Patient Information Forum

# Open letter: A UK framework for safe AI-generated health information

**Dear Rt Hon Kanishka Narayan MP,**

We are writing as a coalition of health charities, professional bodies and healthcare providers who share a common concern about the rapidly growing use of generative artificial intelligence (AI) as a source of health information.

AI has significant potential to improve access to health information and support better health outcomes. However, its adoption is outpacing safeguards to ensure that people receive accurate, evidence-based and trustworthy information when making decisions about their health.

Use of generative AI for health information is increasing rapidly, with more than 6 in 10 users reporting that they use tools such as ChatGPT for health or wellness information. At the same time, 4 in 10 people report being exposed to inaccurate or misleading health information online. These trends underline both the opportunities and the risks associated with AI-generated health information and the need for a coordinated response.

The UK benefits from a strong ecosystem of trusted health information providers. AI should build on, rather than bypass, these trusted sources.

We urge the UK Government to lead the development of a UK-wide framework for safe AI-generated health information, ensuring that people are directed to trusted, evidence-based sources when seeking health advice online.

Specifically, we ask Government to:

- **Convene AI companies, the health system, regulators, patient organisations and the voluntary sector to agree minimum safety standards for AI-generated health information. This would include, but not be limited to:**
    - **Establishing a recognised verification framework for trusted UK health information sources, building on existing initiatives such as the PIF TICK.**
    - **Ensuring AI systems operating in the UK prioritise and reference verified NHS and UK-based accredited health information sources when responding to health-related queries.**
    - **Developing guidance on high-risk health topics where users should be directed to trusted information and support services rather than relying solely on AI-generated responses.**

    - **Requiring mandatory transparency measures, including appropriate warnings where health information is AI-generated and may contain inaccuracies.**

    - **Promoting effective signposting to NHS services, healthcare professionals and specialist support organisations for information and support where appropriate.**

- **Establish a framework to monitor and evaluate the impact of AI-generated health information on patient safety, public health outcomes and health inequalities.**

These measures would help realise the benefits of AI while ensuring that patient safety, public trust and evidence-based information remain at the centre of digital health innovation.

We stand ready to work with the UK Government, the health system, regulators and technology companies to develop and implement a shared framework that improves the safety, quality and trustworthiness of AI-generated health information.

Yours sincerely,

- **Claire Sadler - Chief Customer and Marketing Officer, British Heart Foundation**
- **Jo Harby - Director of Information and Involvement, Cancer Research UK**
- **Steven McIntosh - Chief Partnerships Officer, Macmillan Cancer Support**
- **Sam Royston - Executive Director for Research and Policy, Marie Curie**
- **Sue Farrington - Chair, Patient Information Forum**

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- Mona Khedr - Chief Operations Officer, AMPM Training
- Marcus Green - Interim CEO, AMR Action UK
- Kate Taylor - CEO, Amyloidosis UK
- Emilia Fulford-Dobson - Health Information & Services Officer, Anaphylaxis UK
- Tom Bishop - Head of Patient Information, Anthony Nolan
- Antonio Melechi - Health Information Manager, Arthritis UK
- Joann Leeding - Head of Information & Involvement, ARUK
- Raisa McNab - CEO, Association of Translation Companies (ATC)
- Mike McKevitt - Director of Services, Asthma + Lung UK
- Sue Millman - CEO, Ataxia UK
- Radostina Gancheva - Paediatric Diabetes Specialist Nurse, Barking, Havering and Redbridge University Trust Hospitals
- Rachel Yarham - Health Information Manager, Blood Cancer UK
- Silvia Kraft - Awareness and Policy Lead, Bone Cancer Research Trust
- Sarah Sweenie - Health Information and Evidence Manager, Bowel Cancer UK

- Will Jones - Chief Executive, brainstrust
- Helen Bulbeck - Director of policy and services, brainstrust - the brain cancer people
- Hilary Nathan - Director of Policy and Communications, Breakthrough T1D
- Alison Raven - Head of health information, Breast Cancer Now
- Professor Bryan Williams - Chief Medical Officer, British Heart Foundation
- Naomi Shefford-Thomas - Health Information Officer, CCLG: The Children & Young People's Cancer Association
- Peter Allen - Chair, CLL Support Association
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- Emma Austin-Lobley - Health Information Manager, Crohn's & Colitis UK
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- Alison Tebbutt - Health Information Lead, Epilepsy Action
- Andree Mayne - Education, Information & Support Services Manager, Epilepsy Society
- Knut Schroeder - GP and Founder, Expert Self Care Ltd
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- Gaynor Leech - Founder and Patient Advocate, L-W-O Community
- Colin Dyer - Chief Executive, Leukaemia Care
- Serena Deyal - Patient Information Writer, Leukaemia Care
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- Karen Friett - Chief Executive, Lymphoedema Support Network
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- Susanna Daniels - CEO, Melanoma Focus
- Tom Nutt - CEO, Meningitis Now
- Elaine Devine - Director of Communications and Engagement, Meningitis Research Foundation
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- Raphaelle Broughton - Publications Officer, Mind
- Sally Hughes - Director of Services & Partnerships, Motor Neurone Disease Association
- Andy Tattersall - Advocacy Coordinator, MPN Voice
- Ceri Smith - Head of Policy and Evidence, MS Society
- Lucy Taylor - CEO, MS Trust
- Emma Rushton - Director of Information and Services, Multiple System Atrophy Trust
- Emma Pellegrini - Head of Digital, Myeloma UK

- Peter Foxton - Chief Executive, National Rheumatoid Arthritis Society
- Karen Cockburn - Charity Director, Nerve Tumours UK
- Tracey Garbarino - Knowledge Support Manager, North Cumbria Integrated Care NHS FT
- Jenny Wordsworth - CEO, OVUM
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- Julia Hewer - Operations Executive, Peaches Womb Cancer Trust
- Jon Coleman-Reed - Head of Operations, Prevent Breast Cancer
- Nick Ridgman - Head of Support Services, Prostate Cancer UK
- Laura Stevenson - Deputy Chief Executive, Psoriasis UK
- Jo McNamara - Therapeutic Radiographer, Rad Chat
- Sarah Quinlan MBE - Charity Director, Radiotherapy UK
- Dom Horton - Information Lead, Rethink Mental Illness
- Sarah Thornton - Vice President, Royal College of Anaesthetists
- Amy Matthews - Health Information Manager, Royal Osteoporosis Society
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- Giles Lomax - CEO, Spinal Muscular Atrophy UK
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