Introduction

The Saudi Human Genome Program (SHGP) is a national program for the identification of disease-associated variants for rare and common diseases. The ultimate objective of this endeavor is to create a national database for genetic variants at KACST and to make this information available for the national and international scientific community. This database in combination with other knowledge bases will pave the way for the application of personalized medicine in daily clinical practice. In addition to its scientific value, the SHGP is expected to have a significant impact on the improvement of healthcare services in the kingdom.

The SHGP is funded and managed by King Abdulaziz City for Science and Technology (KACST). KACST has a central Next Generation Sequencing and bioinformatics facility. In addition, KACST supports the establishment of different satellite labs in participating institutions to collectively achieve targets of the program.

This document is an agreement between KACST and the satellite lab institution. It is an extension of the MOU signed by the participating institutes.
Agreement Terms

KACST Commitments:

- KACST provides Equipment for Next Generation Sequencing and analysis.
- KACST provides the maintenance and technical support to facilitate operation of the satellite laboratory.
- KACST provides training of the satellite laboratory team recruited by the participating institution to assure high quality of sequencing and data analysis.
- KACST provides scientific and technical consultations for the formulation medical questions, experimental design, genome sequencing and data analysis.

Commitments of the Participant Institute:

- The participating institution provides the necessary space to host the lab, related reagents and Internet access for connection of the satellite laboratory to the central databases in KACST.
- The satellite laboratory should be named "KACST Laboratory for the Saudi Human Genome Program".
- The participating institution provides/recruits a local team for genome sequencing, Information Technology, and clinical/project coordination.
- The participating institution uses the equipment for achievement of goals and objectives of the Saudi Human Genome Program and to establish the centralized variants database hosted by KACST.
The team of the participating laboratory should submit proposals to specify and justify the purpose and the scale of the sequencing activities undertaken. Financial support, including DNA sequencing kits, will be sent to the laboratory only after approval of the proposal(s). The KACST scientific team is ready to provide necessary support and consultation towards the preparation of solid proposals.

The delivered equipment (sequencing and IT) and kits are the property of KACST and may be restructured or relocated only by KACST as per the requirements of the program. KACST will be solely responsible for all maintenance and upgrades.

The participating institution should provide all ethical approvals for each submitted proposal from the relevant committees in charge in accordance with the National Committee.

Subject to KACST’s policies and procedures, sample associated data including sequence generated by the Saudi Human Genome Program will be deposited in a central database in KACST. The confidentiality of this data will be maintained by KACST and the submitting PI, with the following exceptions. This data will be made exclusively available to the PI submitting samples for a period of 6 months from generation. All data generated by the SHGP will be collated and made openly available for academic purposes 12 months after generation. The central database in KACST will be owned and managed exclusively by KACST and licensed or provided as appropriate for non-academic use including but not limited to diagnostics exclusively at the discretion of KACST.

The participating institution submits progress reports to KACST twice a year and cooperates with KACST reviewers and auditors.
Representatives of the satellite laboratory should attend major program meetings.

- All publications based on this collaboration and accessing ANY resources of the Saudi Human Genome Program including sequencing infrastructure, IT resources and databases should include the following:

  - Include explicit acknowledgement of KACST and the Saudi Human Genome Program
  - Automatic affiliation of investigators to "KACST, Saudi Human Genome Program", as a primary or secondary affiliation.
  - Include scientists and researchers from the Saudi Human Genome Program as co-authors based upon standard academic practice for scientific collaboration and contribution.

مع المدينة يخصص المراقبة والتفتيش. وكذلك يحضر ممثلين عن المشاريع الأساسية للبرنامج.

- كل résultat العلمي الناتج من خلال العمل أو الذي يتضمن استعمال أي إمكانيات البرنامج الجينوم البشري السعودي بما في ذلك أجهزة الترميز أو قواعد البيانات أو القدرات الحاسوبية يجب أن يتضمن الآتي:

  - أن يحتوي على جملة عرفان برنامج الجينوم البشري السعودي
  - أن يضم بيان إتمام كل إعفاء الفريق من العمل الفرعي لمشروع الجينوم البشري السعودي (مدينة الملك عبد العزيز للعلوم والتقنية) كإتمام أولي أو ثاني بعد الالتمام للجهة الأم.
  - أن يضم أسماء الباحثين والعلماء المشرفين على بنية الترميز وتحليل المعلومات كمؤلفين مشتركون وذلك طبقا لما هو معروف عليه من قواعد الممارسة العلمية والعمل العلمي المشترك.

التوقيع

الجهة المتعاونة ومن يمثلها

رئيس مدينة الملك عبد العزيز للعلوم والتقنية

د. تركي بن سعود بن محمد آل سعود

المستشار العام التنفيذي على المؤسسة العامة لمستشفى الملك فيصل التخصصي ومركز الأبحاث في مدينة الرياض

د. قاسم بن عثمان القطبي