Cao, an immunologist at Peking University in Beijing.

*(What about other viruses? What about Flu? What about Flu and Covid?)*
Figure 12: Respiratory DataMart weekly positivity (%) for other respiratory viruses, England

What about other viruses?

6th Oct (week 40)

Figure 10: Respiratory DataMart samples positive for influenza and weekly positivity (%) for influenza, England

Australian Influenza Surveillance Report and Activity Updates

Australia monitors influenza through a number of complimentary systems. The Australian government advises caution is required in interpretation of these due to the effects of COVID-19, particularly inter-year comparisons. Caution should also be applied in assessing the implications of influenza activity in Australia to the UK. It is not possible to reliably predict the course of the 2022 southern hemisphere influenza season or the implications for the following 2022 to 2023 northern hemisphere season, such as the timing, activity and impact of the 2022 to 2023 influenza season in the UK. Australia is one of many countries from which flu may arrive in the UK, including other countries which are more populous and or have more frequent inbound travel. Australia’s influenza activity reflects its specific epidemiological circumstance and has no bearing on the local persistence of influenza in the UK in our inter-seasonal period.

For further information on influenza in Australia please see the Australian Influenza Surveillance Report and Activity Updates.
NHS facing cuts to appointments over ‘twindemic’ threat from covid and flu

Act now to avoid Covid and Flu double whammy, says Manchester’s public health chief

British health officials warn of difficult winter with flu and COVID

"There are strong indications we could be facing the threat of widely circulating flu, lower levels of natural immunity due to less exposure over the last three winters and an increase in COVID-19 circulating," said Susan Hopkins, Chief Medical Advisor at UKHSA.
Vaccinate
Interactions between SARS-CoV-2 and influenza, and the impact of coinfection on disease severity: a test-negative design

Julia Stowe, Elise Tessier, H Zhao, Rebecca Guy, Berit Muller-Pebody, Maria Zambon, Nick Andrews, Mary Ramsay, Jamie Lopez Bernal

Published: 03 May 2021

Abstract

Background

The impact of SARS-CoV-2 alongside influenza is a major concern in the northern hemisphere as winter approaches.

Methods
Press release

Over 30 million people urged to take up ‘vital’ flu and COVID-19 vaccines

UKHSA warns of lower levels of natural immunity to flu this year and increased coronavirus (COVID-19) circulation.

From: UK Health Security Agency
Published 28 September 2022
Last updated 28 September 2022 — See all updates
Conclusion During the first six months of 2022 in the US, booster doses of a covid-19 vaccine provided additional benefit beyond a primary vaccine series alone for preventing hospital admissions with omicron related covid-19.
Dr Susan Hopkins, Chief Medical Advisor at UKHSA, said:

- “strong indications we could be facing the threat of widely circulating flu, lower levels of natural immunity due to less exposure over the last three winters and an increase in COVID-19 circulating with lots of variants that can evade the immune response. This combination poses a serious risk to our health, particularly those in high-risk groups.”

- “The H3N2 flu strain can cause particularly severe illness.”

- “Younger children are unlikely to have built up any natural immunity to flu and therefore it is particularly important they take the nasal spray vaccine this year.”

NHS director for vaccinations and screening Steve Russell said:

- “This winter could be the first time we see the effects of the so called ‘twindemic’ with both COVID-19 and flu in full circulation, so it is vital that those most susceptible to serious illness from these viruses come forward for vaccines in order to protect themselves and those around them.”

- “If you have been offered a flu vaccination or COVID-19 booster you should book in as soon as possible”

Hesitancy for receiving regular SARS-CoV-2 vaccination in UK healthcare workers: a cross-sectional analysis from the UK-REACH study

Neyme Veli¹,², Christopher A. Martin¹,², Katherine Woolf³, Joshua Nazareth¹,², Daniel Pan¹,², Amani Al-Oraibi¹, Rebecca F. Baggaley¹, Luke Bryant¹, Laura B. Nellums⁴, Laura J. Gray⁵, Kamlesh Khunti⁶, Manish Pareek¹,²* and The UK-REACH Study Collaborative Group
A total of 5454 HCWs were included in the analysed cohort.

Discussion
This is the first study to evaluate hesitancy to receive regular SARS-CoV-2 vaccination in the UK. In our study of HCWs, around a quarter of respondents were hesitant about having regular vaccinations against SARS-CoV-2. This is similar to the results from a smaller US study which demonstrated that 83.6% of HCWs would accept a hypothetical yearly SARS-CoV-2 vaccination [18]. In our cohort, individuals who were younger, from Black ethnic groups, who had a previous episode of COVID-19, who had fewer influenza vaccinations in the last two seasons, and who scored higher on a COVID-19 conspiracy beliefs scale, were more likely to be hesitant about receiving regular vaccination. HCWs who reported trusting official information sources (e.g. government or NHS sources) for vaccine-related information were less likely to be hesitant and those who had received information advocating against vaccination from family and friends were more likely to be hesitant to receive regular SARS-CoV-2 vaccination.
Fig. 2

Trusted vaccine information sources (n=5,393)

- Friends
- Colleagues
- Employer
- Television
- Radio
- Newspaper
- Government / NHS adverts
- Twitter
- Other social media
- Government website
- NHS or WHO website
- Other websites
- Local council
- GP or other HCW
- Scientific journals

Sources of information advocating against vaccination (n=5,327)

- Family
- Friends
- Neighbours
- Colleagues

Odds ratio
Cost of Living Crisis
A penny for your thoughts….

Chat BOX

What plans does your organisation have to mitigate issues that are arising and will get worse over the coming months because of the cost of living crisis and its impact on patients, families and staff?
Cost of living crisis: NHS to face ‘challenging winter’ as energy costs rise, warn healthcare leaders

Rising energy costs could “wipe out large parts of the NHS budget”, with healthcare leaders warning this winter will be “particularly challenging”.

NHS worker shares shocking account of life in the energy crisis in North Wales Live heating survey

Almost half of respondents said they will be keeping the heating off as long as possible

Cost of living crisis will pressure NHS this winter - health expert

25 September
The cost of living crisis shows how much inequality matters, and how it affects everyday life.

**Disabled households twice as likely to be struggling with cost of living crisis**

Press release issued: 7 September 2022

Cost-of-living crisis could leave hospital patients too poor to go home, says Belfast Trust chief

Cathy Jack sounds alarm bell as A&Es struggle to cope with rising demand
New analysis published today by the Health Foundation reveals that staff working in care homes are far more likely to live in poverty and deprivation than the average UK worker. Even before the cost-of-living crisis hit, 1 in 5 residential care workers in the UK was living in poverty, compared to 1 in 8 of all workers. Many relied on state support to make up for low income from employment – 20% of the residential care workforce drew on universal credit and legacy benefits from 2017 to 2020, compared to 10% of all workers.
WORKFORCE
NHS Staff 'Leaving for Better Paid Jobs in Retail'

NHS staff quitting for private sector jobs as cost of living crisis intensifies, leaders warn

NHS staff are facing paid jobs in shops

Staff are being forced to skip meals to feed their children or take on second jobs, according to the results of a new NHS survey

A survey for NHS Providers found two thirds (68%) of trusts were reporting a "significant or severe impact" from staff leaving for other sectors where conditions and terms are better.

Anecdotally, senior NHS figures have said they are seeing "huge numbers" of staff in their trusts taking other jobs, or considering second jobs, outside of the NHS.

Staff are also struggling to afford to go to work, with 71% of trust managers surveyed saying this was having a significant or severe impact on their trust.
Secondary care vacancies in England
June 2018 to June 2022

Number of vacancies

- Total
- Nursing
- Medical

Source: NHS Digital: NHS Workforce Statistics
RCP responds to NHS Providers survey on the impact of the rising cost of living

The RCP has responded to the findings of NHS Providers’ survey which examines the impact of the rising cost of living on NHS trusts, their workforce, patients and the communities they support.

In response to the findings, Dr Sarah Clarke, president of the Royal College of Physicians, said:

“It is very concerning to hear so many NHS trusts are worried about the effect of the cost-of-living crisis on the health and wellbeing of their staff. We know that the rising cost of living is having a major effect on people’s health across the country, having conducted our own survey of the general public in May showing that over half of them (55%) thought their health had already been negatively affected by it.
Lack of money in NHS means some staff are quitting to take better paid jobs in pubs and shops

Some nurses are so hard up that they are having to not eat at work in order to feed and clothe their children, research among hospital bosses has found.

Lack of money is also prompting some NHS staff to call in sick in the days before they get paid because they can no longer afford the travel costs for their shifts. Photograph: sturti/Getty Images

More than a quarter (27%) of trusts already operate food banks for staff, and a further 19% plan to open one, to help relieve the acute financial difficulties faced by staff.

The survey also found that some staff:

- Are stopping contributing to their NHS pension in order to free up cash.
- Cannot fill up their cars because of petrol price rises.
- Have mental health issues due to the stress of paying their bills.
Figure 1

Concern about impact of the cost of living on staff

<table>
<thead>
<tr>
<th>Category</th>
<th>Not at all concerned</th>
<th>Slightly concerned</th>
<th>Moderately concerned</th>
<th>Extremely concerned</th>
<th>Don't know</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical wellbeing (n = 149)</td>
<td>19%</td>
<td>48%</td>
<td>33%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mental wellbeing (n = 149)</td>
<td>21%</td>
<td></td>
<td>78%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Financial wellbeing (n = 152)</td>
<td>5%</td>
<td></td>
<td>95%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Recruitment (n = 151)</td>
<td>7%</td>
<td>33%</td>
<td>60%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Retention (n = 149)</td>
<td>8%</td>
<td>28%</td>
<td>64%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Appetite for industrial action</td>
<td>6%</td>
<td>26%</td>
<td>66%</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Figure 2

Impact of cost of living on staff mental and physical health and wellbeing

Cost of living forces Sutton Coldfield cancer charity from hospice

6 days ago

A cancer charity is seeking a new base as it cannot afford a rise in rent and energy prices at its current site.

The Cancer Support Centre (CSC) has leased rooms in St Giles Hospice, Sutton Coldfield for 11 years.

The charity said it has been given notice to quit by 17 January after the increases proved "beyond its reach".

Sue Ryder responds to the new Government’s mini-budget

Today, Friday 23 September, the Chancellor delivered a mini-budget, setting out the Government’s plans to provide support during the cost of living crisis.

Adequate support for charities was noticeably absent in today’s announcement.

We are concerned about the impact this lack of support will have on the already struggling palliative care sector’s ability to continue to provide vital care and support.

Cost of living crisis: Peterborough’s Sue Ryder Thorpe Hall Hospice sees 10 per cent rise in total care costs

The national healthcare charity’s total costs to keep its palliative and neurological care services running has risen by 10 per cent – despite the NHS grants it receives only increasing by one per cent.
Energy price rises 'will devastate hospice care'

Hospices have issued an urgent cash SOS, warning the sector is facing oblivion as income dries up.

By GILES SHELDICK - DAILY EXPRESS CHIEF REPORTER
Helping your employees during the cost of living crisis

NEWS
Northampton and Kettering hospitals plan staff cost of living payment

© 29 September
A penny for your thoughts….

Chat BOX

What plans does your organisation have to mitigate issues that are arising and will get worse over the coming months because of the cost of living crisis and its impact on patients, families and staff?
I am critically dependent on medical equipment. What services are available?

Northern Ireland Electricity Networks (NIE Networks) offer a medical customer care information service to customers who are dependent on life supporting equipment.

If you use electrical equipment that is vital to your health, you may wish to register with NIE Networks to receive up-to-date information during a power cut or interruption to your supply.

You can register for this service on the NIE Networks website or by calling NIE Network's customer helpline on 03457 643 643.

What is our Priority Services Register?

The ScottishPower PSR service will help many customers, including:
- Those in debt through the provision of help and advice. We can also ensure you are on our lowest cost.
- Providing external sources of help.
- The elderly
- The deaf
- Visually impaired
- The ill or disabled

Electrical medical equipment and power cuts

It's important to know what to do if a power cut happens. And if you have electrical medical equipment, it's even more important you're prepared.
Electricity Rebates

When an oxygen concentrator has been installed it will be serviced initially at 3 months and then every 6 months by a Patient Service Representative.

As part of the service, a meter reading from the concentrator will be taken. This meter reading records the number of hours your concentrator has been used.

We can then calculate the electricity that has been used to run your concentrator.

If you have any questions regarding your rebate please call our Patient Service Centre 0800 136 603.
GLASGOW
Tuesday 22 November – Thursday 24 November

Hospice UK National Conference

Finding a way forward

www.hospiceuk.org
Draft Programme is now available and signup

SEC Glasgow from Tuesday 22 November – Thursday 24 November 2022.

http://www.hospiceuk.org/innovation-hub/courses-conferences/national-conference
The paper explores hospice day care and the role of social support within it and how it fits with other approaches eg rehabilitative, medical etc.

Social support appears significant to patients, but measurement is rare.

Innovation in service design is ongoing, and some hospice day centres offer a broad menu of options for group support and activity.

However, there is sparse evidence available to guide decision-making and much of the informal support offered by hospices has not been quantified.

What they did

- An online survey aimed to gain an overview of all hospice day services that facilitated social support for adults outside of their own homes.
- Asked about hospice characteristics, including staff and volunteer roles.
- Respondents were asked to identify services they felt offered social support to patients.
- Data collection took place between August 2017 and May 2018
- Funded by the Economic & Social Research Council
• 103 hospices responded in the UK and ROI (response rate 49.5%)
  • On average, respondents identified 4 and 5 services each
  • Most were located within the hospice main building, and the hospice offered transport and catering, usually for free
  • A quarter offered services in community centres, libraries, or other religious and non-religious buildings
  • 175 (39.2%) of services operated as ‘drop in’.
• Social activities (including cafes and coffee clubs, social programmes, friendship groups, family fun days and special events or excursions) were very commonly ‘drop in’
What did these look like?

What is 'most social'?
More than half of the ‘most social’ services reported no outcome measurement.

15% reported the introduction of all or part of the OACC suite of measures

Volunteers were giving professional or therapeutic expertise including:

- complementary therapists, administrators, hairdressers, chaplains or other religious leaders, psychological therapists, mindfulness or meditation practitioners, and leaders of creative or other activity groups
Thinking towards the future

The significance of social support within an in-person hospice setting remains poorly understood.

More knowledge is needed to understand effectiveness of social support interventions in palliative care - as the building blocks for the next evolution of the hospice movement.
Artwork Gallery Submission Window Open

Submission Timeline

- Submission Window Friday 30 September 2022 to Friday 30 December 2022
- Outcome Emails Issued w/c 9 January 2023 (these will be emailed to the submitting presenter)
- Registration Deadline Friday 27 January 2023 (all artwork presenters to be registered by this date)

Developing excellence in palliative care

Palliative Care Congress

155:09:35:30

Day(s) Hour(s) Minute(s) Second(s)

16 – 17 March 2023
Edinburgh International Conference Centre
The 11th Hour Book Club in conjunction with the Association for Palliative Medicine is proud and excited to announce...

**Hope**

Our new creative writing competition for 2022-23

‘Hope’ is your title and theme.

We invite anyone involved in palliative care to write up to 800 words and submit the short piece via the PCC website.

**Deadline is before 23:59 on the 31st December 2022.**

Themes tend to be short and deliberately ambiguous. ‘Hope’ was chosen because of the range of possibilities it gives. It should go without saying this should not break any confidentiality if referencing actual experiences.

It will be judged by the 11th Hour Book Club Committee consisting mostly of doctors with an interest in medical writing.

The winner will be announced at PCC in Edinburgh on the evening of the 16th March 2023 during the 11th Hour Book Club session.

The winner will receive writing coaching sessions with Author and Palliative Care Physician Dr Rachel Clarke.
I hope everyone managed some rest and relaxation over the summer break. I was grateful myself to get some time away from it all with my daughter and earlier this month waved her off on her first day of secondary school. Where does the time go?

Back to the grindstone now though and we turn our focus once again to workforce. Having been presented with national data at the Royal College of Physicians, we are ever more aware of the shortages of staff across the NHS and independent sector. It is ever more pressing that this is addressed and remodelling considered. I would like to invite anyone with an interest, passion or knowledge of workforce to contact the APM at [office@compleat-online.co.uk](mailto:office@compleat-online.co.uk) so that we can configure a task group to address this.
Palliative Care & Bereavement

Inspire Resource for Integrated Care Boards

12th October 2022

Dr Catherine Millington-Sanders
RCGP & Marie Curie National EOLC Clinical Champion
on behalf of

RCGP & EOLC Think Tank Partners
Special thanks to

Professor Max Watson
Inspire Resource for ICBs

- Every Setting
- 24/7 Bed Access
- Professional Palliative Medicine Advice
- Carer Advice
- Ease of Access to Key Medication & Equipment
- Information Sharing
- Records of ‘What Matters Most’ Conversations
- Quality Improvement, Research & Innovation
- Children’s End of Life Care
- Bereavement Care
- Compassionate Communities

Palliative Care Mandate for Integrated Care Boards

Health and Care Act 2022

How to use document
CONTINUE ➔
Celebrating & Sharing

As palliative care experts, you are in a great position to spread the word about the Inspire Resource and encourage ICBs and teams to celebrate excellent practice and inspire local system progress.

We would really appreciate your support sharing the Inspire Resource with your networks and via your communication channels.

INSPIRE RESOURCE LINK:

https://view.pagetiger.com/bbqohwx

Have we missed something fabulous?

Please get in touch!  catherine.millington-sanders@rcgp.org.uk

@DrCatherineUK
Every Setting

Palliative Care to be available in every setting where people are dying

Enabling Gold Standard Palliative/End of Life care for all the people in every setting with GSF

The Daffodil Standards are UK RCGP & Marie Curie General Practice Standards for Advanced Serious Illness and End of Life Care. The Standards provide a free, evidence-based framework, to help practices self-assess and consistently offer the best end of life and bereavement care for patients. These Standards provide a population-based approach to offer GP teams a simple structure to enable practices to be proactive organisations in which continuous learning and simple quality improvement steps are an integral part of care.

North Bristol Trust – Care Home Interface Project

Part of North Bristol Ageing Well Project

The North Bristol Ageing Well Project is a multidisciplinary group of healthcare professionals spanning primary, secondary and community care. It aims to identify those who are extremely frail, and deliver targeted interventions to improve their quality of life and ensure their priorities are heard and respected.

Every Setting

Homelessness is a health problem not just an accommodation problem. Many of those affected have complex health needs. If you are ill on the streets than this is challenging for both the individual and those trying to provide support. The health system is not built for homeless people and generally fails to deliver equitable care, especially for those who are dying.
24/7 Bed Access

WE ARE MACMILLAN. CANCER SUPPORT

“Given the increased demand for both generalist and specialist palliative care services, the Midhurst Service represents an efficient way of expanding capacity without incurring significant capital costs.”

24/7 Bed Access

Sussex Community NHS Foundation Trust

24/7 access to palliative care beds is a real challenge for many parts of the sector because of workforce issues but also because moving such patients in the middle of the night seldom produces optimum outcomes, though sometimes is crucial for patients and families.
Professional Palliative Medicine Advice 24/7

With many gaps in the palliative care workforce, providing 24/7 advice to clinicians seeking help to manage patients is a major challenge in many parts of the country. Some areas have contracted out the on call advice service to private providers such as Supportive Care UK. Wales has lead the way in developing a National Service of 24/7 on call support.

Professional Palliative Medicine Input 24/7

Marie Curie REACT Responsive Emergency Assessment and Community Team
Marie Curie REACT is an innovative service model developed with system-wide collaboration to improve End of Life Care for the people of Bradford District and Craven, West Yorkshire. At its heart is a partnership between Marie Curie and Bradford Teaching Hospitals Foundation Trust.

Could your patient be cared for at home? Then REACT.
Carer Advice

Care After Death

The need to have accurate up to date access to key information concerning patient care is crucial, and has been highlighted during the pandemic. However too much information and too many protocols and guidelines can easily saturate clinicians. Hospice UK is just one organization among many who through collaboration with others seek to produce clear and inclusive clinical resources. Care after death is an example of this approach.

Carer Support Needs Assessment Tool Intervention (CSNAT-I)

Tailoring support to carers’ self-identified needs: a carer-led intervention

Thinking carers at organizational level

Providing the building blocks to support carers looking after a family member/friend nearing end of life: Hospice UK 10 Recommendations for achieving organisational change.

Carer Advice

A 24/7 telephone support, advice and onward referral service for all patients in our CCG (600,000) who are thought to be in or approaching the last year or so of life.

Carer Advice

The Integrated Mersey Palliative Care Team (IMPaCT) is a consultant-led, integrated, multi-professional palliative care service across Liverpool and South Sefton, for adults with a life-limiting, progressive condition. The IMPaCT model has been developed collaboratively by providers and patient representatives of palliative and end of life services to:

- Address inequities and duplication in the provision of services
- Simplify pathways with a single point of access and referral
Ease of Access to Key Medication and Equipment

The Community Pharmacy Daffodil standards seek to improve the delivery of palliative care with a focus on medicines management.

The Royal Pharmaceutical Society (RPS) has partnered with Marie Curie to develop professional standards in palliative and end of life care for Community Pharmacy. The work aligns with and complements the established RCGP and Marie Curie “Daffodil standards for advanced serious illness and end of life care” for GP practices. The standards are currently being developed for launch before the end of 2022 and will be available for pharmacy teams across the UK. They will provide a broad, evidence-based framework to help community pharmacy teams to self-assess, develop their practice and continuously improve to offer the best quality end of life care to patients and their carers. The scope of the project also includes children and young people where even more complex palliative care needs can exist.
Information Sharing

Systems to ensure that key stakeholders can quickly and safely access information about patients with palliative care needs are crucial in ensuring timely and appropriate care is made available to patients. A range of information sharing systems are in use across the country of which Urgent Care Plan for London (formerly Coordinate my Care (CMC)) and the Electronic Palliative Care Coordinating Systems (EPaCCS) are two examples. The need to share key information in a timely fashion has to be balanced with ensuring that patient data sharing systems are fully GDPR compliant. ReSPECT process is another example.
Records of ‘What Matters Most’ Conversations

Records of "What matters most" Conversations

No Barriers Here To Important Conversations
No Barriers Here is a co-produced, community-based action research project which aims to improve approaches to Advance Care Planning (ACP) for people often excluded from palliative and end of life care, in particular people living with a learning disability and people from Black, Asian, and ethnic minority communities with different cultural and faith backgrounds.

Records of "What matters most" Conversations
MacIntyre's Dying to Talk Project is opening up conversations about death and dying with people who have learning disabilities.

Planning Ahead
What matters most to you?
Provided by hospice

Planning Ahead' – online support tool to encourage well-informed conversations about Advance Care Planning
Quality Improvement, Research & Innovation

The Covid-19 clinical ECHO network was one of Hospice UK’s major responses to support hospices, patients and families as well as palliative care research through the pandemic. Through weekly online meetings using Project ECHO methodology of ‘All Teach, All Learn’, the UK hospice sector (and beyond) joined the network. This fostered collaboration, connection and a sense of ‘all in it together’.

ECHO network highlights and feedback

Mouth Care Matters 2021:

Marie Curie, in partnership with the Royal College of Nursing Pain and Palliative Care Forum, launched the first Mouth Care Matters network in 2021 to build on the success of the Health Education England’s Mouth Care Matters programme.
Quality Improvement, Research and Innovation

Examples of two NHS quality improvement projects which have made substantial savings and improvements to service outcomes.

Ashford and St. Peter's Hospitals
NHS Foundation Trust

GeriPall Project
Epsom and St Helier University Hospitals
NHS Trust

Bringing the best of geriatric medicine and palliative care together for patients approaching end of life with severe frailty, dementia and neurodegenerative conditions. Listening to "What Matters Most"

Research and Innovation

The need for high quality, whole-system research in palliative and end of life care has never been greater. Palliative care research has an essential role in informing and influencing evidence-based clinical practice, service development, education and policy through robust methods and ethical procedures. Research funding for palliative and end of life care research is lacking compared to other clinical areas, and existing research evidence is not used consistently to inform policy and service developments. As Integrated Care Boards implement the Statutory Guidance, there are exciting opportunities for collaboration between researchers and policy-makers to develop, test and evaluate truly evidence-based services.

The RE-EQUIPP Care Partnership: REducing inEQUalities through Integration of Primary and Palliative Care.
(Just one example of integrated research.)
Children's End of Life Care

The particular needs of Paediatric Palliative Care services include being able to support children and their parents across a wide geography with an even more limited specialist workforce than in adult services. Leeds-based paediatric haematology/oncology specialist service with integrated palliative care deliver such a service with a reliance on the CHOONS (children's haematology oncology outreach nursing service).
Bereavement Care

Bereavement Care
Connecting Communities Project

We know that support from family and community is important following a bereavement, but given our discomfort talking about grief, many bereaved people don’t receive the support they need.

Birmingham Project

Working with the NHS through Covid 19

CCG commissioners requested:
7 day a week helpline where bereaved residents could access timely listening support. Increased capacity to ensure waiting times for ongoing support would not exceed 10 weeks and service for 1000 residents per year with ongoing support for all age ranges. Support for NHS staff Suicide Postvention programme. Total contract cost for us and our partners was £359,000.

Borough of Kingston upon Thames has kindly provided the resource of a senior officer who has produced a range of guidance notes across the spectrum of the bereavement ecosystem. The guidance can be read as individual topics or as a whole by residents, carers and End of Life Care practitioners via the RBK/KVA Connected Kingston information portal. Topics covered include how to; register a death, care for the deceased at home, arrange a funeral with or without a funeral director, garden burial and ‘mythbusting’ to demystify and resolve popular misconceptions. The working draft bereavement guidance for residents can be read here.

Bereavement Care
Community Support

The Loss and HOPE project was set up by AtaLoss to equip churches in bereavement support. Churches are in every community and are well placed because of their ethos and volunteer force to provide bereavement support to people. The Loss and Hope project provides everything they need to deliver support - specially created resources, volunteer training, advice and support to enable them to make their churches more 'bereavement friendly'.

Bereavement Care

The increase in deaths caused by COVID and the manner in which COVID fractured families from being with the dying or to receive the normal funeral supports and comforts has left unprecedented numbers of people grappling with unresolved loss. From specialist bereavement services through to population based bereavement support a wide range of voluntary and statutory organizations have been working to help address this huge need.

Bereavement and Compassionate Communities

South West London ICS, Healthwatch Kingston and Kingston Voluntary Action worked with cross-sector partners to develop the public health, compassionate communities approach in order to better understand the impact, experience and equity of bereavement on our local population, supporting underserved needs and communities. This was also an EOLC QI pilot in wave one of NHS England’s Getting to Outstanding programme.
Compassionate Communities

Our work focussed on NHS England's ambition statement for palliative and end-of-life care:

‘Each Community is Prepared to Help’.

G.Peryer@uea.ac.uk  @guy_per

End of Life Doulas provide practical, emotional (and if required, spiritual) support to those living with a life-limiting illness, their families and others who are important to them. End of Life Doulas aim to be a flexible and consistent presence, able to fill gaps in existing support and work alongside health and social care professionals. End of Life Doulas provide support at any stage from point of diagnosis, in the later stages of illness and through the dying process. We work in people’s homes, our Communities, Hospices, Hospitals, Care Homes and with other Charities and voluntary organisations. End of Life Doula UK (EoLDUK) is the community of practice and central point of contact for people seeking support in the UK.

Soul Midwives, nationally and internationally, are helping to transform the personal and collective experiences of dying and living. Our purpose is to help anyone facing the end of life to experience a tender, peaceful and conscious death. Working with local services we advocate for the person to die in the place they desire. In partnership with health and social care professionals we can avoid unnecessary admission to hospital and preventable medical intervention. Our work may begin from point of diagnosis and continue until the final day of life, with encouragement and support to live life fully, until the end.

Compassionate Communities

Compassionate Cities
Thank You!
NO BARRIERS HERE
Identity, culture, ethnicity and race

Dr Jed Jerwood (PhD) Lead Researcher
Presenting on behalf of the co-production team
Background

• No Barriers Here was developed as a pilot project during the Covid-19 pandemic. Co-produced with people with learning disabilities, using arts-based approaches to improve Advance Care Planning (ACP) conversations to address inequity.

• Many of you will have seen the film summarising the project and/or follow it on Twitter @NoBarriersHere.

• What developed from the project was conceptualised as an equity-oriented, arts-based approach to advance care planning for groups and communities often excluded or marginalised in healthcare.
The No Barriers Here team and stakeholders actively acknowledged throughout this work our own intersectional identity and positionality in the space of racial inequity and equity-based work.

Time was taken to reflect upon our own degree of power and privilege, including white privilege, and recognise our differences throughout the project to create inclusive dialogue and a safe space for all.
No Barriers Here: Identity, Culture, Ethnicity and Race

• 2020 – health inequalities exposed by Covid-19 pandemic, particularly for people from Black, Asian and minority ethnic communities; murder of George Floyd and the amplification of the #BlackLivesMatter movement and huge shift in understanding of racism within healthcare

• Editorial in Palliative Medicine, Hussain, Koffman and Bajwar (2021)

• Approached to explore if and how the No Barriers Here model might be used to explore and understand barriers to accessing palliative and end of life care for people from BAME communities

• Through a co-produced research study

• Importance of co-production – language, approach, positionality and privilege, disrupting research frames
What did we do?

• 3 cohorts of participants from 3 different BAME communities in the locality:
  • Black migrant communities (African and Caribbean people)
  • Roma community
  • South Asian community
  • Each cohort took part in three workshops over three weeks
  • Exploring ACP themes creatively
  • Held in community venues
  • Recruitment facilitated by community engagement workers – key to success

• To inform an education programme for healthcare professionals
“If it feels uncomfortable, it probably is……”

Co-production team member
Please now watch the film......

https://youtu.be/G-ToRCT3UiU

For more information about No Barriers Here facilitator training, education or workshops please contact:
gemma.allen@marystevenshospice.co.uk

For research enquiries contact:
j.jerwood@nhs.net

Follow us:
@NoBarriersHere
No Barriers Here
@NoBarriersHere
Do you work in a specialist palliative care setting in the UK?

Please complete this survey on:

Staff experience of racial prejudice and discrimination in specialist palliative care services

Very little is known about the experience of issues related to ‘race’ and racism of staff working in palliative care. This survey aims to explore such experiences and related structural inequalities within palliative care settings.

- The survey is voluntary and anonymous
- People of ALL ethnic backgrounds are encouraged to participate
- We want people working in ALL roles to participate, clinical and non-clinical
- Should take approx. 10-15 mins to complete
- Please forward on this advert to others (if relevant)

Click here for further information and the survey

THANK YOU

Any questions, please email the APM ‘Race’ Equity Committee at: pallmedrec@gmail.com
Click here for information about the committee
Value based palliative care

Idris Baker

12th October 2022

idris.baker@wales.nhs.uk
What good do we do?

• The recipe’s right

• EBM

• And we follow it

• Audit, process measures

• But is the cake any good & do they like it?
What good do we do?

• What effect does our care have in reality on patients & families?

• Does it offer good value compared with other ways the resources could be used?
  • HV vs OPA vs day care...
  • Skill mix
  • Prioritisation
  • Proactive vs reactive
Value-based healthcare is the equitable, sustainable and transparent use of the available resources to achieve better outcomes and experiences for every person.

Welcome to the Welsh Value in Health Centre

The Welsh Value in Health Centre is a Welsh Government funded programme, working to achieve world leading health outcomes for the people of Wales. By providing leadership, support, expertise and the strategic direction for embedding value-based healthcare across NHS Wales, we are driving better outcomes for patients in a way that is sustainable for the long-term. Value-based healthcare encourages us to focus on meeting the goals of our patients and to help manage expectations throughout their care or treatment. Improving how patients are involved in decision making using the best evidence to hand, avoiding any unnecessary variation in care and becoming more creative to determine where the resources we have are best spent for improved patient outcomes.

By working with patients and teams (such as clinical, operational, data, informatics and finance) across the healthcare system in Wales, and collaborating with industry and third sector, we are delivering the outcomes that matter to people with the resources available to us.

Enabling a whole system approach to value-based healthcare for Wales
Value based palliative & end of life care

• What might it entail?

• Measuring outcomes
  • Including PROMs
  • To inform day to day clinical care
  • And to inform whole system thinking
  • Whole journey not just single service
• Measuring experience
• Patients directly
• Families as proxy
• Families as agents
• Measuring cost
Next steps

• New National Clinical Programme being designed round these principles

• Keen to keep learning from other regional & national approaches
What plans does your organisation have to mitigate issues that are arising and will get worse over the coming months because of the cost of living crisis and its impact on patients, families and staff?
Evidence Update  Matt Doré

Research Review  Kate Flemming

Dr Catherine Millington-Sanders - Palliative Care Mandate for Integrated Care Boards

Jed Jerwood - No barriers here

Dr Idris Baker - New value-based national clinical programme

What are we doing? Ideas to share?

Chat Box

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

Please share resources, powerpoint, links etc. with those who would benefit

October 12th 2022
Before you know kindness as the deepest thing inside,
you must know sorrow as the other deepest thing. 
You must wake up with sorrow. 
You must speak to it till your voice catches the thread of all sorrows 
and you see the size of the cloth. 
Then it is only kindness that makes sense anymore, 
only kindness that ties your shoes 
and sends you out into the day to gaze at bread, 
only kindness that raises its head 
from the crowd of the world to say 
It is I you have been looking for, 
and then goes with you everywhere 
like a shadow or a friend.
THANK YOU