Ten years of a community based participatory research program to address the high rate of Long QT Syndrome in First Nations of Northern BC

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In 2004 the representatives of the Gitxsan Nation in Northern British Columbia (BC) requested that researches from the University of British Columbia (UBC) meet to discuss the high rate of Long QT syndrome (LQTS), an inherited disorder predisposing to sudden cardiac arrest. Discussions commenced, and a special advisory group consisting of local health care providers, community members and the Gitxsan Health Society began their work together with the researchers to address this health care priority. Research questions and methods were developed together, and the concept of 'DNA on Loan' was agreed upon to ensure that genetic material was considered part of the participatory process. DNA was considered to be on loan to the researchers specifically for LQTS research, and could be returned to the participant if requested. In addition all research steps, and changes in protocol would be discussed with the Gitxsan Health Society and as well, all manuscripts before publication would be reviewed. Participants would be updated with progress both by regular public presentations and newsletters. To date, more than 700 participants have enrolled. The causative genetic factor, the V205M mutation in KCNQ1 (known to cause LQTS) was discovered and confirmed to predispose to abnormal heart rhythm. More than 125 individuals have been found with the mutation, and clinical care has been put in place locally. Specific times in life have been determined as riskier than others, such as for women of childbearing years, but reassuring to see that children seem to have minimal effects. Further studies are underway to determine if minor genetic factors increase or decrease risk, and whether chronic disease influences outcomes. Ten years later, the on-going relationship between the community and the researchers remains strong. The merits of 'continuous conversation' will be discussed and may be useful for others as they embark on community based participatory methodologies.

References
