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<http://www.kingstonhsc.ca/research>

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SERVICES OF DECISION SUPPORT FOR RESEARCH

KHSC's Decision Support Department offers services for researchers, research staff, students, and trainees who are seeking potential patients (participants) or data for their research project. Data sources that this department use include, but are not limited to, the KHSC Patient Care System (PCS), the Canadian Institute for Health Information (CIHI) database (national, provincial, and local data), the Discharge Abstract Database (DAD) (Inpatient Data), the National Ambulatory Care Reporting System (NACRS), and the Operating Room Scheduling Office System (ORSOS). Examples of research data needs with which Decision Support can assist are:

- **Patient Population Size**

If you would like to know whether a particular patient population exists in our geographical area, Decision Support can provide the number of patients who meet your eligibility criteria, from which you can calculate the appropriate sample size. This service is useful when determining whether your site is feasible for participation in an upcoming clinical trial, completing a grant application, or simply determining if you can find suitable candidates for your newly developed research project. HSREB clearance and TRAQ DSS approval are not required for this type of inquiry.

- **Extracting a List of Potential Patients to Contact**

If you need to recruit participants for your research study, Decision Support can provide you with a list of patients who match the patient population/eligibility criteria for your research study, and who have not withdrawn consent for contact for research purposes. Your research study must have been cleared by the HSREB and also approved by Decision Support through the TRAQ system (TRAQ DSS form) prior to the release of the list. You may then use PCS in order to view the electronic patient records, or request paper records from the Medical Records Department as outlined above if needed.

- **Extracting Data from PCS**

If you need assistance with extracting a large data set from PCS or other data sources as outlined above, Decision Support can pull data for patients who have not withdrawn consent for research purposes. Your research study must have been cleared by the HSREB and also approved by Decision Support through the TRAQ system (TRAQ DSS form) prior to the release of the data set.

HOW TO REQUEST RESEARCH DATA FROM DECISION SUPPORT

For all research data requests, please use the *Decision Support Data Request Form* available on the KHSC Intranet at

<http://mykgh/DSDR/SitePages/NewRequests.aspx>, ensure that you select “Research” for “Purpose of Data Request”, then provide details in all fields. All requests for record level data or low level aggregate data (any cells less than 5 cases) for the purpose of research will require HSREB clearance, TRAQ DSS form approval, and the version of your variable list or spreadsheet that was cleared by the HSREB. For TRAQ DSS form approval, please select KGH-Decision Support and/or HDH-Decision Support on the Approvals tab.

If you change the parameters of your data request beyond your HSREB clearance, you are required to submit an amendment to your HSREB application and an event to your TRAQ DSS form application.

If you would like to ensure the feasibility of your planned request for data, please contact decisionsupport@kingstonhsc.ca in advance of applying for funding/submitting to HSREB. Please include a brief description of your research project, the specific patient population of interest and your specific data needs. If your study is feasible, please ensure the steps above are followed.

Please see below for the flowmap: **Pathways to Decision Support Services for Research** for an illustration of the process above.

Please note:

All hospital and non-hospital researchers who are given access to data from Decision Support are bound by the KHSC Statement of Confidentiality as per KHSC’s Health Research policy 11-150, and are responsible for de-identification of any data received from Decision Support. Data will be sent from Decision Support to KHSC email addresses only. Data will not be sent to Queen’s or other non-KHSC email addresses. All non-hospital researchers are required to be credentialed through KHSC’s Research Hospital Appointment process and obtain a KHSC email address in order to receive data from Decision Support. For more information about the Research Hospital Appointment process and computer access at KHSC, please see “Research Roadmap: Research Hospital Appointments” and “Research Roadmap: Computer Access at KHSC”.

Any actual or perceived breach of privacy if associated with research must be reported immediately to the Queen’s HSREB (or central REB (CTO/OCREB)) **and** to the KHSC’s Privacy Office at:

Andrew Rogers
Privacy Officer (KHSC)
(613) 549-6666 ext. 6640
privacy@kingstonhsc.ca

Dr. Albert Clark
Chair of Queen’s HSREB
1 (844) 535-2988 (Toll free in North America)
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PATHWAYS TO DECISION SUPPORT SERVICES FOR RESEARCH

