Privacy Policy for BETA Study

QIB is the Sponsor for this study based in the United Kingdom. For any (personal) information collected from participants and/or their medical records to undertake this study, QIB will act as the data controller. This means that we are responsible for looking after their information and using it properly. QIB will keep identifiable information about the participants for 15 years after the end of the study in a secure archive at the QIB or designated secure off-site location. The participants rights to access, change or move their information are not affected, as we need to manage their information in specific ways for the research to be reliable and accurate. If the participant withdraws from the study, all personal and identifiable data will be removed, but fully anonymised study data and samples already collected with consent will be retained and used in the study. No further data or samples will be collected, or any other research procedures carried out in relation to the participant.

All information collected about the participant during this study will be kept strictly confidential. We follow Ethics and Research Governance and Good Clinical Practice (GCP) requirements. The collection, storage, processing, and disclosure of the study data will be managed by the study team in adherence with EU General Data Protection Regulation (GPDR) and UK Data Protection Act 2018, with regards to the collection, storage, processing and disclosure of personal information and will adhere to the GDPR and DPA core principles to maintain confidentiality.

The legal bases used under the regulation that we employ to process the participant's personal information is for tasks carried out in the public interest, which this study and associated research is. Their personal information will be stored in lockable filing cabinets at the QIB. Suitable security measures and precautions are also taken for any confidential or personal data process or stored electronically. Their data will be pseudo-anonymised with a unique, study-specific code which cannot be linked to the participant and is stored on a password-protected data file. All biological samples collected will be known by the assigned code.

The trial has a study specific email address (BETA@quadram.ac.uk) and specific contact number (07733 699117), that the research team will use for recruitment purposes and for study-related correspondence with the research participants. The study email address will be a shared QIB account with restricted access to the research team only. We will include an automatic management (timely deletion) of emails and phone logs to ensure participant data protection.

During the study, the participant will be asked to use external services to record study information. The accounts will be created for the participant (as per the process described above). The data collected from the blood samples will be identifiable by the NNUH team at the QI CRF and will be transferred from NNUH Pathology department to QIB for analysis. The data collected from the questionnaires, with no personal or identifiable information, will be transferred to a third party (outside of the EEA) to be analysed by the University of Arizona or the company Viocare®. All the data collected from the questionnaires by will be kept anonymous (no personal identifying information), so the data will not need to be stored on an EU server and no data management agreements are required.

If the participant was to enrol onto the remote study protocol, the additional external service provided by Medichecks® will be used. The kits provided will be sent to QIB's address from Medichecks®, and the study team will process and send the kits to the participant's address with their unique study code. Due to the nature of the service, the participant's age and gender will be shared with Medichecks®. All data are pseudo-anonymised to the study team

and anonymised to Medichecks®. A data management agreement in place from Medichecks® can be found at https://medichecks.com/pages/practitioner-terms-and-conditions. Further information on how Medichecks® handle/process their data can be found via their privacy policy at https://medichecks.com/pages/privacy-policy.

The results of the study including analysed are expected to be published, fully anonymised, for use by the wider scientific community.

To safeguard the participants rights, we will use minimum personally identifiable information possible. A NBI Data Protection Adviser (dpa@nbi.ac.uk) has reviewed the proposed system in terms of adherence with EU GDPR/UK DPA 2018.