Privacy Notice - Research

Woodlands/Clerklands Partnership

Plain English explanation

This practice does not have any ongoing regular arrangements with research organisations who would request patient-identifiable. We will only agree to participate in any project if there is an agreed clearly defined reason for the research that is likely to benefit healthcare and patients. Such proposals will normally have a consent process, ethics committee approval, and will be in line with the principles of Article 89(1) of GDPR.

Research organisations may not approach patients directly but instead may ask us to make contact with suitable patients to seek their consent. Occasionally research can be authorised under law without the need to obtain consent. This is known as the section 251 arrangement[1]. One such organisation who have approval under the section 251 arrangement is the Learning Disabilities Mortality Review programme, also called the LeDeR programme. You can read more about this on their website: http://www.bristol.ac.uk/sps/leder/ We may also use your medical records to carry out research within the practice.

Most research organisations and programmes will contact you directly for your consent before approaching us to request any data. If we do share your data it will be with your explicit consent or when the law allows.

You have the right to object to your identifiable information being used or shared for medical research purposes. Please speak to the practice if you wish to object.

The practice does use a tool called PINCER to identify patients at high risk of harm from medication. The data processor for this tool is an organisation called PRIMIS. They do not under any circumstances take patient-identifiable data from the practice, just the number of patients highlighted by the PINCER tool. PRIMIS is responsible for this data which is held on a secure University of Nottingham server. More information is available about the PINCER project on the University of Nottingham website.

During the coronavirus pandemic, an organisation called UK Biobank has been authorised by the Secretary of State to extract data to enable research and planning during the COVID-19 pandemic. Data will only be extracted for patients who have consented to the process. The specific information regarding this process is as follows:

COVID-19 **Research and Planning**	**Purpose** – for the collection of personal confidential data regarding the diagnosis, testing, self-isolating, fitness to work, treatment, medical and social interventions, and recovery from COVID-19. To enable research and planning during the COVID-19 pandemic. **Legal Basis** - Notice under Regulation 3(4) of the Health Service (Control of Patient Information) Regulations 2002 (COPI), which were made under sections 60 (now section 251 of the NHS Act 2006) and 64 of the Health and

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	Social Care Act 2001. Data will only be extracted for those patients who have consented to the process. **Provider** - BioBank
1**) Data Controller** contact details	Woodlands & Clerklands Partnership Tilgate Way Tilgate Crawley RH10 5BW Tel: 01293 517092/01293 820833
2) Data Protection Officer contact details	Trudy Slade 07833 239618 / Trudy.slade@nhs.net
3) **Purpose** of the sharing	Medical research.
4) **Lawful basis** for processing or sharing	If in the future we participate in research, it will be according to one of the following legal justifications, depending on the research. This privacy notice will be updated to reflect that. Identifiable data will be shared with researchers either with explicit consent or, where the law allows, without consent. The lawful justifications are; Article 6(1)(a) **"**the data subject has given consent to the processing of his or her personal data for one or more specific purposes" or Article 6(1)(e) may apply "necessary for the performance of a task carried out in the public interest or in the exercise of official authority vested in the controller" or Article 9(2)(a) – 'the data subject has given explicit consent…' or Article 9(2)(j) – 'processing is necessary for… scientific or historical research purposes or statistical purposes in accordance with Article 89(1) based on Union or Member States law which shall be proportionate to the aim pursued, respect the essence of the right to data protection and provide for suitable and specific measures to safeguard the fundamental rights and interests of the data subject'. or Article 9(2)(h) – 'processing is necessary for the purpose of preventative…medicine…the provision of health or social care or treatment or the management of health or social care systems and services...'

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5) **Recipient or categories of recipients** of the shared data	The data will be shared with organisations who request the data; these will be known to the individual patients because they will have been contacted to assure their consent. We share information with the LeDeR Programme, which aims to support improvements in the quality of health and social care service delivery for people with learning disabilities and reduce premature mortality and health inequalities for people with learning disabilities. This is under section 251, so sharing information is authorised under law without needing to seek individual patient consent.
6) **Rights to object**	You do not have to consent to your identifiable data being used for research. You can change your mind and withdraw your consent at any time. Contact the Data Controller or the practice.
7) **Right to access and correct**	You have the right to access any identifiable data that is being shared and have any inaccuracies corrected.
8**) Retention period**	The data will be retained for the period as specified in the specific research protocol(s).
9) **Right to Complain**.	You have the right to complain to the Information Commissioner's Office. To do so, you can use this link https://ico.org.uk/global/contact-us/ or you can call their helpline Tel: 0303 123 1113 (local rate) or 01625 545 745 (national rate) There are National Offices for Scotland, Northern Ireland and Wales (see ICO website for details)

1, Section 251 and the NHS Act, Health Research Authority.
https://www.dropbox.com/s/sekq3trav2s58xw/Official%20Section%20251%20guidance%20Health%20Research%20Authority.pdf?dl=0