

# Measuring the Patient's View of the Queue: Challenges and Strategies for Collecting Patient Reported Outcomes Data for Waitlisted Surgical Patients

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## Introduction:

There is little understanding of how surgical wait times are associated with better clinical outcomes. Moreover, patient care metrics often look at outcomes like mortality and morbidity, but neglect to capture the patient's perception of the impact of their condition on their daily life, as well as the impact of their surgery. Patient satisfaction feedback is routinely gathered by health service providers, but these surveys focus primarily on the interactions of the patient with care providers and the various parts of the health care system, and not on health outcomes.

Vancouver Coastal Health (VCH) and the University of British Columbia (UBC) have partnered on the project entitled "Value and Limitations in Hospital Utilization and Expenditures (VALHUE)" to quantify the effects of waiting for surgical care by collecting and analyzing patient reported outcome measures (PROMs). VCH is responsible for the data collection, while UBC is responsible for the data analysis and research.

Selected challenges to collecting PROMs data:

1. How do we ensure that the project is relevant to policy and practice?
2. How do we access patients with the support of the surgical community?
3. Given the quality improvement (QI) mandate of VCH and the research mandate of UBC, how do we design a survey protocol that will pass legal, privacy, and ethics reviews?

## Results:

Figure 1: Building an effective partnership between researchers and decision-makers for knowledge translation

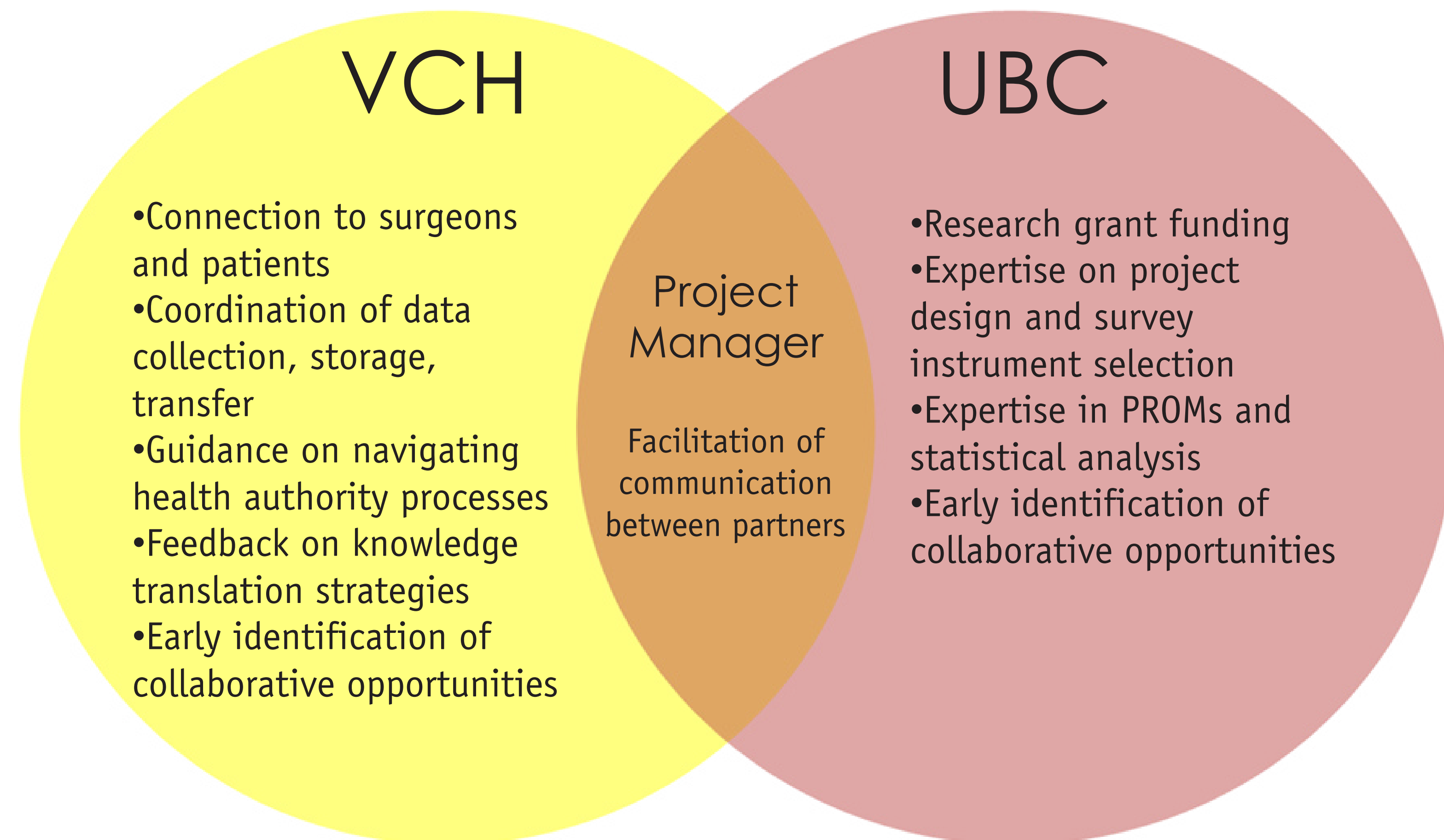


Figure 3: Participating Sites, Surgeons, and Services

Sites	Surgeons	Services
Providence Health Care (St. Paul's Hospital and Mount St. Joseph's Hospital)	11	Urology, ENT, Plastics, *Orthopaedics, *General Surgery
Richmond Hospital	10	Urology, *General Surgery, *Gynecology
Lions Gate Hospital	9	Urology, Gynecology, General Surgery
Vancouver Acute (Vancouver General Hospital and UBC Hospital)	7	Urology, ENT, *Plastics, General Surgery, Neurosurgery
<b>Total: 6 sites, 7 services, 37 surgeons, ~130 elective surgical procedures</b>		
*We also have two spin-off PROMs projects in progress, which developed out of conversations with these participating VALHUE surgeons. These new collaborations help to ensure the relevance of our current and future projects and represent valuable relationships on which to build knowledge translation efforts.		

## Conclusions:

- An important part of knowledge translation is building a relationship between the parties, so that needs and interests are mutually understood and acted upon to the degree possible. Part of the success to date of VALHUE's PROMs data collection is the *integrated partnership* between UBC and VCH; the partners collaborated early in the project design, built support among stakeholders together, and facilitated honest and timely communication with each other with a shared project manager.
- *Stakeholder engagement early in the project's development* is critical to obtaining access to patients. *Continued stakeholder engagement* demonstrates a genuine interest in making the findings useful to clinicians and decision-makers, and also uncovers opportunities for new collaborations and relationship building.
- The divide between quality improvement and research can become unclear when health authorities and scholars partner on a project. The divide is important because it will greatly influence project protocols, project administration, and potentially, response rates. *Legal counsel, privacy officers, and ethics boards should be consulted* to confirm the appropriate protocols and to redefine the roles of partners, if necessary, to simplify project administration and promote patient participation.

## Methods and Approach:

- We developed a *partnership* between the decision-makers and practitioners (VCH) and the researchers (UBC). The partners sought to understand each other's needs and interests, and respond to them with appropriate expertise and resources. We collaborated on the project's concept at the outset, hired a Project Manager dedicated to VALHUE with responsibilities to both partners, and ensured fluid communication between partners.
- We generated *operational and clinical buy-in* by presenting our project to as many surgical services directors, surgeons, departments of surgery, and regional surgical council members, as possible. Due to the schedules of these stakeholders and the nature of discovering and navigating the network of stakeholders, these meetings were held over the course of a year.
- VCH collected the PROMs data as part of its regular quality improvement (QI) mandate. UBC analyses the PROMs data for research purposes. QI and research projects are subject to different privacy laws and ethics reviews, with implications on how patients are recruited. We consulted VCH's legal counsel, privacy office, and UBC's research ethics board on multiple occasions – and ultimately held a joint meeting among all parties – to obtain agreement on an appropriate survey protocol, which would not only meet legal, privacy, and ethical standards, but also simplify survey administration and encourage patient participation.

Figure 2: The roads to building stakeholder support: roadblocks, detours, and breakthroughs (January 2012-February 2013)

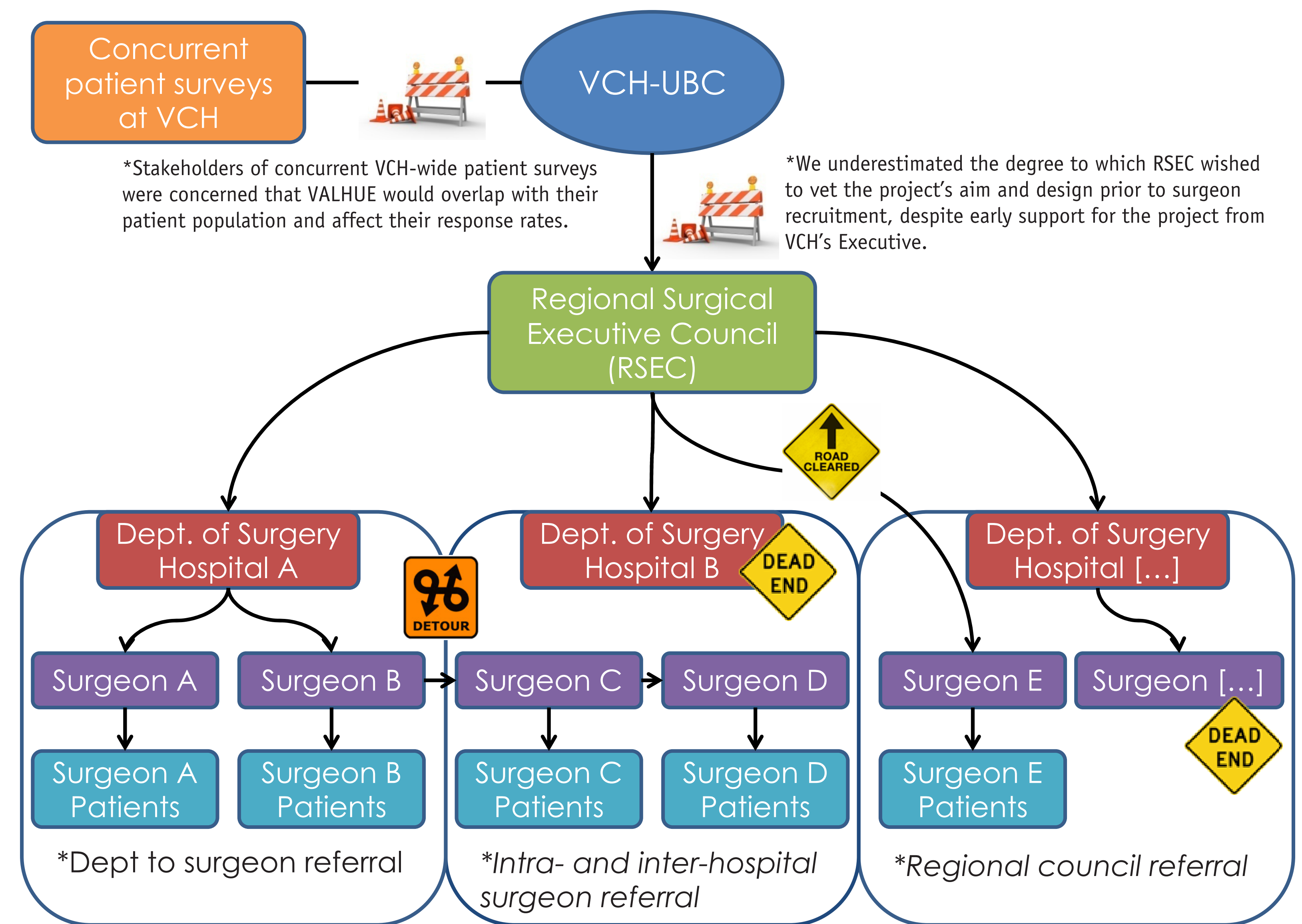
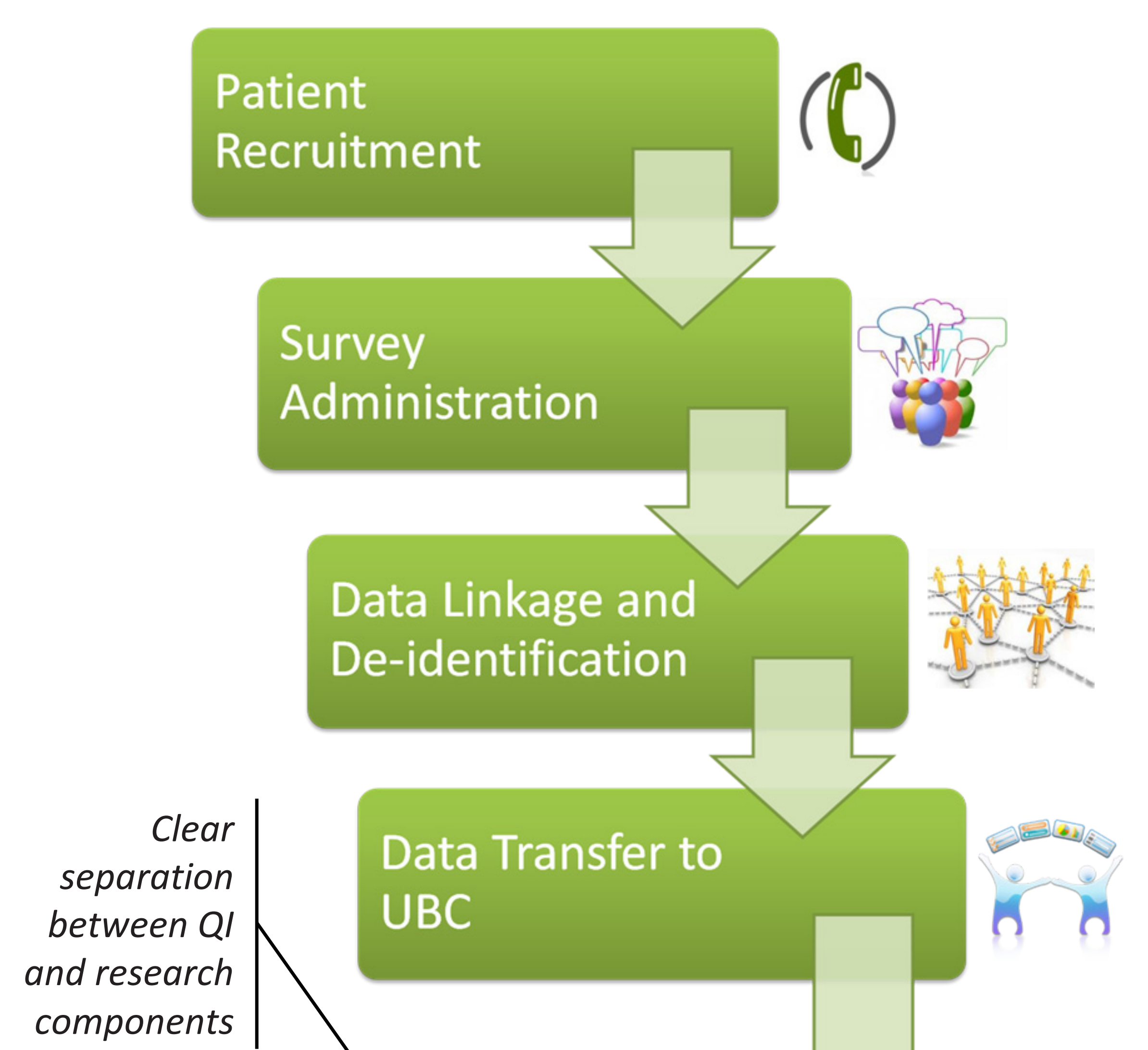


Figure 4: Satisfying legal, privacy, and ethical requirements through a clear separation of tasks – the final protocol

## VCH Quality Improvement (QI) Component



## UBC Research Component



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## Further information:

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