Primary care **M**anagement of lower **U**rinary tract **S**ymptoms in men: Development and validation of a diagnostic and decision-making aid.

Further information sheet: In compliance with the General Data Protection Regulation 2018 (EU 2016/679)

This additional document contains important information on the GDPR (EU) 2016/679 and what this means for your involvement in the PriMUS Study.

All members of the study team and regulatory authorities are trained in data protection issues. They are also bound by the terms of the General Data Protection Regulation (GDPR) (EU) 2016/679.

Who is responsible for looking after my information?

Cardiff University is the sponsor for this study based in the United Kingdom. We will be using information from you and/or your medical records in order to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly. Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally-identifiable information possible.

You can find out more about how we use your information https://www.cardiff.ac.uk/public-information/policies-and-procedures/data-protection

As a University we use personally-identifiable information to conduct research to improve health, care and services. As a publicly-funded organisation, we have to ensure that it is in the public interest when we use personally-identifiable information from people who have agreed to take part in research. This means that when you agree to take part in a research study, we will use your data in the ways needed to conduct and analyse the research study. Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally-identifiable information possible.

Health and care research should serve the public interest, which means that we have to demonstrate that our research serves the interests of society as a whole. We do this by following the UK Policy Framework for Health and Social Care Research.

If you wish to raise a complaint on how we have handled your personal data, you can contact our Data Protection Officer who will investigate the matter. If you are not satisfied with our response or believe we are processing your personal data in a way that is not lawful you can complain to the Information Commissioner's Office (ICO).

Our Data Protection Officer is Matt Cooper and you can contact them at Cooperm1@cardiff.ac.uk.

Will all my information be kept confidential?

Cardiff University will use your name, date of birth and contact details to contact you about the research study, and make sure that relevant information about the study is recorded for your care, and to oversee the quality of the study. Individuals from Cardiff University and regulatory organisations may look at your research records to check the accuracy of the research study. The only people in Cardiff University who will have access to information that identifies you will be people who need to contact you to collect more information, take part in a qualitative interview, send you a shopping voucher, the results of the study or to audit the data collection process. The people who analyse the information will not be able to identify you and will not be able to find out your name, or contact details.

Cardiff University will keep identifiable information about you securely, for a minimum of 15 years after the PriMUS study has finished. This is in line with Cardiff University policies.

Cardiff University will collect information about you for the PriMUS Study from your GP Practice medical records. Your GP Practice will not provide any identifying information about you to Cardiff University. We will use this information to follow up the treatment and management of your Lower Urinary Tract Symptoms following your involvement in the PriMUS Study.

Is my data likely to be used for future research?

When you agree to take part in a research study, the information about your health and care may be provided to researchers running other research studies in this organisation and in other organisations. These organisations may be universities, NHS organisations or companies involved in health and care research in this country or abroad. Your information will only be used by organisations and researchers to conduct research in accordance with the UK Policy Framework for Health and Social Care Research.

This information will not identify you and will not be combined with other information in a way that could identify you. The information will only be used for the purpose of health and care research, and cannot be used to contact you or to affect your care. It will not be used to make decisions about future services available to you, such as insurance.

Should you have any further questions or require further information about taking part you can contact (during normal working hours):

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