

How can pharmaceutical companies work with patients for patients?

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Disclosures

Simon Page is an employee of Ipsen

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Working with patients, for patients



1. Open access to publications



2. Acknowledgement of patients' contributions



3. Plain language summaries for publications



4. Involvement of patients in publications

Open access

to publications



What is "open access"?



The screenshot shows a web browser displaying the article page. A red box highlights the 'OPEN ACCESS' label on the left side of the page. Another red box highlights the 'Article PDF' and 'Article ePUB' buttons, with a red arrow pointing from the 'Article PDF' button to the 'Article ePUB' button. A third red box highlights the abstract and introduction sections of the article. The article title is 'First M87 Event Horizon Telescope Results. I. The Shadow of the Supermassive Black Hole'. The authors listed are Kazunori Akiyama, Anton Alexander Keiichi Asada, Rebecca Azuly, Anne-Kathrin Baczko, David Ball, and Mischa John Barrett. The article is published in 'The Astrophysical Journal Letters', Volume 875, Number 1, in April 2019. The abstract states: 'When surrounded by a transparent emission region, black holes are expected to reveal a dark shadow caused by gravitational light bending and photon capture at the event horizon. To image and study this phenomenon, we have assembled the Event Horizon Telescope, a global very long baseline interferometry array observing at a wavelength of 1.3 mm. This allows us to reconstruct event-horizon-scale images of the supermassive black hole candidate in the center of the giant elliptical galaxy M87. We have resolved the central compact radio source as an asymmetric bright emission ring with a diameter of $42 \pm 3 \mu\text{as}$, which is circular and encompasses a central depression in brightness with a flux ratio $\geq 10:1$. The emission ring is recovered using different calibration and imaging schemes, with its diameter and width remaining stable over four different observations carried out in different days. Overall, the observed image is consistent with expectations for the shadow of a Kerr black hole as predicted by general relativity. The asymmetry in brightness in the ring can be explained in terms of relativistic beaming of the emission from a plasma rotating close to the speed of light around a black hole. We compare our images to an extensive library of ray-traced general-relativistic magnetohydrodynamic simulations of black holes and derive a central mass of $M = (6.5 \pm 0.7) \times 10^6 M_{\odot}$. Our radio-wave observations thus provide powerful evidence for the presence of supermassive black holes in centers of galaxies and as the central engines of active galactic nuclei. They also present a new tool to explore gravity in its most extreme limit and on a mass scale that was so far not accessible.' The introduction begins: 'Black holes are a fundamental prediction of the theory of general relativity (GR; Einstein 1915). A defining feature of black holes is their event horizon, a one-way causal boundary in spacetime from which not even light can escape (Schwarzschild 1916). The production of black holes is generic in GR (Penrose 1965), and more than a century after Schwarzschild, they remain at the heart of fundamental questions in unifying GR with quantum physics (Hawking 1976; Giddings 2017).'

What is "open access"?



Characterizing the Gravitational Wave Signal from Core-collapse Supernovae

David Radice^{1,2}, Viktoriya Morozova², Adam Burrows², David Hiroki Nagakura²

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Abstract

We study the gravitational wave (GW) signal from eight new 3D core-collapse supernova (CCSN) simulations. We show that the signal is dominated by f - and g -mode oscillations of the proto-neutron star (PNS) and its frequency evolution encodes the contraction rate of the PNS, which is known to depend on the star's mass, on the equation of state, and on transport properties in warm nuclear matter. A lower-frequency component of the signal, associated with the standing accretion shock instability (SASI), is also observed in the simulations. The signal is dominated by the f - and g -mode oscillations of the PNS, which are known to depend on the star's mass, on the equation of state, and on transport properties in warm nuclear matter. A lower-frequency component of the signal, associated with the standing accretion shock instability (SASI), is also observed in the simulations.

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Pharmaceutical companies, which fund approximately half of all biomedical research,¹ are now leaders in the publication and disclosure of research.^{2,3} However, access to much company-funded research is restricted by journal paywalls.⁴ We, as Open Pharma, a group of pharmaceutical companies and other research funders, alongside healthcare professionals, regulators, patients, publishers and other stakeholders in healthcare, recognize the importance of publishing research with open access, where papers can be read without payment of a one-off access charge or subscription. Open access ensures that the highest quality, peer-reviewed evidence is available to anyone who needs it, anywhere in the world. Publishing with open access improves transparency, advances medical science and, we believe, ultimately improves patient care.

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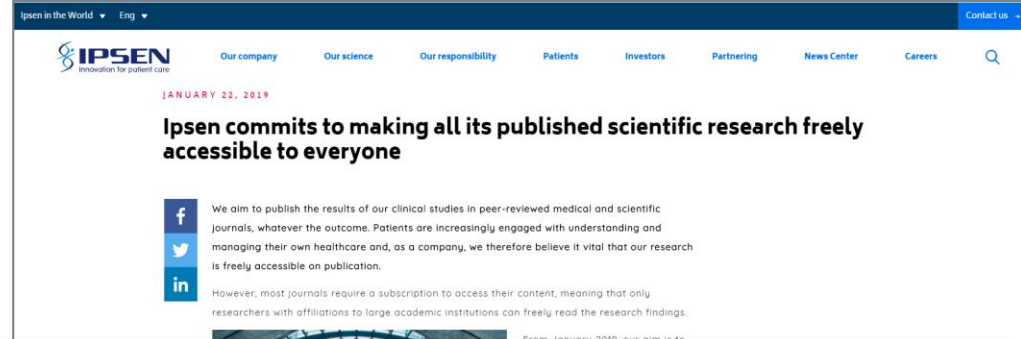
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Open access in pharmaceutical companies



- In January 2019, Ipsen committed to publishing all of its research 'open access'



- We are proud to be meeting this commitment
- **100%** of Ipsen-affiliated research has been published open access during the first half of 2019

“Patients cannot wait.”

David Meek
CEO, Ipsen

Acknowledgement

of patients' contributions



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non-drug therapy use (safety population), Table S3: Concomitant post-stroke medications by therapeutic class (safety population).

Author Contributions: Statistical analysis conducted by: P.M. Study concept and design: J.B., P.M., H.B., and R.L.R. Acquisition, analysis, or interpretation of data: J.B., P.M., and R.L.R. Writing and review of manuscript: R.L.R., J.B., H.B., P.M., K.J.G., W.K., M.M., L.A.L., M.M.D.D.S., C.C., P.T., O.N., and K.H.K.

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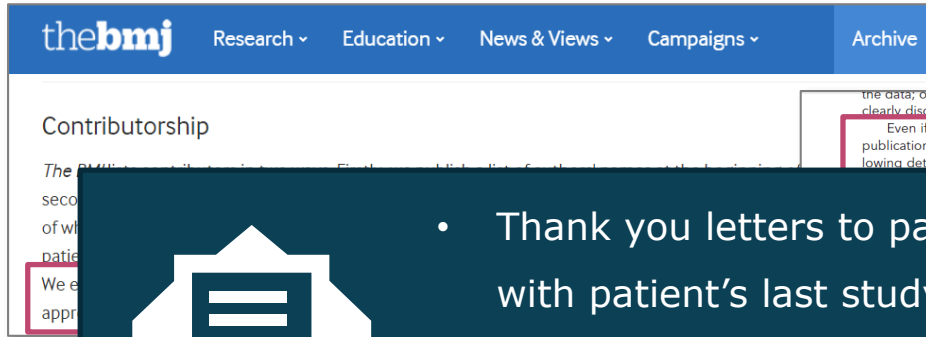
Conflicts of Interest: R.L.R., K.J.G., W.K., and K.H.K. have received consultancy fees from Ipsen. R.L.R. has

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1. BMJ website: <https://www.bmj.com/about-bmj/resources-authors/article-submission/authorship-contributorship> [accessed: 9 December 2019]
2. Battisti WP et al. *Ann Intern Med.* 2015;163:461-464 [accessed: 9 December 2019]
3. Rosales RL et al. *Toxins.* 2018; 10(7):253 [accessed: 9 December 2019]

Saying thank you

Acknowledging patients in publications:



GPP-3

- Thank you letters to patients/families coinciding with patient's last study visit
- Follow-up letter at study end, letting them know that the study is complete & the next development stage planned

Acknowledgments: All members of the ONTIME study group are authors on this paper. The authors thank all of the patients who participated in the ONTIME study and acknowledge the work of the study project managers at Ipsen, Marion Genoulaz and Elodie Blouquit, and the support of the clinical research organization, EPS. In addition, the authors thank Cassandra Hines, MSc and Catherine Jones of Watermeadow Medical, Macclesfield, UK for providing medical writing and editing support, which was funded by Ipsen Pharma, in accordance with Good Publication Practice (GPP3) guidelines.

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Plain language summaries

for publications



Plain language summaries for publications – why?



Beneficial for understanding – for everyone!

Supports discussions between HCPs and patients

Quicker to read than full manuscript

Overcome knowledge or language barriers

Democratises information

Plain language summaries: language matters!



Language in plain language summaries is important.
Words have different meanings in different contexts...

Word	Everyday interpretation	Scientific interpretation
Error/uncertainty	Mistake/lack of certainty	Deviation from true value
Significant	Important	Unlikely to occur by chance
Positive	Good	Greater than 0/Confirmatory
Theory	Hunch/speculation	Scientific understanding
Trial	Test/examination by judge	Medical study
Bias	Unfair prejudice	Systematic offset
Scheme	Unethical plot	Plan of action
Failure	0/10	Was not successful

Plain language summaries – a novel approach...

- Enlist the help of 9-year-olds...

CHRISTMAS 2017: LANGUAGE AND LITERACY

Santa's little helpers: a novel approach to developing patient information leaflets

Asking children to design information leaflets may improve patient understanding of surgical procedures, say **Catrin Wigley and colleagues**

Catrin Wigley *foundation year one doctor*¹, Vittoria Bucknall *speciality registrar*², Simon Fleming *speciality registrar*³

¹University Hospitals Coventry and Warwickshire NHS Trust, Coventry CV2 2DX, UK; ²Royal Infirmary of Edinburgh, Little France Crescent, EH16 4SA; ³Barts Health Whitechapel, London E1 1BB, UK

Obtaining valid consent before any intervention is a legal and ethical principle that underpins patient autonomy.¹ For consent to be valid, the patient must have received sufficient information and understood the nature and purpose of the procedure.²

Emphasis is placed on providing information in a variety of formats that is comprehensible and free from technical jargon, which the average patient cannot reasonably be expected to

Reading age of 9 years

This led us to ask the question, what does a reading age of 9 look like and how does it compare with the patient information leaflets in current use? To answer this question, we assessed the average readability of several patient information leaflets for one common orthopaedic procedure and then revised these leaflets with the help of a group of very bright and helpful

Plain language summaries – a novel approach...

- Enlist the help of 9-year-olds...

Total hip arthroplasty

Indications for the surgery

Mohammed: Because your hips are old and rotten. When you played football, it was weak and it broke. You told me you cannot walk. That is because it is old and you need to have hip surgery.

Jaime: Because yours is rotten. Because it's painful. Because you can't run and you want to be a sprinter. Because yours is wasting away like an old pair. It's past its sell by date.

Complications and risks

Mohammed: You can die!!!!!!

Emily: The bone could be put in badly. The replacement bone could be dirty, and you could get blood poisoning.

The procedure

Amber: Cut open the leg chop off bone, put metal in the bone, put cement in the leg, so the metal doesn't move.

Plain language summaries – a novel approach...

- Enlist t

Total hi

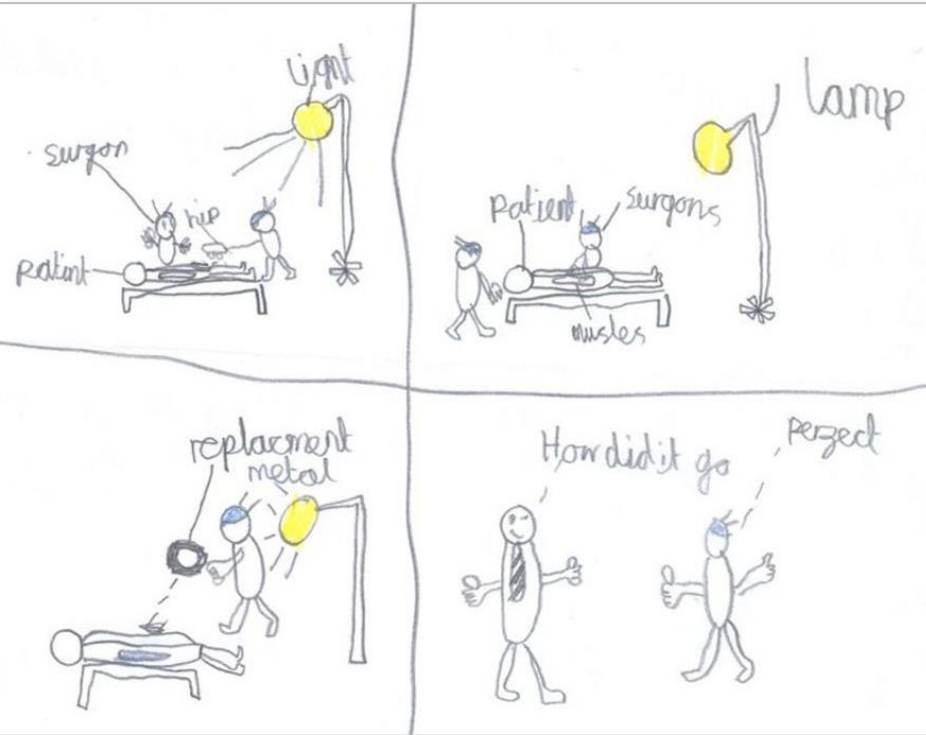
Indications

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The proce

Amber: Cut open
move.

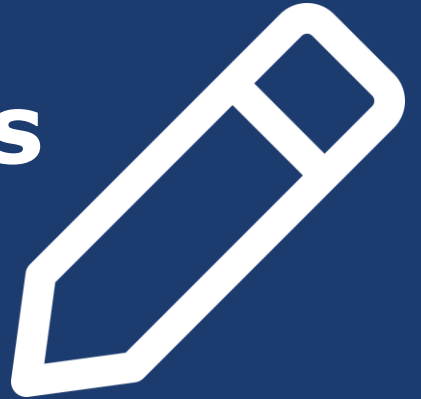


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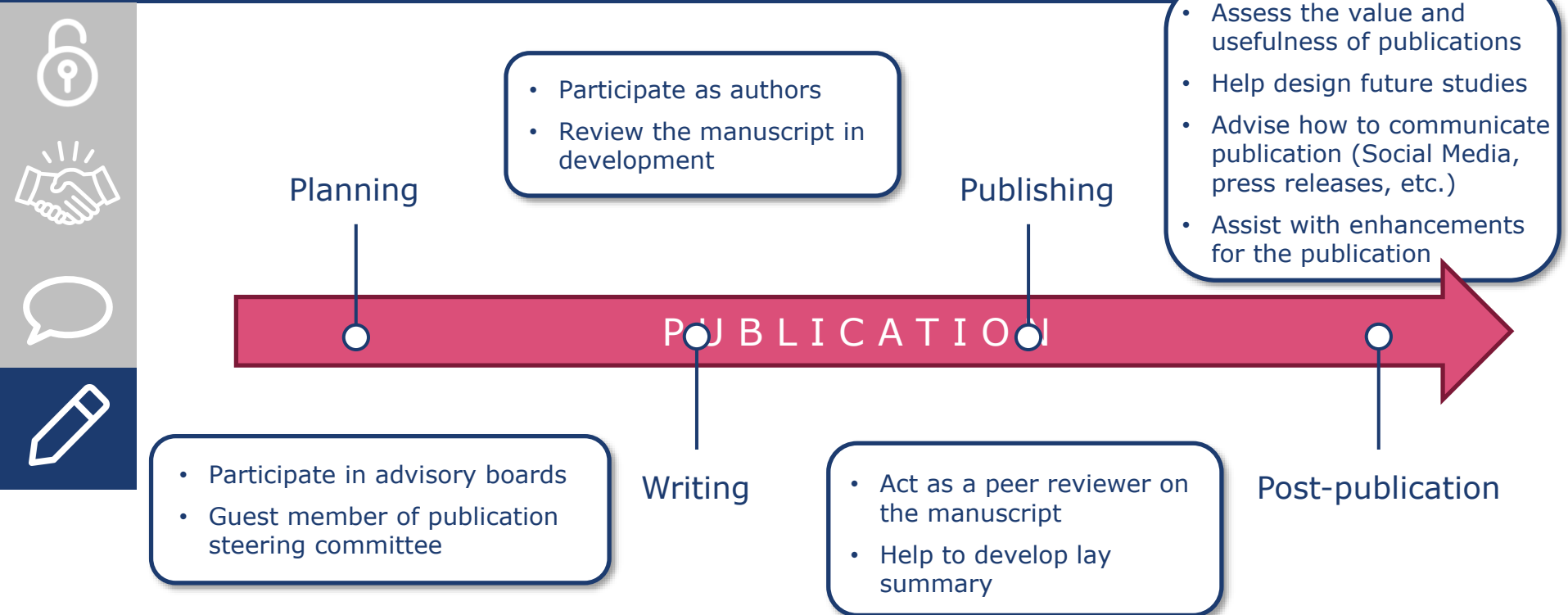
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Involvement of patients

in publications



Where could we include patients in the process?



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Clinical Development Team

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Thank you

Questions?