dpo centre Life Sciences

Welcome to our Life Sciences newsletter!
A quick monthly read with useful information, articles, and views from our team of experienced DPOs on the latest data protection news specific to the Life Sciences.

LIFE SCIENCES IN THE NEWS

Drug trial transparency gap widens: most participants never see the results

A new study in *PLOS Medicine* journal examined 96 clinical trials to assess whether participants are routinely offered the results of the research they helped make possible. The findings are stark. Only around 8% of trials had a plan to share findings.

The authors argue that open science must go beyond publishing data. Returning results to participants in clear, easy-to-understand language shows respect for their involvement and strengthens trust. They urge sponsors and research teams to build result-sharing plans into trial design from the start by:

- Offering participants the choice to receive results
- Preparing accessible, plain-language summaries
- Allocating time, budget, and internal support needed for effective communications

Read the abstract

BLOG

Pseudonymisation under the GDPR: What the latest EU ruling means for organisations

A DPO'S PERSPECTIVE

WHO creates new forum to strengthen clinical trial transparency worldwide

Julian Marku, DPO at The DPO Centre, reflects on what the creation of the Global Clinical Trials Forum (GCTF) means for organisations working with health data, and the key factors for ensuring compliance with the General Data Protection Regulation (GDPR).

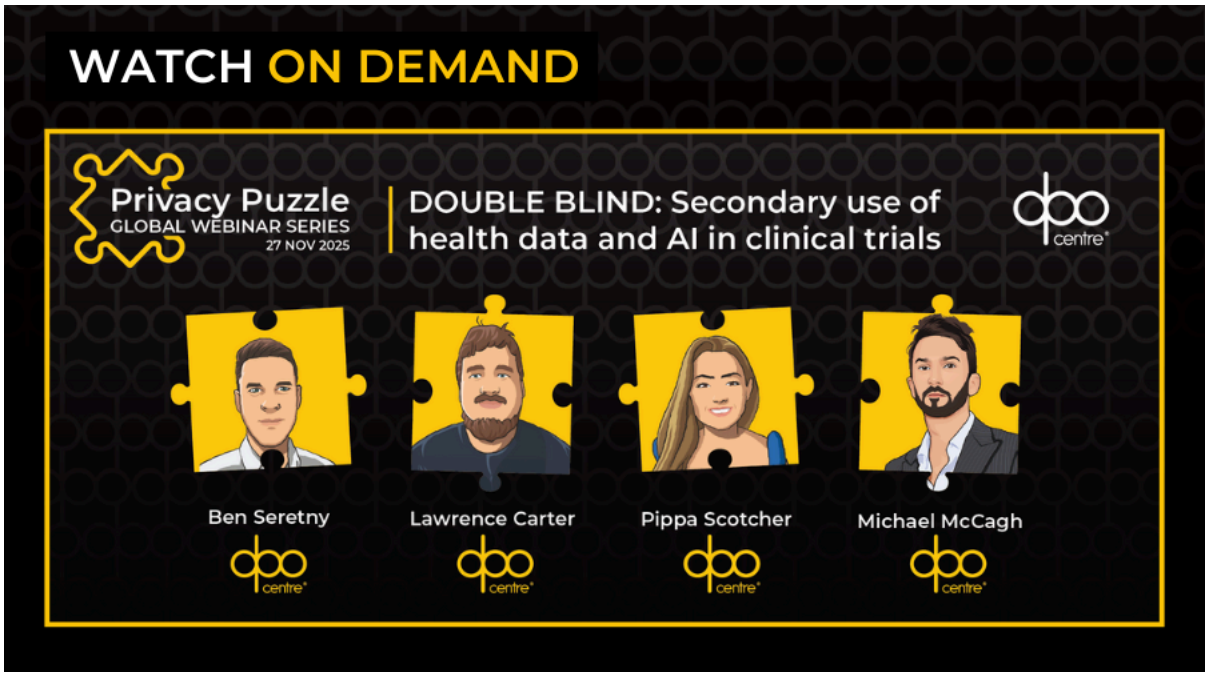
'Clinical trials operate in one of the most tightly regulated sectors in the world. The WHO's GCTF is designed to improve alignment across countries by creating a global space for regulators, industry, researchers, and patient groups to coordinate. However, while harmonising regulations could streamline processes and benefit stakeholders, organisations should stay alert to how countries translate Forum discussions into their own regulatory actions. Without careful coordination, it could lead to duplicated reporting or added administrative burden.

'The GCTF's focus on global data sharing also raises important GDPR compliance considerations, particularly around pseudonymisation (i.e. coded data), anonymisation, local legal requirements, and cross-border transfers of sensitive health data. To manage these risks, organisations need to maintain clear control over how participant personal data is processed, prevent scope creep, and define roles and responsibilities to ensure accountability across all parties. Questions remain about voluntary participation when trial data integrates with healthcare systems, and how informed consent should adapt.
'To ensure compliance with GDPR, organisations should:

- *Conduct Data Protection Impact Assessments (DPIAs) for major data-sharing initiatives and process changes*
- *Assess and map data flows to determine how data moves between all parties*
- *Apply privacy by design, including data minimisation, pseudonymisation, and strong security measures*
- *Define controller and processor roles for all trial stakeholders and implement clear Data Sharing/Processing Agreements*
- *Ensure transparency by informing participants how their data is processed, shared, and protected throughout its lifecycle*

- *Include DPOs or data protection subject matter experts at the beginning of a project or initiative'*

GLOBAL WEBINAR EVENT



For any data protection queries you may have, or for further information about how The DPO Centre can support your organisation, please contact us.

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