Issue 64 January - February 2015

The price of survival

Broadcaster Katrin Zöfel showed the value of good journalism with her half-hour broadcast for Deutschlandfunk, German national radio, which told the stories of people living with long-term effects of being treated for cancer.

Read More ...

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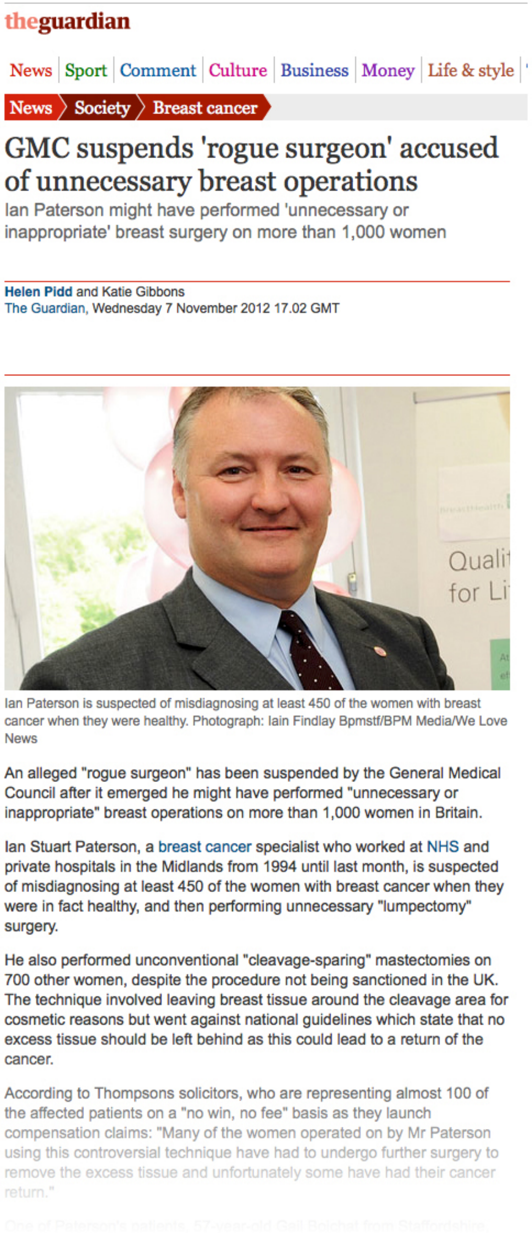
The healthcare scandal story

GMC suspends ‘rogue surgeon’



GMC suspends 'rogue surgeon' accused of unnecessary breast operations

Ian Paterson might have performed 'unnecessary or inappropriate' breast surgery on more than 1,000 women

Helen Pidd and Katie Gibbons
The Guardian, Wednesday 7 November 2012 17.02 GMT

Ian Paterson is suspected of misdiagnosing at least 450 of the women with breast cancer when they were healthy. Photograph: Iain Findlay Bpmstf/BPM Media/We Love News

An alleged "rogue surgeon" has been suspended by the General Medical Council after it emerged he might have performed "unnecessary or inappropriate" breast operations on more than 1,000 women in Britain.

Ian Stuart Paterson, a breast cancer specialist who worked at NHS and private hospitals in the Midlands from 1994 until last month, is suspected of misdiagnosing at least 450 of the women with breast cancer when they were in fact healthy, and then performing unnecessary "lumpectomy" surgery.

He also performed unconventional "cleavage-sparing" mastectomies on 700 other women, despite the procedure not being sanctioned in the UK. The technique involved leaving breast tissue around the cleavage area for cosmetic reasons but went against national guidelines which state that no excess tissue should be left behind as this could lead to a return of the cancer.

According to Thompsons solicitors, who are representing almost 100 of the affected patients on a "no win, no fee" basis as they launch compensation claims: "Many of the women operated on by Mr Paterson using this controversial technique have had to undergo further surgery to remove the excess tissue and unfortunately some have had their cancer return."

One of Paterson's patients, 57-year-old Gail Boichat from Staffordshire,

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Medical oncology scandal

TORONTO SUN
TUESDAY
FEBRUARY 25
2014

NEWS ONTARIO

Third party to oversee diluted chemotherapy drug investigation

BY ANTONELLA ARTUSO ,QUEEN'S PARK BUREAU CHIEF

FIRST POSTED: THURSDAY, APRIL 04, 2013 01:17 PM EDT | UPDATED: THURSDAY, APRIL 04, 2013 02:51 PM EDT

Premier Kathleen Wynne, left, and Health Minister Deb Matthews, background, check out state-of-the-art imaging equipment at the official

TORONTO - Ontario Premier Kathleen Wynne said the province is asking an independent, third party to investigate after cancer patients were given dilute doses of chemotherapy drugs at a handful of Ontario hospitals, as well a in New Brunswick.

"It's unacceptable that this should hav happened, that the doses would not have been accurate," Wynne said.

Wynne was at the official opening of th Louise Temerty Breast Cancer Centre Sunnybrook Health Sciences Centre Thursday, along with her partner Jane who battled breast cancer.

Cancer Care Ontario announced Tuesday that 990 patients undergoing cancer treatment at London Health

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Radiotherapy scandal

Irradiés d'Epinal : prison ferme pour deux médecins et un radiophysicien

Le Monde.fr avec AFP et Reuters | 30.01.2013 à 14h38 • Mis à jour le 30.01.2013 à 14h47

60 personnes le recommandent.

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How is the story framed?

- Pointing the finger of blame.
- Who allowed this to happen? Name the guilty.

or

Asking the question:

- How did this happen?
- Are there “processes” are in place to stop it, and why didn’t they work?
- Could it happen again?
- How do we stop it happening again?
- Is it happening undetected elsewhere?
- How do we find out and IMPROVE?

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Who is to blame for the blame stories?

The medical profession blame the media:

“journalists always want a juicy scandal, they like personalities not complex stories”

But: the medical establishment also likes to blame individuals and individual units departments.

1st instinct: reassure the public “everything is fine” – even though they know it almost certainly isn’t

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Maybe media and medical establishment have an unhealthy relationship

We bring out the worst in each other?

We need to improve

NHS press officers – caught in the middle

Keeping health reporting healthy

Keeping health reporting healthy

© NUJ

27 August 2013

The NUJ's campaign on health reporting has been launched against a background of a growing concern that health specialists, especially those in the regions, are a rarity at a time when the NHS in England is undergoing major change and budget cuts.

The service has failed to be open with the public and to release information about its performance.

This cutback in specialist reporter numbers is not new – but it does have serious consequences.

The campaign is taking a new approach and focusing equally on health writers and PRs working in health. They face growing pressures at a time when hundreds of NHS staff are being made redundant. NHS PRs work in small, often relatively isolated teams in an organisation that can easily be as hostile as it can supportive.

The ability to "speak the truth" may be compromised by senior managers who are woefully ignorant about what the press does

What to do when things go wrong

An example from journalism

Is Jennifer Couzin-Frankel in the pay of tobacco giants?

NEWS | *IN DEPTH*

BIOMEDICINE

The bad luck of cancer

Analysis suggests most cases can't be prevented

By **Jennifer Couzin-Frankel**

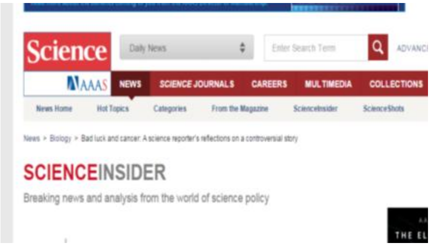
Why? That's the first word on many lips after a cancer diagnosis. "It's a perfectly reasonable question," says Bert Vogelstein, a cancer geneticist at Johns Hopkins University in Baltimore, Maryland, who has spent a lifetime trying to answer it. Thanks to his friendship with a recently minted Ph.D. in applied mathematics, the two now propose a framework arguing that

Random mutations in healthy cells may explain two-thirds of cancers, like this one in the colon.

who studies mathematics and biology at Harvard University and has worked with Tomasetti and Vogelstein. "It's a baseline risk of being an animal that has cells that need to divide."

The idea emerged during one of the pair's

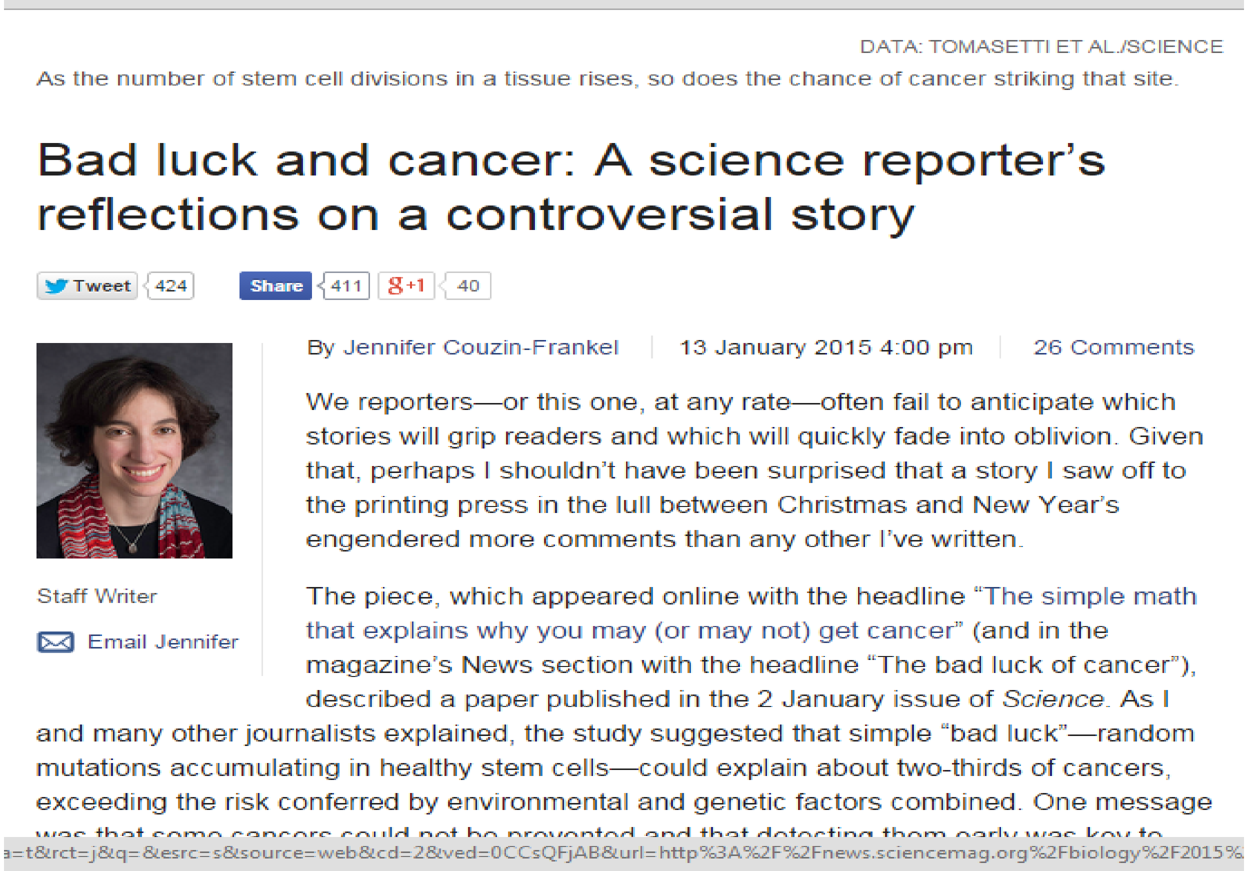
The line between mutations and cancer isn't necessarily direct. "It may not just be whether a mutation occurs," says Bruce Ponder, a longtime cancer researcher at the University of Cambridge in the United Kingdom. "There may be other factors in



News > Biology > Bad luck and cancer: A science reporter's reflections on a controversial story

SCIENCEINSIDER

Breaking news and analysis from the world of science policy



DATA: TOMASETTI ET AL./SCIENCE

As the number of stem cell divisions in a tissue rises, so does the chance of cancer striking that site.

Bad luck and cancer: A science reporter's reflections on a controversial story

Staff Writer

By Jennifer Couzin-Frankel | 13 January 2015 4:00 pm | 26 Comments

We reporters—or this one, at any rate—often fail to anticipate which stories will grip readers and which will quickly fade into oblivion. Given that, perhaps I shouldn't have been surprised that a story I saw off to the printing press in the lull between Christmas and New Year's engendered more comments than any other I've written.

The piece, which appeared online with the headline "The simple math that explains why you may (or may not) get cancer" (and in the magazine's News section with the headline "The bad luck of cancer"), described a paper published in the 2 January issue of *Science*. As I and many other journalists explained, the study suggested that simple "bad luck"—random mutations accumulating in healthy stem cells—could explain about two-thirds of cancers, exceeding the risk conferred by environmental and genetic factors combined. One message was that some cancers could not be prevented and that detecting them early was key to

a=t&rct=j&q=&esrc=s&source=web&cd=2&ved=0CCsQFjAB&url=http%3A%2F%2Fnews.sciencemag.org%2Fbiology%2F2015%

"It's a tricky story. Should I have done it better? How could I have done it better?"

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End the culture of blame

- Should health services and the medical establishment be more open about how difficult it is to do everything right all the time in every setting?
- It’s about processes to stop things going wrong, not about individual rogue surgeons or incompetent radiation oncologists

Trust the public or they won’t trust you

- “There’s huge variability in quality” says the profession
- Public gets data on? Waiting times!
- Where are the high levels of re-ops?
- Where are the below-guideline levels of post breast conserving therapy RT?
- How satisfied are patients?

More transparency is good for improving quality

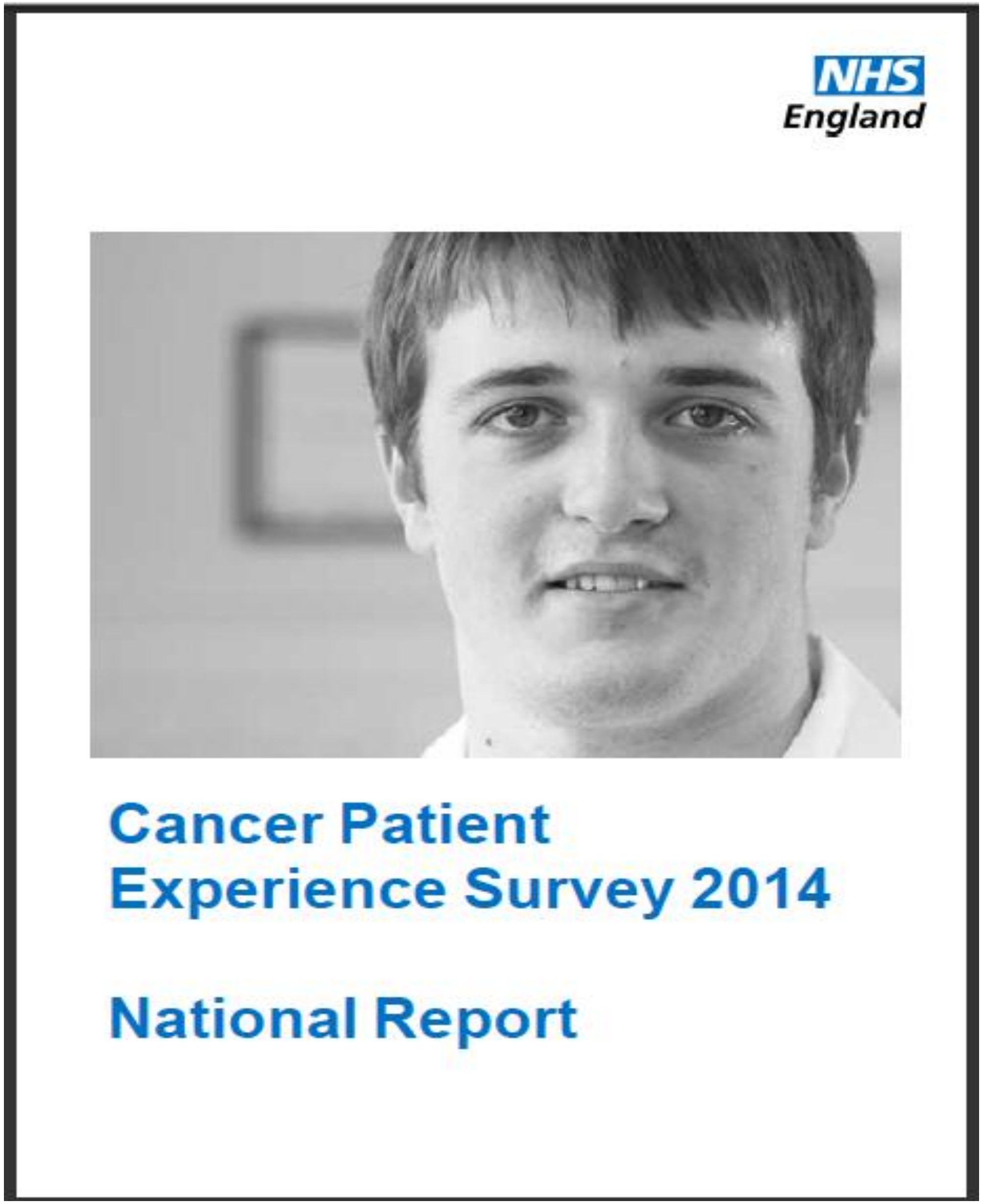
- If data are available, we can all have a go at interpreting them: media, patient advocates, anyone
- If they are secret, who is being protected? Public? Or professionals?

A good example from cancer care

Patient-reported

Process measures: did they do things right?

Transparent. Individual hospitals are scored and ranked, and also ranked for how they have improved or deteriorated from the previous survey

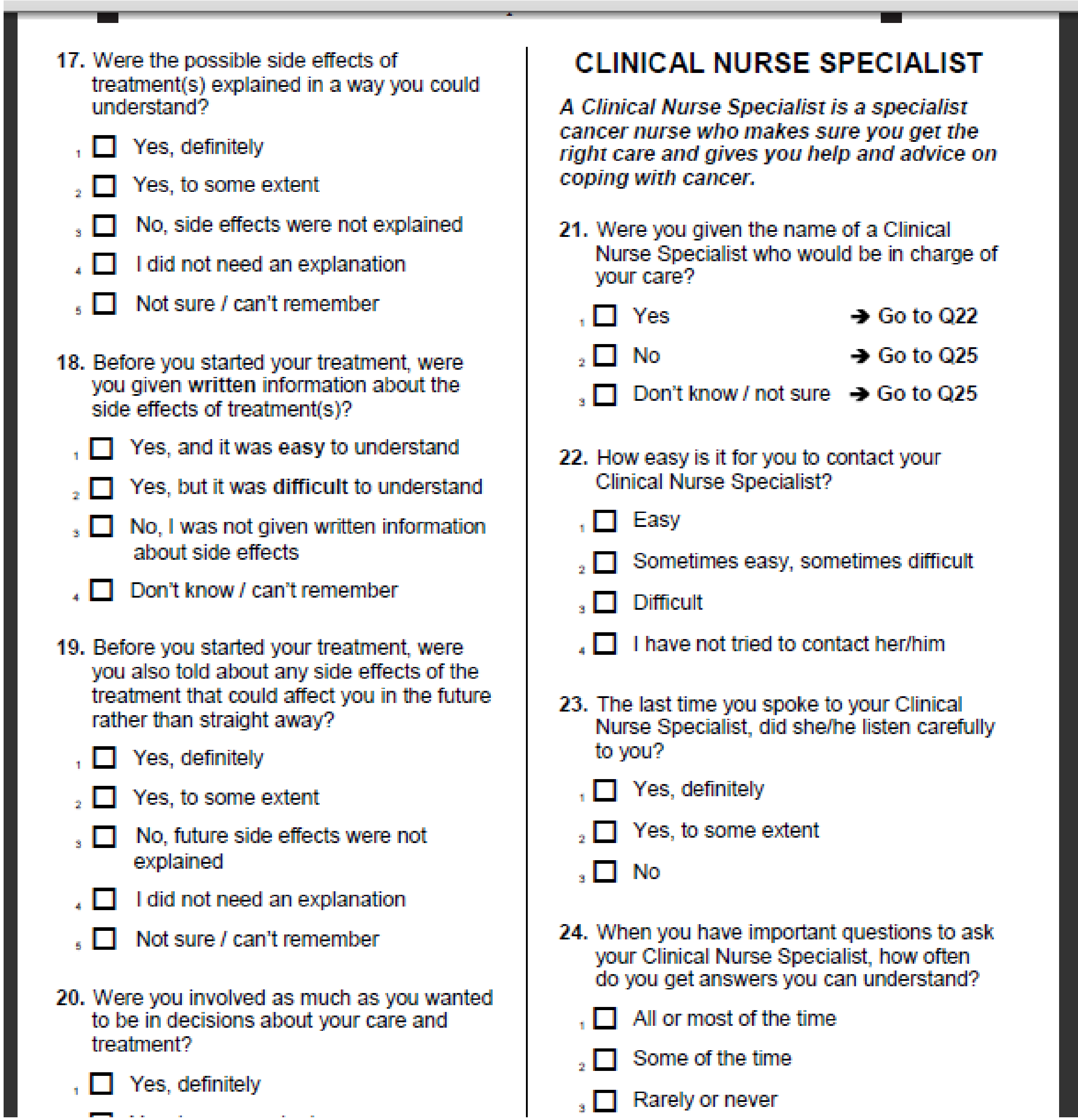

NHS
England

Cancer Patient Experience Survey 2014

National Report

More meaningful questions than:

Do you have 2 clinical nurse specialists



17. Were the possible side effects of treatment(s) explained in a way you could understand?

1 ☐ Yes, definitely
2 ☐ Yes, to some extent
3 ☐ No, side effects were not explained
4 ☐ I did not need an explanation
5 ☐ Not sure / can't remember

18. Before you started your treatment, were you given **written** information about the side effects of treatment(s)?

1 ☐ Yes, and it was **easy** to understand
2 ☐ Yes, but it was **difficult** to understand
3 ☐ No, I was not given written information about side effects
4 ☐ Don't know / can't remember

19. Before you started your treatment, were you also told about any side effects of the treatment that could affect you in the future rather than straight away?

1 ☐ Yes, definitely
2 ☐ Yes, to some extent
3 ☐ No, future side effects were not explained
4 ☐ I did not need an explanation
5 ☐ Not sure / can't remember

20. Were you involved as much as you wanted to be in decisions about your care and treatment?

1 ☐ Yes, definitely

CLINICAL NURSE SPECIALIST

A Clinical Nurse Specialist is a specialist cancer nurse who makes sure you get the right care and gives you help and advice on coping with cancer.

21. Were you given the name of a Clinical Nurse Specialist who would be in charge of your care?

1 ☐ Yes ➔ Go to Q22
2 ☐ No ➔ Go to Q25
3 ☐ Don't know / not sure ➔ Go to Q25

22. How easy is it for you to contact your Clinical Nurse Specialist?

1 ☐ Easy
2 ☐ Sometimes easy, sometimes difficult
3 ☐ Difficult
4 ☐ I have not tried to contact her/him

23. The last time you spoke to your Clinical Nurse Specialist, did she/he listen carefully to you?

1 ☐ Yes, definitely
2 ☐ Yes, to some extent
3 ☐ No

24. When you have important questions to ask your Clinical Nurse Specialist, how often do you get answers you can understand?

1 ☐ All or most of the time
2 ☐ Some of the time
3 ☐ Rarely or never

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Aysha King’s proton therapy and the NHS

An example of when both sides do better

“poor media, couldn’t find a ‘baddie’”

Why?

Because for once the NHS got its communications right… after getting it terribly wrong

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Battling on, Ashya has his first proton treatment in Prague, 19 days after his parents removed him from NHS hospital

- Ashya King had first course of treatment for his brain tumour earlier today
- Five-year-old will now undergo further 29 sessions at Prague proton centre
- Czech doctors say 70-80 per cent of patients in Ashya's condition survive
- News comes 19 days after parents removed Ashya from an NHS hospital
- Sparked international manhunt after taking him from Southampton General Hospital without permission in bid to get specialist treatment oversees

By JOHN HALL FOR MAILONLINE and CLAIRE ELLICOTT IN PRAGUE FOR THE DAILY MAIL

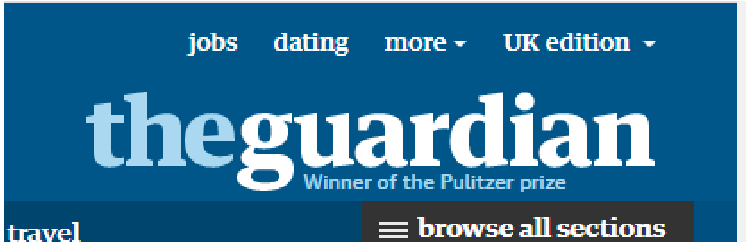
PUBLISHED: 09:52 GMT, 15 September 2014 | **UPDATED:** 00:34 GMT, 16 September 2014

Looking pale but alert, this is little Ashya King yesterday after his first day of long-awaited cancer therapy.

The five-year-old brain tumour patient, whose parents fought to secure proton beam treatment for him, underwent the first of 30 sessions of the therapy at a clinic in Prague.

The session followed a week of tests after Ashya was flown to the Czech capital from Spain by private jet.

Scroll down for video



Why we shouldn't sneer at Ashya King's parents

Andrew Holding: It's easy to dismiss the parents of Ashya King as scientific illiterates in need of a good education, but science engagement that assumes and mocks ignorance is offensive and rarely effective. **(Guest Post)**

Andrew Holding

Friday 5 September 2014 11.07 BST

The real story

No idiots

No hidden agendas

No betrayals

It’s tough when your child has a brain tumour and you want to get the best side-effect/benefit balance

… back to Angelina Jolie

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The value for money agenda

- Why clinicians shouldn’t stand on the sidelines

Value for money: the “exceptional approach” to cancer is changing

The Telegraph

Cancer is the best way to die and we should stop trying to cure it, says doctor

Dr Richard Smith said cancer gave sufferers time to say goodbye and pain could be endured through 'love, morphine, and whisky'

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Taboo issues are being discussed

THE SUNDAY TIMES

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NEWS

Doctor wants to deny elderly cancer drugs

Sarah-Kate Templeton, Health Editor Published: 4 May 2014

Comment (163) Print

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Is dementia the new cancer?

10 September 2014 Last updated at 02:07 GMT

Dementia patients 'face unfair care tax'

By Nick Triggle
Health correspondent, BBC News

q=&esrc=s&source=web&cd=1&ved=0CB8QFjAA&url=http%3A%2F%2Fwww.bbc.com%2Fnews%2Fhealth-291

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Mirror

News · Ampp3d · Dementia

Two-thirds of the cost of dementia is picked up by families and friends

13:41, 10 September 2014 | By **Sophie Warnes**

The NHS pays just a third of the cost of caring for dementia sufferers - the rest is borne by family and friends. The Alzheimer's Society has branded this an unfair "dementia tax".

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Get involved

- Doctors who want to do their best for patients need to engage with these debates
- That means engaging with the media (including social media)

www.thecancerblog.net

THE CANCER BLOG

Conversations for collaboration and change

Recent Posts

WOF @ Davos: reigniting the ambitions of the Paris Charter Against Cancer

Davos: another milestone in global efforts to control cancer

The real problem with genetic testing: time

Is it time to curb the charity fear factor?

Why should older patients pay the price of failures of holistic care and HTA?

Bold policies for progress north and sou

Why should older patients pay the price of failures of holistic care and HTA?

A debate between two medical oncologists over whether younger patients should get priority when it comes to access to very expensive drugs with the potential to prolong life was recently published online by Cancer World. In this guest post, **Roger Wilson,** a patient advocate and Honorary President of Sarcoma Patients Euronet, argues that giving patients a voice in these discussion is the only way to move on from these "simplistic, inward looking solutions".

The push to use age as a determining factor in drug funding permissions is blatantly discriminatory. There are better methods and measures for discerning eligibility, if only someone researched them properly.

The pharma industry is not interested in this research. Its business model (which determines its approach to pricing) is encouraged by the current inadequacy of HTA and political decisions such as

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