



Evaluation

*of the Diabetic
Retinopathy Remote
Screening Pilot Project
among Quebec
First Nations*



FIRST NATIONS OF
QUEBEC AND LABRADOR
HEALTH AND SOCIAL
SERVICES COMMISSION

Drafting team

Update: April 2013

Jacinthe Briand-Racine, FNQLHSSC
Benoît Éthier, FNQLHSSC
Émilie Grantham, FNQLHSSC
Josiane Perreault, FNQLHSSC

Research team

Jacinthe Briand-Racine, FNQLHSSC
Benoît Éthier, FNQLHSSC
Émilie Grantham, FNQLHSSC
Nancy Gros-Louis McHugh, FNQLHSSC
Josiane Perreault, FNQLHSSC
Marie-Claude Raymond, FNQLHSSC

Evaluation working group

Serge Desrosiers, FNIHB-QC
Jean-Paul Fortin, *Université Laval* and *Direction de la santé publique de l'Abitibi-Témiscamingue*
Catherine Power, FNQLHSSC
Jennifer Presseault, Eagle Village Health Centre
Sophie Picard, FNQLHSSC
Louise Tanguay, FNQLHSSC
Jacques Thibault, *Ministère de la Santé et des Services Sociaux*

Other collaborators

Louise Boyer, FNIHB-QC
Michelle Deschamps, FNIHB-QC
Sandro Échaquan, Manawan Health Centre

Graphic design and page layout

Chantal Cleary and Anne P. Savard, FNQLHSSC

The unabridged version of this document is available on the FNQLHSSC's website located at: www.cssspnql.com.

The appendices of this report are available in the document entitled *Evaluation of the Diabetic Retinopathy Remote Screening Pilot Project among Quebec First Nations - Appendices*.

© Intellectual property of the FNQLHSSC

© FNQLHSSC - 2013

Legal deposit – 1st trimester of 2013

Bibliothèque nationale du Québec

Library and Archives Canada

ISBN: 978-1-926553-56-6

ACKNOWLEDGEMENTS

This evaluation would not have been possible without the precious collaboration of the communities that participated in the pilot project: Eagle Village, Timiskaming, Winneway and Wolf Lake.

We would like to express our sincere appreciation to everyone who participated in this evaluation: the health directors, workers, service users, members of the evaluation working group and the various partners and collaborators of the project such as RUIS McGill, the Algonquin Nation Programs and Services Secretariat (ANPSS) and Health Canada's First Nations and Inuit Health Branch, Quebec Region (FNIHB-QC). We would also like to thank the *Laboratoires de la rétine RD* for their contribution to performing the economic analysis of the project, as well as two other collaborating communities, Wemotaci and Listuguj.

The diabetic retinopathy remote screening pilot project was made possible thanks to the financial contributions of Canada Health Infoway and FNIHB-QC.

This evaluation of the pilot project became a reality thanks to the financial contribution from FNIHB-QC.



SUMMARY

The diabetic retinopathy (DR) remote screening pilot project was implemented in 2010 in four Algonquin (Anishinabeg) communities of Quebec: Eagle Village, Timiskaming, Winneway and Wolf Lake (screening offered in Eagle Village). One of the objectives of this pilot project was to offer a DR remote screening service to community members while reinforcing the service corridors with the Quebec health network, thereby allowing for the provision of follow-up and care for diabetic patients.

This evaluation was conducted in four components: the evaluation of the relevance, the evaluation of the implementation, the evaluation of the short-term effects and the economic analysis of the project. Thanks to the evaluation of the relevance, the observation was made that the communities that were selected for the pilot project benefitted from profiles that were sufficiently adequate to implement the new service. The evaluation of the implementation demonstrates that collaboration between the project partners as well as the training provided are key elements. The evaluation of the short-term effects highlights that the community workers and users are satisfied with the new screening service and have perceived numerous benefits. Finally, the economic analysis of the pilot project reveals that the financial and societal costs associated with the DR screening are diminished when the service is provided within the communities.

In light of these observations, various lessons learned and recommendations are presented with the objective of improving the implementation of the project, but also the implementation of other services offered by the community health centres through telehealth.



TABLE OF CONTENTS

Chapter 1 - Introduction.....	1
Chapter 2 - Context.....	5
2.1 The First Nations of Quebec.....	5
2.2 Diabetes.....	5
2.2.1 Diabetes among the First Nations.....	6
2.3 Diabetic retinopathy.....	7
2.4 The screening of diabetic retinopathy.....	9
2.4.1 The screening of diabetic retinopathy through telehealth.....	9
2.5. The costs and benefits of telehealth.....	11
Chapter 3 - Pilot Project.....	13
3.1 The objectives of the diabetic retinopathy remote screening pilot project.....	13
3.2 The implementation phases of the project.....	14
3.3 The role of the partners involved in the diabetic retinopathy remote screening pilot project.....	17
3.3.1 The role of the First Nations of Quebec and Labrador Health and Social Services Commission.....	17
3.3.2 The role of the Algonquin (Anishinabeg) communities of Eagle Village (Kipawa), Timiskaming, Winneway (Long Point) and Wolf Lake.....	17
3.3.3 The role of the Algonquin Nation Programs and Services Secretariat.....	18
3.3.4 The role of the First Nations and Inuit Health Branch – Quebec Region and Canada Health Infoway.....	18
3.3.5 The role of the evaluation working group.....	19
3.3.6 The other partners that participated in the implementation and application of the project.....	19
3.3.7 Committees and working groups created for the development and implementation of the project.....	19
3.4 The team responsible for the screening service in the communities.....	22
3.5 The diabetic retinopathy screening process in the context of the pilot project.....	23
3.5.1 Screening invitations and setting appointments.....	23
3.5.2 The preparatory steps for taking photographs.....	24
3.5.3 Photography.....	24
3.5.4 Transmission and analysis of the photographs.....	26



3.5.5 The archiving and preservation of the data by the Laboratoires de la rétine RD.....	27
3.5.6 Utilisation of a mobile camera.....	27
3.6 Trajectories of the patients in the context of the remote screening pilot project ...	28
3.7 Number of anticipated screenings	29
Chapter 4 - Evaluation and methodology framework	31
4.1 The mandate of the evaluation	31
4.2 The evaluation working group.....	31
4.3 The objectives of the evaluation	32
4.4 The relevance of the evaluation of the diabetic retinopathy remote screening pilot project	33
4.4.1 The social relevance.....	33
4.4.2 The relevance for the decision-makers and the organisations	33
4.4.3 The relevance for the patients	33
4.4.4 The relevance for the workers.....	34
4.5 Evaluation approach and model: the case study.....	34
4.6 The types of evaluation	35
4.6.1 The evaluation of the relevance of the context of the project	35
4.6.2 The evaluation of the implementation	35
4.6.3 The evaluation of the short-term effects.....	36
4.6.4 The evaluation of the efficiency.....	36
4.7 Data collection methods	36
4.7.1 The document analysis.....	36
4.7.2 Non-participant observation	37
4.7.3 The use of the clinical and administrative data.....	37
4.7.4 Conducting the semi-structured interviews and focus groups.....	37
4.7.5 The administration of the satisfaction questionnaires among the users.....	38
4.7.6 Meetings of the evaluation working group.....	38
4.7.7 A data collection process in two waves.....	38
4.8 Data analysis and organisation strategies.....	39
4.9 Limitations of the evaluation	39
4.9.1 Limitations related to the methodology.....	39
4.9.2 Limitations related to the team of researchers	40
4.10 The ethical consideration of the research among the First Nations.....	41



4.10.1 The principles of OCAP	41
4.10.2 The validation of the results	41
Chapter 5 - Evaluation of the relevance.....	43
5.1 The community selections	43
5.2 Scan of the communities and organisation of the services before the implementation of the pilot project	43
5.2.1 Timiskaming	44
5.2.2 Eagle Village.....	49
5.2.3 Winneway	53
5.2.4 Wolf Lake	58
5.3 Summary of the evaluation of the relevance	58
Chapter 6 - The evaluation of the implementation	60
6.1 Statistics on the participation of the diabetic individuals of the communities participating in the pilot project	60
6.1.1 Anticipated participants and screenings performed.....	60
6.1.2. Participation of the diabetic population of Timiskaming	61
6.1.3 Participation of the diabetic population of Eagle Village and Wolf Lake.....	62
6.1.4 Participation of the diabetic population of Winneway	62
6.2 Evolution of the roles and responsibilities and the collaborative relationship between the partners.....	65
6.2.1 The participating First Nations communities.....	65
6.2.2 The regional and local partners.....	66
6.2.3 The problems related to defining the roles and responsibilities of each.....	69
6.3 The training provided to the technicians and nurses	70
6.3.1 The unfolding of the training	70
6.3.2 General satisfaction related to the training	71
6.3.3 Differences between the perceptions of the nurses and the technicians with respect to the training provided	75
6.4 Utilisation of the camera	75
6.4.1 The quality of the images.....	75
6.4.2 The difficulties related to the utilisation of the equipment	75
6.5 The reorganisation of the services and human resources of the health centres...	76
6.6 The adoption of the project by the workers and the mobilisation of the members of the participating communities	78



6.7 Summary of the evaluation of the implementation	79
chapter 7 - The evaluation of the short-term effects	81
7.1 Community control over the service and local capacity-building	81
7.2 Diabetes awareness and knowledge transmission.....	82
7.3 The post-screening follow-up with an ophthalmologist.....	83
7.4 Satisfaction of the users of the diabetic retinopathy remote screening service.....	84
7.4.1 Participation of the service users in the evaluation.....	84
7.4.2 General satisfaction regarding the service	85
7.4.3 Proximity of the service.....	85
7.4.4 Development of the diabetes-related knowledge	85
7.4.5 Local competencies	86
7.4.6 Follow-up with an ophthalmologist	87
7.4 Summary of the evaluation of the short-term effects.....	88
Chapter 8 - Economic analysis.....	89
8.1 Introduction	89
8.2 Challenges of the economic analysis.....	90
8.3 Presentation of the project costs.....	92
8.3.1 Definition of the project's start-up, pre-implementation, implementation and operational costs	93
8.3.2 Estimated start-up, pre-implementation, implementation and operating costs	96
8.3.3 Not estimated project costs.....	101
8.3.4 Projection of the costs for the upcoming years.....	102
8.4 Costs associated with the patient trajectories	103
8.4.1 Definition of the costs associated with screening and follow-up for the patients	103
8.4.2 Costs associated with the model trajectories of the diabetic patients without the implementation of the DR remote screening pilot project	105
8.4.3 Costs associated with the model trajectories of the diabetic patients with the implementation of the remote screening pilot project	108
8.5 Amortization of the costs and profitability of the project	111
8.6 Societal advantages of DR remote screening.....	112
8.6.1 Travelling avoided by the patients.....	113
8.6.2 Systematic screening and possible increase in the number of diabetic people screened	113



8.6.3	Regular and more frequent follow-up of the patients	114
8.6.4	Decrease in treatment complexity	114
8.6.5	Decrease in the costs associated with blindness.....	114
8.6.6	Decrease in the costs related to wait times	114
8.6.7	Relief for the public health system.....	115
8.6.8	Local capacity-building	115
8.7	Food for thought to increase the cost-effectiveness of the service	115
8.7.1	Systematic screening of the entire population.....	115
8.7.2	The integration of the remote screening service into the provincial health network.....	115
8.7.3	Improving calendar management for equipment sharing	115
8.8	Summary of the efficiency evaluation	116
Chapter 9 -	Summary and recommendations	117
9.1	The diabetic retinopathy remote screening pilot project	117
9.2	The objectives of the evaluation of the pilot project.....	118
9.3	Discussion on the results of the evaluation.....	118
9.4	Lessons learned and recommendations	122
9.4.1	Recommendations intended for the workers of the First Nations communities (nurses, technicians and health directors).....	123
9.4.2	Recommendations for the coordinators of the DR remote screening project	124
9.4.3	Recommendations for the project's funding organisations and partners	125
9.5	The evolution of the DR remote screening project	127
9.6	Conclusion.....	128
Bibliography		131



LIST OF TABLES

Table 3.1. Roles of the nurses and technicians in the context of the DR remote screening pilot project	22
Table 3.2. Number of expected screenings according to the population ages 30 years and up in the communities of the pilot project*	30
Table 6.1. Number of anticipated and actual participants for each of the communities participating in the pilot project	61
Table 6.2. Number of participants, screening tests and referrals made in the context of the pilot project.....	64
Table 6.3. Observations based on the analysis of the satisfaction questionnaires for the training sessions provided to the pilot project community workers (n=9)	74
Table 6.4. Summary of the factors that facilitated or hindered the implementation of the project	80
Table 8.1. Contributions allocated to the FNQLHSSC and actual operating expenditures of FNIHB-QC for the pilot project.....	93
Table 8.2. Estimated and not estimated costs	94
Table 8.3. Estimated and not estimated pre-implementation, implementation and operating costs.....	96
Table 8.4. Estimated start-up costs	97
Table 8.5. Estimated pre-implementation costs	98
Table 8.6. Estimated implementation costs	99
Table 8.7. Estimated operating costs (year of reference: 2010).....	100
Table 8.8. Summary of the estimated project costs	101
Table 8.9. Time taken into consideration for the calculation of the societal costs	105
Table 8.10. Operating costs associated with the trajectories of the patients without the implementation of the pilot project, per community, for scenario 1 (referral for ophthalmology made by a general practitioner)*	106
Table 8.11. Operating costs associated with the trajectories of the patients without the implementation of the pilot project, per community, for scenario 2 (referral for ophthalmology made by an optometrist following a first screening indicating an anomaly)*	107
Table 8.12. Operating costs associated with the patient trajectories with the implementation of the pilot project, per community*	109
Table 8.13. Total cost of the patient trajectories with and without the implementation of the pilot project, per community.....	110



Table 8.14. Costs of the patient trajectories with and without the implementation of the pilot project by diabetic patient known by the health centres	110
--	-----



LIST OF FIGURES

Figure 3.1. Implementation phases of the DR remote screening project.....	16
Figure 3.2. Constitution of the committees and working groups.....	21
Figure 3.3. Tono-Pen used for measuring intraocular pressure in the context of the DR screening pilot project	24
Figure 3.4. Non-mydriatic camera used in the context of the DR screening pilot project.....	25
Figure 3.5. Example of a photograph of the back of the eye taken in the context of the DR screening pilot project	25
Figure 3.6. Trajectory of the patients after the implementation of the remote screening pilot project.....	29
Figure 5.1. Trajectories of the patients from Timiskaming for a diabetic retinopathy screening test before the implementation of the pilot project*	48
Figure 5.2. Trajectories of the patients from Eagle Village for a diabetic retinopathy screening test before the implementation of the pilot project*	52
Figure 5.3. Trajectories of the patients from Winneway for a diabetic screening test before the implementation of the pilot project*	57



LIST OF ACRONYMS

AANDC: Aboriginal Affairs and Northern Development Canada

ANPSS: Algonquin Nation Programs and Services Secretariat

CHSLD: *Centre d'hébergement et de soins de longue durée*

CLSC: *Centre local de services communautaires*

CSSS: *Centre de santé et de services sociaux*

DR: Diabetic retinopathy

FNIHB-QC: First Nations and Inuit Health Branch, Quebec Region

FNQLHSSC: First Nations of Quebec and Labrador Health and Social Services Commission

FNRLHS: First Nations Regional Longitudinal Health Survey

RUIS: *Réseau universitaire intégré de santé*



CHAPTER 1 - INTRODUCTION

Over the course of the past century, the way of life of the First Nations of Quebec and Canada has been subjected to significant changes. Forced settlement and the integration of new nutritional habits had harmful effects on the health conditions and well-being of the First Nations. Diabetes is one of the chronic diseases that a significant number of First Nations people are struggling with. Even though prevention is being carried out among the community members in order to decrease the appearance of chronic diseases such as diabetes, there are few existing projects focused on preventing and screening the complications associated with this disease. Furthermore, access to treatment and health specialists is sometimes very limited in the more isolated communities.

In 2007, the First Nations of Quebec and Labrador Health and Social Services Commission (FNQLHSSC) developed, in collaboration with the First Nations communities, the 2007-2017 First Nations of Quebec Health and Social Services Blueprint which includes the mandate to strengthen the early screening activities related to diseases such as diabetes and its complications. The Blueprint states the following: “this disease seriously jeopardizes quality of life, results in long-term health care needs and involves significant economic costs for the communities, families and individuals (p. 32)”. It underlines the importance of restraining the appearance of this disease and adopting a community-based holistic approach targeting prevention, promotion and early screening (FNQLHSSC, 2007a).

That same year, the 2007-2010 Telehealth Strategic Plan, developed by the FNQLHSSC and its various partners, targeted four major strategic orientations. One of these orientations deals with the prevention, reduction and management of diabetes and its complications, including diabetic retinopathy (DR). The possibility of conducting pilot projects in connection with various aspects of telediabetes (telediagnosis, teleconsultation, telecare, etc.) was raised (FNQLHSSC, 2007b).

A DR remote screening clinical project, funded by Health Canada’s First Nations and Inuit Health Branch, Quebec Region (FNIHB-QC) and Canada Health Infoway was therefore set up in four Algonquin (Anishinabeg) communities in the Abitibi-Témiscamingue region [Eagle Village (Kipawa), Timiskaming, Winneway (Long Point) and Wolf Lake (by way of Eagle Village)] in partnership with the community representatives. Using telehealth technologies, the project aims to facilitate access for diabetic First Nations individuals to DR screening and specialised ophthalmological care.

The implementation of the pilot project anticipates a series of activities including: 1) the evaluation of the organisation of the services in each of the participating communities and the connections with the required services in the Quebec health network; 2) the development of a screening, treatment and follow-up process for diabetic individuals; 3)



the planning and organisation of the training and information activities; and 4) the initiation of the clinical screening by the duly trained personnel.

This DR remote screening initiative is a prevention project that is included within the context of a project with a broader scope aiming to control diabetes in the First Nations communities. Ultimately, this project aims to reduce the incidence of blindness and ocular deficiency among the First Nations people while fostering improved treatment provided by First Nations for diabetic individuals. More specifically, this diabetes control program must enable the communities: 1) to consolidate the activities related to diabetes in order to gradually develop a complete program to combat diabetes including prevention, early detection and access to treatment for diabetes and the associated problems; 2) to improve access to general practitioners and specialists; 3) to improve treatment and follow-up for diabetic individuals; and finally 4) to develop the capacity of the communities to develop and implement a complete program to combat diabetes including DR screening and program evaluation.

This evaluation report scans and documents the set up process and the factors facilitating and limiting the implementation of the screening pilot project and attempts to demonstrate the short-term effects of the project for the Algonquin (Anishinabeg) communities of Eagle Village (Kipawa), Timiskaming, Winneway (Long Point) and Wolf Lake.

Firstly, chapter 2 of this report presents pertinent information regarding diabetes: the prevalence of diabetes among the First Nations, the consequences of DR and the importance of early DR screening in order to avoid its major complications. Still with the goal of providing context for the project, the use of telehealth is emphasised as a way of screening DR in the First Nations communities, as are the costs and benefits of various telehealth programs in Canada.

Chapter 3 presents the DR remote screening pilot project, the general and specific objectives of the pilot project and its implementation phases within the First Nations communities as well as the roles of the partners involved. It also deals with how the project works, meaning the way in which a screening session unfolds as well as the newly created service corridors.

Chapter 4 addresses the mandate and the objectives of this evaluation as well as the recommended methodology in order to meet these objectives. Furthermore, this chapter reports on the retained evaluation model, the case study, and the different types of evaluations addressed. The various methods that were used to collect and analyse the information are also presented in this chapter. The chapter concludes with the limitations of this evaluation in addition to a few ethical considerations.

Chapter 5 presents the results obtained with respect to the evaluation of the relevance. Moreover, for each of the communities participating in the project, a description of the geography, demographics and available services allows for evaluating to what extent the



addition of a new DR screening service allows for addressing a local population need. The implementation of the remote screening project in a community demands that this community possess adequate human and material resources. This chapter explains how the profiles of the participating communities and their available resources contributed to the project's success.

Chapters 6 and 7 respectively address the evaluation of the implementation of the project and the evaluation of its short-term effects. The results are presented in a comprehensive manner for the four communities however the characteristics of any of the communities that may have influenced the project's implementation or outcomes are also presented.

As for chapter 8, it focuses on the economic analysis of the project. This chapter therefore provides an economic assessment of the project by outlining the costs of the project as well as the costs associated with the various possible trajectories of the patients with and without the implementation of the service within the four participating communities.

Finally, chapter 9 presents a summary reviewing the main elements discussed throughout all of the chapters. A list of the lessons learned that can be used for recommendation purposes during the implementation of a similar project or to continue this project is also included.



CHAPTER 2 - CONTEXT

This chapter provides information that allows for providing context for the diabetic retinopathy (DR) remote screening pilot project. Information regarding First Nations, diabetes, DR and its screening as well as telehealth is presented here.

2.1 THE FIRST NATIONS OF QUEBEC

In Canada, as stipulated in the Canadian Constitution, the Aboriginal population is divided into three groups that are different from each other from a cultural, linguistic and geographic perspective: the Inuit, Métis and First Nations. Nearly 4% of the Canadian population identifies with one of these three groups (Statistics Canada, 2008). Composed of 41 communities established on the territory of Quebec, the First Nations are divided into ten Nations: Abenaki, Algonquin, Anishinabeg, Atikamekw, Nehirowisiwok, Cree, Innu, Malecite, Mi'gmaq, Mohawk, Naskapi and Huron-Wendat. Each of these ten Nations has its own specific history, beliefs, way of life, know-how and life skills. Furthermore, between the communities of a same Nation, notable differences, particularly from a historical and cultural perspective, can be observed. However, the First Nations share a similar colonial history and a former way of life that is based on the practices of hunting, fishing, the gathering of berries and vegetables and small-scale agriculture (in the case of the Iroquois Nations¹).

From a demographic perspective, nearly half of the First Nations community population is less than 30 years of age (Statistics Canada, 2008). The birth rate is increasing and in 2000, it was set at 23.4 births per 1000 residents, which is nearly double the Canadian rate (*Secrétariat aux affaires autochtones*, 2009). For many years, rapid demographic growth among the First Nations population of Quebec has also been observed. Moreover, even though the number of First Nations living in urban areas is increasing, more than 70% of the individuals still reside within one of the 41 communities (Health Canada, 2005).

2.2 DIABETES

Diabetes is a chronic disease caused by an insufficient or complete lack of insulin secretion. Insulin is a hormone that is secreted by the beta cells of the Islets of Langerhans of the pancreas which facilitates glucose absorption. When there is a dysfunction associated with insulin secretion, excess sugar circulates in the blood. To

¹ The First Nations of Quebec are divided into two large linguistic families: the Iroquois family and the Algonquin family. Today, the Iroquois family unites the Mohawk and Huron-Wendat nations which are divided into four communities. In addition to sharing common linguistic roots, these two nations share an ancestral way of life based on small-scale agriculture (corn, squash, and beans), hunting, fishing and the gathering of berries and plants. These populations, contrarily to the nations of the Algonquin linguistic family, had a semi-sedentary way of life. The nations of the Algonquin linguistic family make up the majority of the First Nations of Quebec. It includes ten nations divided among 41 communities. These populations were spread out over the entire territory of Quebec (and neighbouring provinces and states) and lived a nomadic lifestyle centred on hunting, fishing and the gathering of berries and plants.



this day, the actual cause of diabetes remains unknown. However, certain risk factors such as heredity, obesity and pregnancy can influence the onset of diabetes. First Nations are included among the at-risk populations. Three main types of diabetes exist: type 1, type 2 and gestational diabetes. The latter is named that way due to the fact that it develops during pregnancy (Canadian Diabetes Association, 2008).

Type 1 diabetes generally appears during childhood, at the beginning of adolescence and among young adults (Health Canada, 2002). It is characterised by an absolute insulin secretion deficiency (Canadian Diabetes Association, 2008). The lives of those with type 1 diabetes therefore depend on daily insulin injections (Canadian Diabetes Association, 2008; Health Canada, 2002).

As for type 2 diabetes, it usually appears at around 40 years of age. The vast majority (90%) of people with diabetes are afflicted with type 2 diabetes (Health Canada, 2002). Recently, among certain at-risk populations, it has been observed that type 2 diabetes appears at a younger age and can even be diagnosed during childhood. A genetic predisposition, being overweight and obesity, malnutrition and a lack of physical activity contribute to the appearance of type 2 diabetes (Daniel and Gamble, 1995; Grimaldi and coll., 2004; Lee and coll., 2004; McDermott and coll., 2000; Pollex and coll., 2006; Szathmary, 1994; Young and coll., 2000; Yu and Zinman, 2007). It develops insidiously, without any severe symptoms, and can therefore be present for several years before being diagnosed (Canadian Diabetes Association, 2008).

The insufficient production of insulin or the body's inability to use it correctly leads to the excessive presence of glucose in the blood. This state has repercussions on the entire human metabolism causing permanent damage to various systems and organs of the body such as the retina, kidneys and arteries (Canadian Diabetes Association, 2008).

2.2.1 Diabetes among the First Nations

Diabetes is a significant health problem that the First Nations are currently faced with. Even though we do not precisely know the genuine scope of the problems, studies indicate that at least 15% of the First Nations population of Canada is diabetic (Harris and coll., 1997; Health Canada, 2000; Young and coll., 2000). According to the First Nations Regional Longitudinal Health Survey (FNRLHS) that was conducted in 2002 in the Quebec region, 14.5% of the adult population declared being afflicted with diabetes (16.4% of the women and 12.5% of the men) compared to 7 to 10% among the global Canadian population (FNQLHSSC, 2006). It is possible to believe that this percentage could be higher since until recently the systematic screening of diabetes was rarely performed in the First Nations communities (Young and coll., 2000). Furthermore, it is important not to exclude the significant growth in type 2 diabetes among the increasingly younger age groups (Lee and coll., 2004) in addition to the adolescents (Acton and coll., 2002). According to the Scan on Diabetes among First Nations Communities of Quebec (2011), the proportion of diabetic people varies between 13% and 22% according to geographic isolation zone (FNQLHSSC, 2011). Still according to the Scan on Diabetes,



the highest proportions of diabetes and prediabetes² were observed among those ages 55 years and up. Among the diabetics, 63.0% are over 55 years of age and 34.6% are between the ages of 35 and 54 years. No diabetic person identified in the context of this study was under 17 years of age.

Among First Nations, the complications resulting from diabetes do not only appear earlier, they are also more common than among the general population (Health Canada, 2000). A report submitted by the *Agence d'évaluation des technologies et des modes d'intervention en santé* (AETMIS) underlines that DR is the main cause of blindness in many First Nations communities (AETMIS, 2008).

Over the course of the 20th century, a vast majority of the First Nations of Quebec were forced to set aside their nomadic way of life, based on hunting and gathering, in favour of a sedentary lifestyle. Today, only a minority of the First Nations population acquires the major part of its diet through hunting and fishing (Young and coll., 2000). This quick change in the lifestyle of the First Nations was followed by a rapid growth in the prevalence of obesity and type 2 diabetes.

The abandonment of the traditional diet that is low in sugar and high in complex carbohydrates, micronutrients and protein (NHMRC, 2000), and especially its substitution with a diet composed of processed foods (Lee and coll., 2004; Burke, 2007) that are high in saturated fat, refined sugars and carbohydrates (Szathmary, 1994; Daniel and Gamble, 1995) often including the consumption of alcohol, is one of the major risk factors of type 2 diabetes (Young and coll., 2000).

The relationship between food and culture has always been of great importance to the First Nations. Among certain Aboriginal and Indigenous communities, the adoption of new nutritional habits had a negative impact on the personal and social relationship associated with food such as the sharing of the fruits of hunting and fishing and certain traditional ceremonies and rites of passage (NHMRC, 2000). Furthermore, these changes have caused environmental and ecological problems such as a deterioration of the ecosystem through the use of all-terrain vehicles and the contamination of traditional food such as fish by heavy metals (lead, mercury, etc.) (Milburn, 2004). In the recommendations made in the Scan on Diabetes among First Nations Communities of Quebec, the importance of developing an intervention approach and tools in order to reduce diabetes that are adapted and directly connected to the know-how and life skills of the First Nations is mentioned (FNQLHSSC, 2011).

2.3 DIABETIC RETINOPATHY

Type 2 diabetes can lead to many ocular complications including DR. Two forms of DR exist: the nonproliferative form and the proliferative form. Generally-speaking, DR starts

² Prediabetes is associated with a blood sugar level that is elevated but under the diagnostic threshold for diabetes (Canadian Diabetes Association, 2008).



with a nonproliferative form and progresses towards a proliferative DR. In the nonproliferative form, normal vessels lose their permeability and leak fluid and lipids that can lead to an edema of the retina. In the proliferative form, the most severe form, small abnormal vessels grow to make up for the lack of blood and then invade the retina. When these vessels break, they provoke haemorrhages (AMOQ, n.d.).

DR, a common complication of diabetes, is the main cause of blindness in the world and among the active population (Mohamed and coll., 2007; Swanson, 2005). It is estimated that approximately 40% of people with diabetes are carriers of a DR. In the case of type 1 diabetes, DR generally does not appear before seven years of evolution. However, 20 years after being diagnosed, 90 to 95% of those with type 1 diabetes have a DR, 40% of which is of the proliferative variety. As for people with type 2 diabetes, more than 20% of them are already carriers of a DR when they discover they have diabetes and, in the long-term, 20% of these diabetic individuals will have a proliferative DR and 60% will have a macular edema³ (Canadian Diabetes Association, 2008; Kohner and coll., 1998). According to a study by Oster and coll. (2009), the prevalence of DR among Aboriginal and non-Aboriginal people is the same, approximately 40%. In short, the prevalence of DR is directly related to the duration of the diabetes (Canadian Diabetes Association, 2008; Soto-Pedre, 2009).

DR usually does not have any symptoms except in the presence of macular edema or haemorrhages (AMOQ, n.d.). DR is one of the main causes of blindness among 88% of those with type 1 diabetes and among 33% of those afflicted with type 2 diabetes (Canadian Diabetes Association, 2008; Klein and coll., 1984). In the FNRLHS, nearly 30% of the respondents indicated having visual problems without however specifying the nature of these problems often due to the absence of a diagnosis (FNQLHSSC, 2006)⁴.

DR is associated with several risk factors such as hyperglycaemia, hypertension and dyslipidemia (high levels of lipids in the blood (Canadian Diabetes Association, 2008; Chew, 2003). Also a 2% increase of glycated or glycosylated haemoglobin (HbA1c) increases the risk of developing a DR by 1.7 times (Rema and coll., 2005) and a high level of LDL cholesterol (Low-Density Lipoprotein) is also associated with the progression of DR among afflicted patients (Lloyd and coll., 1995). Therefore, the incidence and progression of DR can be reduced by controlling glycaemia and blood pressure.

In closing, the key to decreasing the prevalence and the consequences associated with DR remains early screening, both for diabetes and its complications. This is particularly

³ The macula is located on the retina, at the posterior pole of the eye. The macula is the zone that is the richest in cones, cells that are capable of capturing, with proper lighting conditions, the details and colours, thereby allowing for better visual acuity. Macular edema is the primary cause of blindness among diabetics. It is defined by a thickening of the macula or the collection of hard exudates (Zghal-Mokni and coll., 2001).

⁴ An important point to consider is that there is a discrepancy between the statistics that are found in the various epidemiological studies regarding the prevalence and incidence of DR and macular edema among diabetics. This is partly explained by the differences in the methodological choices made by each of these studies (Williams and coll., 2004).



important for the at-risk populations such as First Nations people. Diabetic patients should be thoroughly treated and monitored for the modifiable risk factors in order to prevent the development and progression of the DR (Chew, 2003). Furthermore, an annual ophthalmological evaluation of the diabetic individuals is essential.

2.4 THE SCREENING OF DIABETIC RETINOPATHY

There are two processes for screening DR: a slit-lamp indirect ophthalmoscopy with pupil dilation and fundus photography followed by classification (photography of the back of the eye) (AETMIS, 2008). The second screening technique is the recommended technique that allows for reducing the rate of blindness or ocular deficiency by 90%. International recommendations advise annual surveillance of the back of the eye. However, the asymptomatic nature of DR, discomfort related to pupil dilation, the difficulty associated with accessing specialists and the need for particular expertise in order to perform the examination make it so that this recommendation is seldom applied. Retinal photography with pupil dilation seems to be the most effective test for detecting DR early on (Hutchinson and coll., 2000).

2.4.1 The screening of diabetic retinopathy through telehealth

Telehealth is defined as the use of digital information production, transmission, management and sharing tools to the benefit of both medical and medico-social practices:

Telehealth refers to the health and social services preventive and curative care and treatment provided remotely through a telecommunication method including audiovisual exchanges for the purposes of information, education and research and the processing of clinical and administrative data (free translation (Froissart, 2010)).

Telehealth encompasses telemedicine which is a form of remote medical practice using information and communications technologies. It provides a connection between patients and health professionals. It allows for monitoring the state of patients, the establishment of diagnoses, performing preventive or post-therapeutic follow-up and the prescription of medical products, services or acts.

The limited access to general practitioners renders the necessary medical follow-up for controlling diabetes and its complications potentially difficult or even inexistent for First Nations people (Kaur and coll., 2004; Maberley and coll., 2003). Often residing in isolated or semi-isolated regions, the members of the communities do not have access to specialised medical services and many of them, for diagnosis purposes, visit the large urban centres such as Montreal or Quebec or even other neighbouring provinces. One of the promising solutions to improve these problems related to accessing specialised care and services is the use of telehealth. This service delivery method offers the



possibility of providing a connection between a patient and first-, second- and third-line health professionals⁵. While promoting the development of local competencies and the active participation of the First Nations people in terms of taking control over their own health services, when practiced in the First Nations communities, telehealth allows for addressing specific local needs within a culturally-appropriate environment within the actual community.

The use of telehealth for DR screening purposes appeared during the 2000s. In fact, non-mydriatic cameras coupled with an electronic system through an interface – allowing for the entry of clinical data and the visualisation of images of the back of the eye – have made the remote screening of DR possible.

Various DR remote screening pilot projects have taken place in isolated communities across Canada. These projects enabled patients, without needing to leave their communities for screening purposes, to be directly referred after diagnosis to a retina specialist for treatment (Tennant and coll., 2000). The majority of these programs and pilot projects were concurrently submitted to an evaluation in order to determine the effectiveness of the equipment being used for screening purposes, compare the costs of various screening programs and determine the specificity and sensitivity⁶ of the screening and images according to the equipment used and the human resources required in order to perform the screening.

Studies have shown that the effectiveness of DR screening by ophthalmoscopy varies depending on whether it is performed by an optometrist, resident physician, diabetes specialist or nurse. Therefore, the screening is not as effective when it is not performed by an ophthalmologist or a retina specialist (Hammond and coll., 1996; Singer and coll., 1992). However, when the screening is performed using a camera, the sensitivity and specificity are the same, regardless of the profile of the individual taking the photographs (Maberley and coll., 2003; Maberley and coll., 2004; Sinclair, 2006). Similar results were found among the First Nations when health workers who had received two weeks of training proceeded to take photographs for DR screening purposes (Karagiannis and coll., 1996).

The observation can therefore be made that several studies support the effectiveness of the use of non-mydriatic cameras⁷ (Diamond and coll., 1998) and teleophthalmology (Whited, 2006) for the screening of DR. Research performed in Aboriginal settings have

⁵ The first-line of service corresponds to general medical and social services. The second-line is defined as the specialised services offered. As for the third-line, it refers to the subspecialised medical and social services (*Ministère de la Santé et des Services sociaux du Québec*, 2010).

⁶ The specificity of a screening test refers to its capacity to provide a negative result when the disease is not present in a patient. The sensitivity is the capacity of a test to give a positive result when the disease is in fact present in a patient.

⁷ The term “non-mydriatic” refers to the word “mydriasis” which means the dilation of the pupil. Non-mydriatic cameras are therefore devices that do not require pupil dilation in order to perform DR screening.



also focused on evaluating the effectiveness of other types of cameras and agree that their use is more effective than regular screening (McConnell and coll., 1993).

2.5. THE COSTS AND BENEFITS OF TELEHEALTH

Many people with diabetes do not have access to the recommended annual examination in order to evaluate their retinas and the level of evolution of their DR (Silva and coll., 2009). Therefore, the screening of DR through telehealth can have many benefits for patients and the practitioners who work with them. In fact, the use of a camera has many advantages such as the fact that it can be transported into various geographically isolated communities while the captured images can be preserved in order to compare the evolution of a DR over time (Maberley and coll., 2003).

The study by Malberly and coll. (2003) demonstrates that the use of a mobile camera, instead of the usual method where the individual must travel in order to meet with a specialist (clinical examination of the back of the eye), allows for achieving considerable savings. A DR remote screening program in a Cree community in Ontario was subjected to a cost-benefit analysis. The results indicate that the costs per person are reduced by more than half: from \$842 during the clinical examination of the back of the eye to \$403 with the use of the camera. In addition, since the camera is more effective and sensitive, the years of sight saved over ten years are greater while the years lost are lower. That being said, the cost adjustment for the quality-adjusted life year (QALY) is \$15 000 for the screening program with a camera compared to \$37 000 for traditional screening. The cost for saved sight is also lower with screening by camera (\$3 900 compared to \$9 800).

The earlier the DR is treated, the more the cost-benefit ratio is beneficial (Kamholz and coll., 2009). That being said, screening at the early stages of a great number of people using an effective method, combined with quick treatment of the disease, allows for saving a considerable amount of money while increasing years of life without blindness. However, this does not imply that, regardless of the stage of the disease, each individual will have the same number of years of sight saved. It is also important to keep in mind that the effectiveness and efficiency of the application of telemedicine are highly influenced by the realities and trajectories of each patient, thereby not allowing the results of the studies to be applied in a general fashion (Ohinmaa and coll., 2001).

The following are some of the benefits of a DR remote screening program justifying its relevance (Gagnon and coll., 2006):

- 1) Increases the availability of the information;
- 2) Facilitates regional access to specialised services;
- 3) Improves the continuity of the services;
- 4) Improves the practice of the physicians by facilitating continuing medical education, contact with peers and access to a second opinion;
- 5) Fosters the retention of the local expertise;



- 6) Supports the development of regional referral centres;
- 7) Generates savings.

Studies have demonstrated the importance of considering the cost-benefit ratio over a long enough period because in the short-term the cost of remote screening may seem similar to the cost of screening performed outside of the communities. For example, the study by Martin and Yidegiligne (1998) focused on the cost of the DR screening program outside of the communities for 450 people originating from communities in British Columbia established the cost for an on-site screening service (cost of meals, accommodations and travelling) at \$164 000 and \$132 256 for a remote screening service including the cost of screening, camera and maintenance, insurance, fuel for the vehicle used for transporting the camera between communities, etc. However, as years pass, the cost related to the camera decreases.

A study reported that only 33% of diabetic individuals living in Aboriginal communities have access to an annual retinal examination (Kaur and coll., 2004). The DR remote screening program will therefore allow for reaching the diabetic patients and offering the service on an annual basis to nearly all of the diabetic patients (Martin and Yidegiligne, 1998).

Thus, as will be explained in the following chapter, one of the objectives of the DR remote screening project is to foster First Nations access to DR screening services within their communities and at a lesser cost. This chapter will provide details on the implementation phases of the project within the communities and the partners involved.



CHAPTER 3 - PILOT PROJECT

This chapter describes the pilot project that has been implemented in the First Nations communities of Quebec. First of all, it addresses the objectives of this pilot project, its implementation phases and the roles of the various partners involved. The following sections provide details on the technological and operational elements of the pilot project.

3.1 THE OBJECTIVES OF THE DIABETIC RETINOPATHY REMOTE SCREENING PILOT PROJECT

The diabetic retinopathy (DR) remote screening pilot project, thanks to the implementation of a telehealth solution, is a complete screening project. Indeed, the development of this project was carried out with the objective of strengthening the service corridors with Quebec's health network, thereby allowing for the provision of follow-up and treatment to the diabetic patients. Furthermore, the project aims to increase knowledge and foster capacity-building among the First Nations as well as to develop partnerships and collaborative agreements between the First Nations communities and the partners of the network.

The primary objective of the project is to implement a remote screening service for DR in the First Nations communities through the use of telehealth by using a mobile non-mydratric camera⁸ connected to an analysis centre located in an urban centre (the *Laboratoires de la rétine RD*, situated in Montreal). Secondly, the project aims to establish a continuum of services, involving first- to third-line services, for the treatment and follow-up of DR and the diabetic individuals in the First Nations communities of Quebec. This continuum includes the creation of service corridors and the establishment of technological solutions allowing for the provision of services from a distance. Ultimately, the implementation of this project aims to reduce the incidence of blindness and ocular deficiency among the First Nations members while fostering First Nations control over care for diabetic individuals. Furthermore, it is hoped that the project will be successful in enabling the communities to strengthen their activities in connection with the fight against diabetes while consolidating a complete diabetes control program including activities related to the prevention and early detection of diabetes and its complications. Finally, the implementation of the project aims to foster collaboration between the communities as well as First Nations capacity-building.

⁸ Nidek AFC-230 model: This model was chosen mainly due to its user-friendliness since it requires very little handling on behalf of the technician.



Specifically, the project's objectives are to:

- ❖ Ensure access to DR screening tests as close to the patient's home as possible;
- ❖ Ensure access to competent specialists to analyse and interpret the images taken when performing screening in the community;
- ❖ Ensure follow-up for people with DR;
- ❖ Decrease the need to travel for DR screening purposes;
- ❖ Raise awareness among the First Nations communities regarding the benefits related to the use of telehealth;
- ❖ Foster collaboration and mutual aid between the communities;
- ❖ Foster First Nations capacity-building;
- ❖ Improve the services offered in connection with diabetes in the communities;
- ❖ Allow for better collaborative connection with the provincial network (sharing of information with the health centres, access to a family physician, etc.).

3.2 THE IMPLEMENTATION PHASES OF THE PROJECT

It was anticipated that the deployment of the project would take place in several phases in order to evaluate the implementation process and make the necessary corrections during the subsequent phases. This approach allowed for gradually increasing knowledge about the project among all of the First Nations communities of Quebec in order to generate their interest in getting involved in the project's implementation in their communities. It should be noted that the implementation of the screening service is carried out on a voluntary basis; it is up to the communities to decide whether or not they wish to participate depending on their community realities and priorities. The three phases anticipated for the project were as follows:

Phase 1: The project is set up and implemented in four Algonquin (Anishinabeg) communities in the Abitibi-Témiscamingue region: Eagle Village (Kipawa), Timiskaming, Winneway (Long Point) and Wolf Lake (through Eagle Village). This implementation phase began to unfold in the winter of 2010.

Phase 2: The project is extended to other Algonquin (Anishinabeg) communities in the Abitibi-Témiscamingue region: (Kitcisakik, Kitigan Zibi, Lac-Simon, Pikogan and Rapid Lake). The implementation of this phase began to unfold in the spring of 2011.

Phase 3: The project is offered to all of the First Nations communities of Quebec and implemented in many interested communities. The implementation sequence is established according to the interest of the communities, their level of preparation and the availability of the resources in the communities.



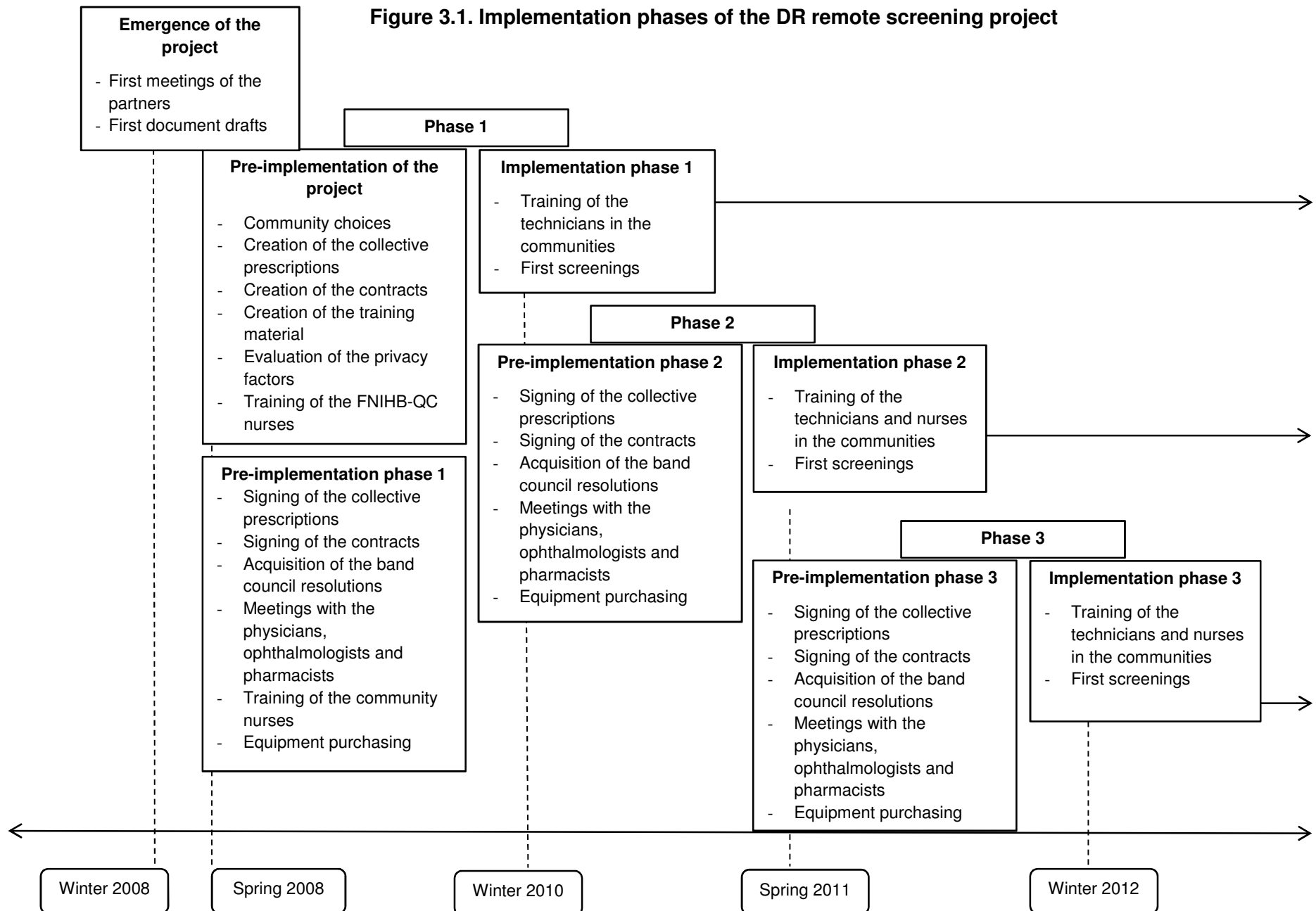
This evaluation focused on phase 1 of the project which involves the pilot project. The observations, lessons learned and recommendations made by this evaluation have served and will continue to serve during the implementation and application of the project over the course of the two subsequent phases. To that end, constant communication was established between the team responsible for the evaluation and the E-Health Agent of the First Nations of Quebec and Labrador Health and Social Services Commission (FNQLHSSC) responsible for the coordination of the project.

The diagram on the following page (figure 3.1) allows for gaining an understanding of the various phases of the project and situating in time the key events that led to the implementation of the screening service in the four communities of the pilot project and then in the subsequent project dissemination phases. The diagram also outlines the fact that activities associated with the pre-implementation⁹ of phase 1 unfolded concurrently to the pre-implementation activities of the project for which the product will serve for all the implementation phases.

⁹ In the context of this evaluation, the term pre-implementation refers to all of the activities preceding the implementation of the services that are required for the smooth unfolding of the implementation of the activities (training and screening) in the communities.



Figure 3.1. Implementation phases of the DR remote screening project



3.3 THE ROLE OF THE PARTNERS INVOLVED IN THE DIABETIC RETINOPATHY REMOTE SCREENING PILOT PROJECT

3.3.1 *The role of the First Nations of Quebec and Labrador Health and Social Services Commission*

The DR remote screening project was developed by the FNQLHSSC, the First Nations and Inuit Health Branch, Quebec Region (FNIHB-QC) and McGill University's *Réseau universitaire intégré de santé* (RUIS McGill). The FNQLHSSC is responsible for the coordination of the project with the health facilities of the participating First Nations communities. It is also in charge of providing the human resources required to implement the project, follow the project's advance, ensure that the budget and timelines are respected, provide administrative and technical support and keep the partners informed for the entire duration of the project.

The E-Health Agent of the FNQLHSSC plays a very important role for the FNQLHSSC. In fact, the E-Health Agent works in close collaboration with all of the players concerned by the project: the Algonquin Nation Programs and Services Secretariat (ANPSS), FNIHB-QC and the First Nations communities involved. The E-Health Agent also acts as a liaison among all of the non-Agreement First Nations communities¹⁰ of Quebec and the Naskapi in order to explain the project and examine with them the possibility of integrating the remote screening project into their communities. This person ensures the project management as a member of the management committee, a member of the clinical committee and a member of the evaluation working group. These committees are defined in section 3.3.7. The FNQLHSSC is also responsible for the evaluation of the pilot project.

3.3.2 *The role of the Algonquin (Anishinabeg) communities of Eagle Village (Kipawa), Timiskaming, Winneway (Long Point) and Wolf Lake*

In terms of the services provided, the participating communities provide the human resources required to perform the screening in their communities. The human resources in place participate in training provided by FNIHB-QC, determine the adequate space for the DR screening test and promote the project in order to increase awareness among the members of their communities. The communities are also responsible for organising the camera's arrival in their communities and ensuring that the camera moves according to the schedule they have established. A local working group, made up of the technicians, nurses and health directors of the four communities participating in phase 1 of the project, the FNQLHSSC E-Health Agent and the nurse responsible for the project at FNIHB-QC, was established in order to ensure follow-up for the development of the

¹⁰ The Cree and Naskapi nations are different from the other First Nations of Quebec due to their status as agreement communities. These nations have reached agreements with the Quebec government giving them political and administrative autonomy as well as access to provincial public services (James Bay and Northern Quebec Agreement, 1975, and the Northeastern Quebec Agreement, 1978).



project and foster the exchange of information and a concerted approach between the First Nations communities.

3.3.3 The role of the Algonquin Nation Programs and Services Secretariat

The Algonquin Nation Programs and Services Secretariat (ANPSS) was approached as of the project's pre-implementation phase in order to gauge its interest with respect to the project and collect its comments and suggestions regarding the work plans and the possible ways of moving forward. During the project's pre-implementation phase, the ANPSS worked on promoting the project, performing the follow-up among the participating communities and collecting comments from its members.

3.3.4 The role of the First Nations and Inuit Health Branch – Quebec Region and Canada Health Infoway

During the pre-implementation phase of the project, the First Nations and Inuit Health Branch, Quebec Region (FNIHB-QC) met with the general practitioners who serve or have ties with the communities participating in phase 1 of the project in order to present the project and encourage them to collaborate in it. FNIHB-QC developed the collective prescriptions required for the work of the community nurses and took care of ensuring that these prescriptions were signed.

Follow-up was carried out by the FNIHB-QC personnel in order to ensure communication and collaboration between the communities and the regional ophthalmologists. The FNIHB-QC was in charge of providing training to the nurses and technicians in the First Nations communities participating in the project to ensure the capacity-building needed to perform the DR remote screening test (pupil dilation, handling of the retina photography material, forwarding of the images to the ophthalmological clinic). The training for the nurses was provided in Montreal and the training for the technicians took place within the communities during the implementation of the project. The FNIHB-QC is also responsible for the technical support offered to the community nurses and technicians responsible for performing the screening tests. A human resource is therefore available to answer any questions and to help resolve any technical difficulties encountered by the technicians and nurses when taking the pictures.

Representatives from Canada Health Infoway and FNIHB-QC as well as the E-Health Agent of the FNQLHSSC are part of the project management committee responsible for coordinating the implementation of the project among the First Nations communities of Quebec. Representatives from FNIHB-QC, Innova company (the camera supplier), the FNQLHSSC and ophthalmologist consultants also established a clinical committee that is entrusted with the mandate to develop training manuals and create the collective prescriptions required by all of the pilot project's communities.

The financial support for the implementation phase of the project was provided by Canada Health Infoway. This funding was granted in 2008 and will continue until the end



of this phase in December 2012. The evaluation as well as the fees related to analysis and infrastructure for the *Laboratoires de la rétine RD* is funded by FNIHB-QC. The establishment of this new screening service will entail recurring fees for the communities. These should be covered by FNIHB-QC either through the e-Health Program or the Aboriginal Diabetes Initiative (ADI).

3.3.5 The role of the evaluation working group

An evaluation working group was set up in order to contribute to the development and realisation of the evaluation of the first phase of the DR remote screening project among the First Nations communities. This working group is made up of the members of the Research Sector of the FNQLHSSC involved in the evaluation, the FNQLHSSC Research Manager, the FNQLHSSC E-Health Agent, a FNIHB-QC manager, a nurse from Eagle Village, an expert in measurement and evaluation from the *Ministère de la Santé et des Services Sociaux du Québec* (MSSS), an expert in telehealth project evaluation from *Université Laval* and the *Direction de santé publique de l'Abitibi-Témiscamingue* and a telehealth expert from the community of Manawan. The role, composition and relevance of the working group are described in detail in the following chapter.

3.3.6 The other partners that participated in the implementation and application of the project

Other partner organisations of the project participated in its development and implementation: the telehealth team of the McGill University Health Centre (MUHC), RUIS McGill and the *Laboratoires de la rétine RD*. The latter partner was retained on an interim basis by FNIHB-QC and the FNQLHSSC given the fact that the service was not yet developed within the public health network (regional player, August 25, 2010).

It should be noted that the project was first of all proposed by RUIS McGill which gradually withdrew. RUIS McGill continued to remain interested in the development of the project in order to learn from this project and benefit from points of reference for future regional telehealth service implementation projects. The evolution of the partnership in the context of the implementation of this pilot project is discussed in chapter 6 focused on the evaluation of the implementation.

3.3.7 Committees and working groups created for the development and implementation of the project

In order to see this project through, besides the evaluation working group, various committees were set up during the pre-implementation of the project that must continue their mandates until the end of the three phases of implementation. It is also hoped that other local working groups will be established during the implementation of the project in other regions since the project aims to foster collaboration between the communities.



Project management committee: The mandate of the project management committee is to supervise the unfolding of the project in all of its steps (pre-implementation, implementation, post-implementation), ensure respect for the initial orientations, timelines and budget and manage the risks associated with the project (Terms of Reference of the Management Committee, 2009).

Local working group: The mandate of the local working group is to advise, share expertise, assist in the planning and implementation of the project and coordinate all of the activities associated with the project (Terms of Reference of the Local Working Group, 2009).

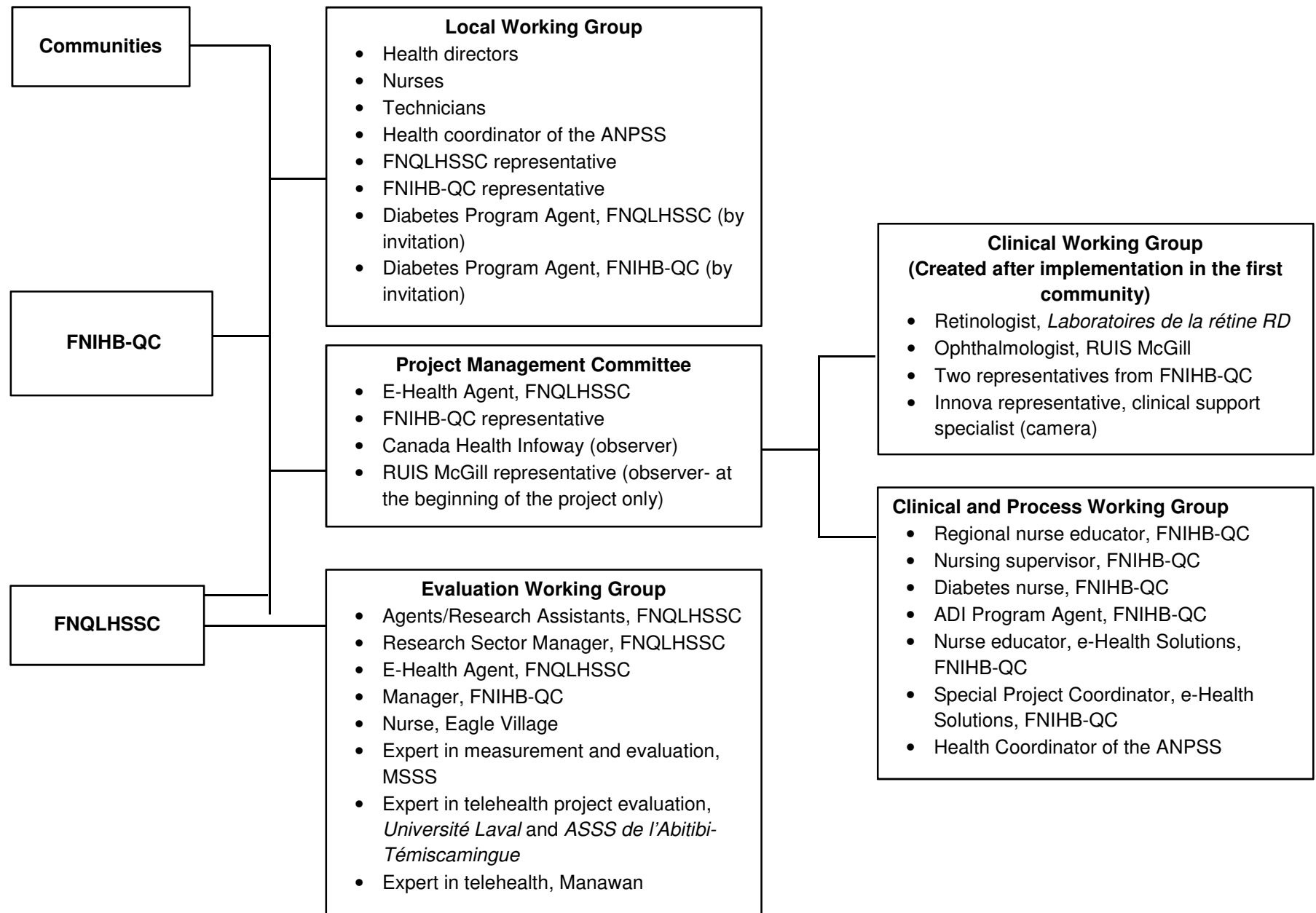
Clinical working group: The mandate of the clinical working group is to advise and provide the expertise in order to define the clinical processes and quality insurance standards to be established for the implementation of the project (Terms of Reference of the Clinical Working Group, 2009).

Clinical and process working group: The mandate of the clinical and process working group is to provide the support and expertise required for the development, planning, implementation and maintenance of the project. The group will be responsible for developing the training program and tools required to perform the diabetic retinopathy screening test as well as planning the training sessions in the First Nations communities (Terms of Reference of the Clinical and Process Working Group, 2009).

The flow chart on the following page (figure 3.2) presents the composition of these committees.



Figure 3.2. Constitution of the committees and working groups



3.4 THE TEAM RESPONSIBLE FOR THE SCREENING SERVICE IN THE COMMUNITIES

Within the context of the pilot project, the health centre director in each of the communities is entrusted with the mandate to train and supervise a team of three workers (a nurse and two technicians¹¹) that are responsible for offering the DR remote screening service. Therefore, one nurse and two technicians per community were trained in order to refine their skills related to DR screening. The training provided in the context of the pilot project and its appreciation will be addressed in the following chapter.

With respect to the screening process, the nurses and technicians in each of the communities have pre-defined roles as presented in the following table.

Table 3.1. Roles of the nurses and technicians in the context of the DR remote screening pilot project

Roles of the nurse	Roles of the technician
❖ Inviting diabetic individuals and setting appointments ❖ Measuring intraocular pressure ❖ Pupil dilation ❖ Collecting clinical and demographic data with the patients ❖ Raising awareness and performing prevention and promotion among the patients ❖ Making ophthalmological appointments for the patients requiring follow-up ❖ Integrating the DR screening service into the health centre's complete program aiming to fight against diabetes ❖ Referring the patients to other health professionals as needed	❖ Explaining the screening test and how it unfolds ❖ Explaining the consent form and ensuring it is signed ❖ Raising awareness and performing prevention and promotion among the patients ❖ Visual acuity test ❖ Taking photographs ❖ Transmitting the images to the <i>Laboratoires de la rétine RD</i> ❖ Ensuring that the equipment functions properly

¹¹ In the context of this project, the technician title refers to the person responsible for taking the photographs and transmitting these to the analysis centre which is the *Laboratoires de la rétine RD*. The term "technician" therefore does not refer to college level certification as is often the case in the medical field.



3.5 THE DIABETIC RETINOPATHY SCREENING PROCESS IN THE CONTEXT OF THE PILOT PROJECT¹²

3.5.1 Screening invitations and setting appointments

The health centres of the First Nations communities are tasked with offering first-line services to their populations. In the context of this project, these centres are responsible for inviting the diabetic individuals in their communities to receive a DR screening test and for setting the screening appointments. The invited population includes people who are known to be diabetic following individual screening or the holding of diabetes screening days organised by the community. The terms of the invitations and the setting of appointments were determined by the communities according to the availability of the human resources and the manner in which their health services operate.

To send out the invitations, different methods were therefore favoured by the communities. To promote the service among the diabetic population of Eagle Village, a letter of invitation was sent out to all of the health centre's known diabetic patients. Therefore, 40 letters were sent out during the first year of screening and 43 were sent out during the second. Furthermore, all of the diabetic patients who did not respond to the written invitation were contacted by telephone. In some cases, the patients may have received up to two or three telephone calls reminding them that the camera would be arriving at the health centre and that it was necessary to set an appointment.

In Timiskaming, the promotion of the project was essentially performed by way of word of mouth, through advertisement that appeared in the newsletter disseminated by the community health centre and a message posted on the health centre's bulletin board. In order to contact the patients in Winneway and invite them to use the new screening service, posters were created and all of the diabetic individuals known by the health centre¹³ were forwarded a memo. After these were sent out, the health centre personnel received numerous telephone calls from people wanting to obtain more information regarding the new screening test being provided. Also, when diabetic individuals visited the health centre when the camera was on-site, they were approached regarding the screening test. The number of people who were invited to take part in the screening test in Timiskaming and Winneway was not compiled by the health centres.

¹² The information presented in this section is derived from the document entitled *Diabetic Retinopathy: First Nations of Quebec Distance Screening Project* developed by the various partners and presented to Canada Health Infoway to obtain the funding required for the deployment of the project. This information was also completed through exchanges with the E-Health Agent of the FNQLHSSC and the workers responsible for offering the service in the communities of the pilot project.

¹³ Contrarily to the other communities participating in the pilot project, the community of Winneway possesses a nursing station rather than a health centre. The nursing station offers 24 hour emergency services while the health centre mainly offers community health services during office hours (MSSS, 2007). For the sake of conciseness, the term "health centre" will encompass both health centres and nursing station.



3.5.2 The preparatory steps for taking photographs

Before the patient's arrival at the health centre for DR screening purposes, a few preparatory steps must be performed in order to take photographs of the retina: collecting clinical and demographic data, explaining how the session will unfold, explaining the consent form and having it signed, measuring intraocular pressure (see figure 3.3), measuring visual acuity and dilating the pupils.

Figure 3.3. Tono-Pen used for measuring intraocular pressure in the context of the DR screening pilot project



Source: Training manual. Used with permission. © Health Canada.

The dilation of the pupils is performed by the nurse of the community health centre who is specially trained to perform this medical act. Collective prescriptions covering the administration of the dilation agents (drops required for the measuring of intraocular pressure and the pupil dilation drops needed for photography purposes) were delivered by the *Conseils des médecins, dentistes et pharmaciens* (CMDP) of the *Centres de santé et de services sociaux* (CSSS).

3.5.3 Photography

In the context of this project, it was decided to use the 2008 clinical practice guidelines of the Canadian Diabetes Association for the prevention and treatment of diabetes in Canada. The method of choice for DR screening is colour stereoscopic photography of the back of the eye by a qualified professional. The images of the back of the eye are captured by the community technician who is specially trained for this purpose using a digital non-mydratic camera (see figure 3.4). Therefore, the recommended solution in the context of this project is a seven field exam (six fields of the retina and one of the anterior eye as needed) with systematic dilation of the pupils (see figure 3.5).



Figure 3.4. Non-mydriatic camera used in the context of the DR screening pilot project



Source: www.innovamed.com

Figure 3.5. Example of a photograph of the back of the eye taken in the context of the DR screening pilot project



Source: Training manual. Used with permission. © Health Canada.

The completion of screening slips by the community of Eagle Village during the second year of screening allowed for determining that a screening session (from the patient's arrival until his/her departure) takes approximately one hour (between 50 and 100 minutes with an average of 57 minutes). Various difficulties encountered by the workers can cause these times to be prolonged such as issues related to achieving the appropriate degree of pupil dilation or the need to retake poor quality photographs. As of the implementation of the pilot project, it was anticipated that the health centres would



be performing up to seven screening tests per day. In reality, the number of tests performed per day varied from one community to the next. For the second year of screening in Eagle Village, as reported in the completed slips, between one and five screenings were performed per day. Different reasons can explain this disparity between the number of screening tests anticipated and performed per day such as the difficulties encountered by the health centres when setting appointments with the patients.

3.5.4 Transmission and analysis of the photographs

After the examination, the technician forwards the photographs and clinical data of the patient to the server of the *Laboratoires de la rétine RD* and ensures that this is performed appropriately. The photographs and clinical data are encrypted and then separately transmitted electronically without being compressed to the server of the *Laboratoires de la rétine RD*. The matching of the clinical data and the photographs is performed in the central server during the analysis and interpretation of the photographs by the ophthalmologists. No matching of the patient's clinical data with his/her back of the eye photograph is performed locally.

The ophthalmologists of the *Laboratoires de la rétine RD* ensure that the reading and interpretation of the images is performed and make recommendations regarding the type of follow-up to be carried out. They can access the server through authentication (user name and password). They can then examine the clinical data and denormalised images on their computer in order to perform the analysis and interpretation in light of the patient's clinical information.

The interpretation of the images is performed according to a protocol and based on the criteria of the *Early Treatment Diabetes Retinopathy Study* and can lead to various diagnoses: 1) no anomaly is detected leading to the recommendation of annual follow-up for the patient; 2) an anomaly is detected, but at a moderate stage requiring reimaging in the subsequent four to six months; 3) an anomaly is detected at a more advanced stage requiring follow-up with an ophthalmologist. In the latter case, a referral is made and the delay prescribed for the consultation varies according to the degree of urgency determined by the ophthalmologist of the *Laboratoires de la rétine RD*.

A report is generated automatically either in English or French, depending on the language used in the community, and then forwarded by mail or electronically to all of the physicians involved in the patient's care. The ophthalmologist of the *Laboratoires de la rétine RD* also provides to the community health centre this same report for each patient screened. This report indicates whether or not reimaging in four or six months or medical follow-up with an ophthalmologist is necessary. It also indicates the prescribed delay regarding the medical follow-up for each of these patients. A letter detailing the results is also sent to the patient in order to inform him/her whether or not his/her examination is normal, if reimaging in the four or six months is necessary or if he/she must be examined by an ophthalmologist.



The images taken in the context of the remote screening can be transmitted to the patient's ophthalmologist if he/she requests it from the *Laboratoires de la rétine RD*. If medical follow-up is necessary, the community health centre commits to setting up an appointment with an ophthalmologist in the region or as nearby as possible from the patient's place of residence as identified when defining the service corridor.

An added advantage of this screening service is that, in addition to DR, this screening test can allow for identifying the presence of other eye pathologies such as glaucoma, cataracts and macular degeneration. In the context of this evaluation, it was impossible to identify the types of pathologies that were detected by the ophthalmologists of the *Laboratoires de la rétine RD*.

3.5.5 The archiving and preservation of the data by the Laboratoires de la rétine RD

The objectives of the archiving of the clinical data and images are to: 1) comply with the ethical and medico-legal standards; 2) improve follow-up for the patients requiring regular screening tests; 3) allow for a return to remote screening for patients whose abnormal images have returned to normal; and 4) develop a DR registry that will be used to evaluate the results of the project associated with screening (registry developed and used by the *Laboratoires de la rétine RD*).

Therefore, all of the clinical data and images of the patients participating in the project will be preserved for ten years by the *Laboratoires de la rétine RD*. While taking into consideration the principles of OCAP¹⁴ (ownership, control, access and possession of the data), those who participate in the project will be informed of this component of the project and be required to sign a consent form to that effect.

3.5.6 Utilisation of a mobile camera

One of the important characteristics of this pilot project is the sharing of the same camera between three health centres offering the service. During the pilot project's pre-implementation phase, the community of Eagle Village was designated as the owner of the camera. It is also the responsibility of Eagle Village to facilitate the camera's transportation between the three communities. During the first two years of the pilot project, transportation for the camera was therefore ensured by one of the community's technicians. The camera's movements coincided with the movements of a person who also performs water testing in the context of another mandate for the communities of Timiskaming and Winneway.

In addition to the non-mydratic camera, the equipment that must be transported from one community to the next includes a laptop, an adjustable table that the camera must

¹⁴ The principles of OCAP, as stipulated in the First Nations of Quebec and Labrador Research Protocol (Assembly of First Nations of Quebec and Labrador, 2005) are the expression of self-determination in the field of research. The notions conveyed by these principles are related to collective ownership by a group, First Nations control over the research and information, access to the data and its management and the physical possession of the data.



be placed on, a Tono-Pen used for measuring ocular pressure, a table flipchart as well as spoons for the visual acuity test. The training required for the proper use of this equipment is presented in chapter 6.

A detailed diagram illustrating the screening process, from the invitations to the screening test to the emission of the reports and the treatment of the patients is appended to this document.

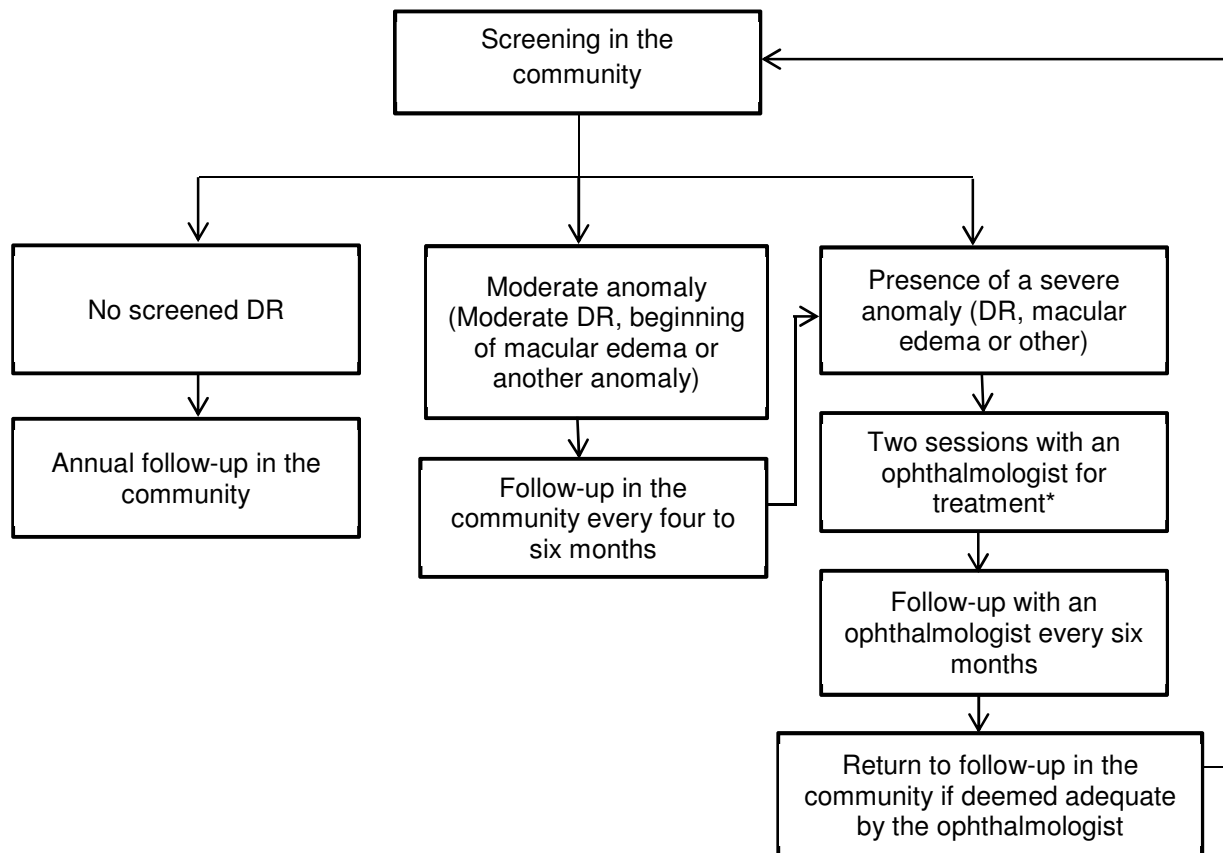
3.6 TRAJECTORIES OF THE PATIENTS IN THE CONTEXT OF THE REMOTE SCREENING PILOT PROJECT

After the implementation of the DR remote screening pilot project, the trajectory of the patients wishing to receive a DR screening test was defined and the patient's trajectory highly facilitated (see the trajectories of the patients before the implementation of the project in chapter 5).

The following figure (3.6) outlines the trajectory of the patients having access to the screening service in their community health centres.



Figure 3.6. Trajectory of the patients after the implementation of the remote screening pilot project



* A minimum of two sessions is required for the treatment. The number of sessions is determined by the ophthalmologist.

The previous figure outlines the fact that, for all of the patients of the pilot project's participating communities, the same trajectory was defined. However, since participation was on a voluntary basis, it is possible that diabetic people in these communities received referrals from their family physicians or optometrists to receive screening from an ophthalmologist.

Following the screening in the community, there are three possible image interpretations: no anomaly, moderate anomaly or severe anomaly. In the event that an anomaly that is deemed severe is detected, the patient is referred to an ophthalmologist to receive the appropriate follow-up and treatment. A return to screening in the community, when the ophthalmologist decides it is appropriate, is possible.

3.7 NUMBER OF ANTICIPATED SCREENINGS

Health data focused on First Nations community members is difficult to access. However, according to the literature that was consulted by the team in charge of the development of the project, the percentage of diabetic individuals is estimated to be at



least 15% among people ages 30 years and up. As of the project's conception, diabetic patients ages 30 years and up were established as the targeted clientele.

Table 3.2 presents the population ages 30 years and up among the communities participating in the pilot project as well as the anticipated number of participants (15% of the population ages 30 years and up).

Table 3.2. Number of expected screenings according to the population ages 30 years and up in the communities of the pilot project*

Communities	Population ages 30 years and up living on the territory of the community*	Anticipated number of participants
Eagle Village	164	25
Timiskaming	277	42
Winneway	149	22
Wolf Lake	n/d	n/d
Total	590	89

* These numbers were derived from the document entitled *Diabetic Retinopathy: First Nations of Quebec Distance Screening Project* developed by the various partners and presented to Canada Health Infoway to obtain the funding required for the deployment of the project.

The preceding table indicates that when the DR remote screening project was being developed, 89 screening tests per year were anticipated for all of the communities participating in the pilot project.



CHAPTER 4 - EVALUATION AND METHODOLOGY FRAMEWORK

4.1 THE MANDATE OF THE EVALUATION

The Research Sector of the First Nations of Quebec and Labrador Health and Social Services Commission (FNQLHSSC) was entrusted with the mandate of carrying out this evaluation. The objective of this evaluation is to document and evaluate the implementation of phase 1¹⁵ of the diabetic retinopathy (DR) remote screening project among the four targeted First Nations communities. Furthermore, this evaluation aims to identify the short-term effects of adding this new service and the factors that influence them. Finally, it also aims to foster local capacity-building and the development of a culture of evaluation among the organisations. Health Canada's First Nations and Inuit Health Branch, Quebec Region (FNIHB-QC) contributed financially to the evaluation of phase 1 of the project.

4.2 THE EVALUATION WORKING GROUP

In order to support the Research Sector of the FNQLHSSC in conducting the evaluation of the DR remote screening project, a working group composed of experts was set up. This group includes members who can provide expertise in the following fields: nursing care, program evaluation, economy, public health, health service organisation and telehealth. More specifically, the working group includes a representative of the participating communities, a representative of FNIHB-QC, an expert on telehealth, health service organisation and project evaluation, an expert on measurement and evaluation and a First Nations expert on telehealth. The Research Sector of the FNQLHSSC is represented on this working group by the Research Agents who are responsible for the evaluation as well as the Research Sector Manager. The E-Health Agent and the Health Sector Manager of the FNQLHSSC, both of whom participated in developing the project, complete the composition of the working group.

The working group's mandate is to participate in the development and realisation of each of the steps of the project's evaluation process. In line with a relationship based on equality and respect, the group of experts provides advice and recommendations. The working group met periodically (eight meetings spread out over a period of two and a half years, see the appended meeting calendar) to follow-up on the progress of the work and guide the evaluation process. These work sessions allowed for presenting and validating the evaluation design, the data collection tools and the preliminary results obtained as well as for collecting the recommendations allowing for the analysis of this data in a comprehensive manner and in such a way as to reflect the opinions of the participants while putting the community realities into context. The actions of the evaluation working group are in line with the First Nations of Quebec and Labrador Research Protocol (2005) of the Assembly of First Nations of Quebec and Labrador

¹⁵ Also referred to as the pilot project.



(AFNQL) as well as the principles of **O**wnership, **C**ontrol, **A**ccess and **P**ossession (OCAP) of the data and the management of the information.

The work that was performed by the Research Agents of the FNQLHSSC and supported by the working group was submitted to a validation exercise with the communities participating in the project.

4.3 THE OBJECTIVES OF THE EVALUATION

The general objective of this evaluation is to support the project and evaluate the relevance, the implementation, the short-term effects and the efficiency, particularly with respect to the services provided in the context of phase 1 of the DR remote screening project (pilot project) among the four targeted First Nations communities.

The evaluation of the relevance, meaning the context in which the project was implemented, allows for identifying the clinical, organisational, demographic, strategic and technological characteristics required for carrying out the remote screening project among the First Nations communities. The evaluation of the implementation explains the application of the project, establishes the portrait of the interventions performed, identifies the factors that are likely to contribute to or hinder the achievement of the project's objectives and identifies the success factors of the implementation of the project. The evaluation of the effects¹⁶ namely defines the short-term effects of the pilot project on the patients, workers and services. The evaluation of the efficiency allows "to establish the relationships between the resources and the effects observed (free translation)" (p. 54) (Brousselle et al., 2011) and comparing them with previous solutions.

In order to guide the evaluation process, four specific objectives were defined:

- ❖ Identifying the conditions associated with the emergence of the DR remote screening project in the four First Nations communities;
- ❖ Evaluating the implementation and application of phase 1 of the DR remote screening project in the four First Nations communities and identifying the facilitating and constraining factors;
- ❖ Evaluating the short-term effects of the DR remote screening pilot project in the four First Nations communities;
- ❖ Documenting the conditions implemented in order to ensure the adoption of the pilot project by the workers of the four communities (health directors, nurses and technicians) as well as the dissemination and sustainability of the project.

¹⁶ In the context of this evaluation, the term "effect" refers to the short-term repercussions of the project in terms of the use of the screening services as well as the organisational, clinical and technological transformations occurring among the community health centres.



For each of these objectives, sub-objectives were identified as well as a list of indicators allowing to target the information required in order to accomplish this evaluation.

The observations, experiences and lessons learned in the context of the evaluation of phase 1 of the project were and will be taken into consideration during the continuation of the dissemination of the new screening service. From this perspective, this evaluation process can contribute to the fight against diabetes in the First Nations communities.

4.4 THE RELEVANCE OF THE EVALUATION OF THE DIABETIC RETINOPATHY REMOTE SCREENING PILOT PROJECT

4.4.1 The social relevance

This evaluation of the implementation of the pilot project allowed for documenting the factors that facilitated in addition to those that hindered the implementation of the DR screening pilot project among the four participating communities. This information will be able to serve in assisting the communities that will later join the screening project during its subsequent phases. In fact, this information will guide the communities in their implementation processes, thereby allowing them to avoid certain difficulties that could have an impact on the smooth unfolding of the project while allowing them to benefit from the successes achieved by other communities.

4.4.2 The relevance for the decision-makers and the organisations

From a formative perspective, an evaluation provides information allowing to improve or modify the interventions. Evaluation fosters the actuation of the solutions in order to correct a situation that could potentially hinder the smooth unfolding of the process. This evaluation allowed for documenting the organisation of the services in the communities of the project while following the changes that occurred over time. The conducted evaluation was also summative since it provide knowledge on the short-term effects of the screening project and therefore guided and will continue to guide the actions and decisions associated with the next steps related to the project's implementation.

The collection tools and the methods of organising the data developed in the context of this evaluation are accessible by the communities which will be able to use them in order to perform follow-up on their intervention and document the significant impacts of the project in their settings. The local use of the collection tools fosters the sharing of knowledge, an increase in the local capacities and the development of an evaluation culture. These tools may also serve the players involved in the implementation of the project for the purpose of identifying the medium- and long-term effects of it while guiding the decision-making process with respect to future orientations.

4.4.3 The relevance for the patients

The evaluation allows for documenting the services received by the patients and, at the same time, assists in raising awareness among the patients, increasing their relationship



of trust with the workers and the services provided in the community in addition to fostering the self-management of their disease.

4.4.4 The relevance for the workers

For the workers in the participating communities, the evaluation process allows for reflecting on the services that are offered to their patients. Furthermore, the workers, by being involved in all of the steps of the process, were able to develop skills in order to be able to look at their work and the services provided from an evaluation perspective. Finally, the dissemination of the results obtained will be able to assist the workers in making the necessary changes in order to allow them to enhance their interventions and improve the continuum of services offered to the patients of the concerned communities.

4.5 EVALUATION APPROACH AND MODEL: THE CASE STUDY

Considering the innovative nature of this project, the progressive implementation strategy and the short observation period, an exploratory and descriptive evaluation was selected. First of all, the evaluation process was conducted through a case study approach, which according to Yin (1989; 1993) is particularly advisable when it is difficult to isolate the object of the evaluation from its context. It was also addressed from a multiple case analysis perspective according to Stake (2006) in order to take into consideration the characteristics of the four sites of the study. Then, to gain a better understanding of the object of the study, comprehensive, pluralistic and results-based approaches were combined in such a way as to provide an overview of the project. Comprehensive, in order to describe and understand as completely as possible the facts related to the development, implementation and unfolding of the project (Guba and Lincoln, 1989; Rossi and Freeman, 1993). Pluralistic, in order to take into consideration the different visions of the workers regarding the project, the hypotheses and the mechanisms implemented (Patton 1997, Monnier, 1992). Results-based, in order to compare with the previous situation the results associated with the introduction of the innovation in terms of advantages, risks and cost factors (Field, 1996). As a whole, this process also aims to identify explanations for the successes, failures or changes in a project.

With respect to the implementation of this project, each community presents its own specific context. The case study therefore allows for gaining an overview of the implementation sites and taking into consideration the particularities of each. Therefore, in order to address the objectives established by this evaluation, the analysis unit used is the community.

The population participating in the evaluation is therefore composed of those who benefitted from the remote screening service, the partners who contributed to the implementation and realisation of the project as well as the workers of the health centres of the participating communities (nurses, technicians and health directors). The sampling derived from this population allows for documenting the points of view of three groups of players:



- ❖ The local players: the workers of the community health centres who offered the new screening service (the nurses, technicians and health directors);
- ❖ The regional players: the designers and funding agencies of the project (FNIHB-QC and the FNQLHSSC) and the other partners of the project (ANPSS, the *Laboratoires de la rétine RD* and RUIS McGill);
- ❖ The users of the new DR remote screening service: the population of the four communities of phase 1 that participated in the remote screening waves.

4.6 THE TYPES OF EVALUATION

4.6.1 The evaluation of the relevance of the context of the project

The evaluation of the relevance, meaning the context in which the pilot project was implemented, allows for identifying the relevant clinical, organisational, demographic, geographic, strategic and technological characteristics associated with the realisation of the remote screening project among the First Nations communities. It indicates whether or not there is a balance between the needs of the patients in the First Nations communities and the objectives and activities of the DR remote screening project.

4.6.2 The evaluation of the implementation

The evaluation of the implementation describes the application of the project, establishes the portrait of the interventions performed, identifies the factors that are likely to contribute to or hinder the achievement of the objectives and identifies the success factors related to the project's implementation. The evaluation of the implementation deals with the quality of the process of putting the project into operation (Patton, 2008). In other words, this type of evaluation “consists of studying the relationships between an intervention and its context during its application. It aims to gain an appreciation of how, within a particular context, an intervention provokes change” (free translation) (Champagne and coll., 2009). This type of evaluation has a formative purpose, since it is performed during the implementation of the project and allows for adapting and correcting, if necessary, the manner in which the activities are carried out. It also has a certain summative purpose, since it provides information explaining the effects of the project which therefore contributes to the decision-making process for the project's subsequent steps.

This evaluation therefore allows for establishing a portrait of the activities performed and the resources invested as well as understanding the internal dynamics of the DR screening project. Moreover, the factors that facilitated the implementation process as well as those that hindered the evaluation process in the communities are identified.



4.6.3 The evaluation of the short-term effects

The evaluation also aims to study the short-term effects of the project. Since the project is short-term in nature and the evaluation unfolded over the course of its implementation, this is therefore particularly a matter of examining the results of the utilisation of the new service and the effects on the existing services (trajectories of the clientele, patient follow-up, roles of the workers, etc.).

Considering the characteristics, the context and the state of progress of the project, an evaluation of the effectiveness requiring the establishment of a causality relationship between the project and its effects is not possible here.

4.6.4 The evaluation of the efficiency

An evaluation of the efficiency allows for establishing a relationship between certain effects obtained and the resources used (human, material, informational and financial). It demonstrates whether or not the results obtained are commensurate with the amount spent and if the resources have been properly mobilised. In this situation, it is therefore a matter of comparing the costs associated with the new screening project with the costs that were involved when the patients in the four communities were required to travel in order to access DR screening services. The calculations were performed based on the financial costs and the societal costs related to the screening tests for the year 2010.

4.7 DATA COLLECTION METHODS

In order to ensure the thoroughness of the process, the use of different data collection methods and sources were favoured allowing for the triangulation of the data. This method allows the researcher or evaluator to address the gaps and biases associated with each of the information sources and methods used. In this sense, the triangulation of the data allows for ensuring that the analysis is supported by a more solid foundation (Roy, 2003).

The data required for the evaluation of the DR remote screening project was collected with the assistance of five sources. The various data collection tools used are presented in the appendices.

4.7.1 The document analysis

The realisation of a document analysis regarding the project allowed for determining the logic behind the project and the implementation of the services. It was a matter of identifying all of the relevant documentation related to the project: identification of important works focused on the evaluation of DR screening projects facilitated by telehealth, various documents developed during the project's pre-implementation process, minutes of the meetings and the training manuals intended for the community nurses and technicians. These documents were provided to the research team by the E-Health Agent of the FNQLHSSC.



4.7.2 Non-participant observation

In order to comprehend the main stakes and the implementation dynamics of the DR remote screening project, the research agents participated in an observer capacity in the various trainings provided in Montreal or the communities to the workers who would be offering the service. Furthermore, a research agent attended a local working group meeting.

4.7.3 The use of the clinical and administrative data

In order to document the services being offered and the conditions in which these services were implemented, clinical and administrative data was consulted. This data was derived from the screenings slips that were filled out by a community health centre, reports providing information on the number of patient screenings submitted on a monthly basis by the *Laboratoires de la rétine RD* to the FNQLHSSC and the image analysis registry established by the *Laboratoires de la rétine RD*. Frequent telephone conversations with the community nurses and technicians as well as discussions with the E-Health Agent of the FNQLHSSC allowed for collecting additional clinical and administrative data. It is important to mention that all of the clinical data collected in the context of this evaluation was denominated.

4.7.4 Conducting the semi-structured interviews and focus groups

Interviews with key players in the project allowed for documenting in greater depth certain aspects related to the emergence, pre-implementation and implementation of the pilot project. These semi-structured interviews were performed with the workers of the four communities (technicians, nurses and health directors), a human resource from the Algonquin Nation Programs and Services Secretariat (ANPSS), a human resource from McGill University's *Réseau universitaire intégré de santé* (RUIS McGill), the E-Health Agent of the FNQLHSSC and various health professionals such as an ophthalmologist from the *Laboratoires de la rétine RD*. In the context of the efficiency evaluation, many conversations by telephone or in writing took place with human resources from the ophthalmology and optometry clinics of Quebec and Ontario. Furthermore, regular telephone conversations with the community workers and discussions with the E-Health Agent also allowed for improving the information held by the team in charge of the evaluation.

Two focus groups were held during the second data collection wave in the summer of 2011 in two different communities. Each of these focus groups brought together the community health centre personnel who are responsible for providing the service: the two technicians and a nurse. These focus groups allowed for collecting the information on the establishment of the service in the community as well as the problems encountered.



4.7.5 The administration of the satisfaction questionnaires among the users

The collection of information among the users of the DR remote screening service was carried out through the use of two written questionnaires administered by field agents in each of the communities. The first questionnaire aimed to gain an understanding of the appreciation of the users following their first screening received within their communities. This questionnaire also allowed for getting to know their expectations regarding the screening service and the medical services that they had access to prior to the implementation of the screening service in their communities. During the second year of the screening service, a second questionnaire was filled out by the users in order to take into consideration the changes observed in terms of the service being provided and to understand the appreciation of the participants regarding the support they receive from their community health centre or hospital when follow-up with an ophthalmologist is necessary.

4.7.6 Meetings of the evaluation working group

Besides the previously mentioned data sources, the evaluation working group meetings also allowed for exchanging information between the members of the group, particularly between the E-Health Agent and the team in charge of the evaluation. These meetings led to many discussions clarifying various components of the project as well as improving the understanding of the research agents performing the evaluation.

4.7.7 A data collection process in two waves

In order to understand the dynamics of the implementation of the project and document how it operates as well as its short-term effects, the data collection process was performed in two waves. The first wave, performed between March and December 2012, allowed for documenting the context of the project's emergence and studying the implementation and establishment of the services as well as the user satisfaction during the first year of screening. This data collection was performed retrospectively. The second wave of the collection aimed to document the phase during which the population accessed the services. This second collection unfolded between March and November 2011. The user satisfaction was measured among the patients who obtained a follow-up appointment following a first screening as well as among the patients who were screened for the first time.

Besides these two data collection waves, information was also collected in an ongoing fashion through telephone conversations with the nurses and technicians of the communities.



4.8 Data analysis and organisation strategies

The collected data was transcribed and coded manually which allowed for indexing and sorting the bodies of data according to the variables of interest. Each case was analysed independently and an inter-case comparison was performed in order to identify their recurring and original characteristics. The coding of the information obtained through the interviews, questionnaires and focus groups allowed for identifying and grouping the elements observed in connection with the objectives of the evaluation.

The quantitative data collected using the satisfaction questionnaire in addition to the data derived from the clinical and administrative files stemming from the *Laboratoires de la rétine RD* and the community health centres were recorded in a database and analysed using the Excel software program. Among other things, a descriptive analysis allowed for determining the number of people screened and establishing a portrait of their characteristics.

This analysis process was monitored very closely by the evaluation group in order to ensure its validity in particular.

This mixed approach based on the use of mainly qualitative data combined with the collection of a certain amount of quantitative data allowed for gaining an understanding in a comprehensive fashion of the implementation of this pilot project.

The literature review that were written in the beginning of the evaluation, the discussions held with the E-Health Agent responsible for the project and the understanding of the pilot project that improved over the course of the data collection process and the discussions that took place during the evaluation working group meetings had an impact on the analysis of the collected body of data. Furthermore, the evaluation objectives that were set in collaboration with the E-Health Agent at the beginning of the evaluation process also guided the analysis.

Finally, in order to foster the optimal comprehension of the implementation of this pilot project, the analysis of the results obtained took place according to a transversal analysis and an inter-case analysis.

4.9 LIMITATIONS OF THE EVALUATION

4.9.1 Limitations related to the methodology

A main limitation of this evaluation process is related to the unique local contexts of the various communities which often complicates the harmonisation and systematisation of the evaluation process in addition to the analysis of the project. The particularities of the communities however allow for the studying of a wider range of factors and contexts that can have an impact on the implementation of a project. However, these particularities greatly complicate the generalisation of the results for all of the First Nations communities of Quebec. Nonetheless, the process allows for identifying the factors that



seemingly facilitate or hinder the implementation of a new screening service and these lessons learned will be useful for the deployment of the screening service among all of the communities.

Due to the amount of time dedicated to the evaluation of phase 1 of the project and the limitations related to the financial resources, it is impossible to determine the long-term effects of adding this screening service on the health of the population of these four communities. However, this evaluation allows for observing the changes related to the organisation of the services that may have an impact on the health of the patients. The evaluation also allows for gauging the satisfaction of the users and patients with respect to the new DR screening service and the short-term effects of the project.

Another limit of this evaluation is related to the data collection process. There were several situations that limited the systematic and complete collection of the data such as the fact that one of the communities was unable to carry out a second wave of screening due to the absence of a nurse. Moreover, the health centres of the participating communities do not have a standardised follow-up management system allowing them to collect information in an optimal manner on the interventions performed. There was also a significant delay in the dissemination of a questionnaire in one of the communities which may have had a negative impact on the response rate.

Also in connection with the data collection, another important limitation of this evaluation is related to the sharing of the information stemming from a main partner. In fact, certain members of the FNIHB-QC personnel involved in the pre-implementation and implementation of the pilot project were invited to participate in the evaluation. These people opted not to take part in some of the data collection activities. Therefore, several elements that are addressed in this report only reflect the points of view of the other players involved in the project. The FNIHB-QC however shared the information needed to perform the economic analysis for the project. A FNIHB-QC manager also participated in several meetings of the evaluation working group and was therefore able to validate some of the information included in this report.

Finally, the social desirability phenomenon, according to which a participant may try to avoid looking bad in the eyes of the researcher, could potentially taint the data collection (Gauthier, 2003). In order to diminish this bias, the participants were ensured of the confidentiality of their answers. Also, the interview questions and satisfaction questionnaires were developed in such a way as to be as neutral as possible.

4.9.2 Limitations related to the team of researchers

Another limitation of the study is related to the researcher's subjectivity. In fact, past experiences, preconceived notions and the reading performed in the context of a research endeavour make it so that the research is not, at first sight, completely objective when collecting and analysing data (Saint-Cyr Tribble and Saintonge, 1999). In the context of this project's evaluation, the realisation of the result validation sessions among the players involved and the evaluation working group contributes to decreasing



the influence of this subjectivity with respect to the interpretation of the information collected.

4.10 THE ETHICAL CONSIDERATION OF THE RESEARCH AMONG THE FIRST NATIONS

4.10.1 The principles of OCAP

This evaluation was conducted while respecting the First Nations of Quebec and Labrador Research Protocol of the AFNQL (2005) and the principles of OCAP. These four principles are as follows: **O**wnership of the collective data by the First Nations members, **C**ontrol over the research process and the information collected, **A**ccess to the information and data and, finally, the physical **P**ossession of the data. Also, the evaluation was performed in compliance with the standards associated with quality, methodological rigour, respect for confidentiality and the protection of the data as stipulated in the Code of Research Ethics adopted within the context of the First Nations Regional Longitudinal Health Survey (2004).

4.10.2 The validation of the results

Some of the information appearing in this report such as the scan of the communities – see the evaluation of the relevance – was validated by the community health centres in order to ensure that the information is in line with the socio-demographic realities as well as the realities of the health services that are provided within each of the four communities.

This evaluation report was also forwarded to the community health centres that took part in the project. This allows the players that participated in the implementation and development of the project to become familiar with the contents of the report, make certain clarifications and modify some of the information presented.



CHAPTER 5 - EVALUATION OF THE RELEVANCE

This chapter specifies the criteria that were retained for the purpose of selecting the communities that would be included in the diabetic retinopathy (DR) remote screening pilot project. It also describes their main characteristics at the beginning of the project which allows for gaining a better understanding of the project within its context, providing more justifications for it and establishing an initial situation that allows for evaluating the transformations, results and effects stemming from the project. This will allow for measuring the degree of achievement of the pilot project's objectives more effectively.

5.1 THE COMMUNITY SELECTIONS

The four communities that are included in phase 1 of the project are: Eagle Village, Timiskaming, Winneway and Wolf Lake (the services are provided to the members of Wolf Lake by way of Eagle Village). Many reasons led to selecting these communities for phase 1 of the DR remote screening pilot project: 1) they are part of the same socio-sanitary region served by McGill University's *Réseau universitaire de intégré de santé* (RUIS McGill) that benefits from telehealth experience in the Aboriginal settings; 2) one of the communities already uses telehealth to offer services and therefore has experience in this field; 3) the presence of an interested general practitioner with experience in the use of telehealth; 4) the collaboration and involvement of the Algonquin Nation Programs and Services Secretariat (ANPSS); 5) the presence of a collaborative relationship between the health directors of these communities; and 6) the presence, within these communities, of activities related to the prevention and treatment of diabetes. It is important to note that the four band councils concerned officially authorised their communities' participation in the project.

In the context of the evaluation of the relevance, it was deemed necessary to evaluate the degree of harmony between the health services offered in the communities and the objectives of the remote screening project. This evaluation would allow for specifying the connections between the services required to improve First Nations control as well as the service follow-up.

5.2 SCAN OF THE COMMUNITIES AND ORGANISATION OF THE SERVICES BEFORE THE IMPLEMENTATION OF THE PILOT PROJECT

In partnership with the local players of the four First Nations communities, the First Nations of Quebec and Labrador Health and Social Services Commission (FNQLHSSC) and the First Nations and Inuit Health Branch, Quebec Region (FNIHB-QC) produced a first description of the organisation of each community's health services. These scans were updated in the context of the evaluation and then validated by the four communities. The four scans allowed for identifying the most relevant organisational, demographic, geographic, strategic and technological characteristics for the realisation of the remote screening project among the First Nations communities. Performing the



scan of the communities prior to the implementation of the project also allowed for identifying the changes that were made thanks to the new remote screening services which will be described in the evaluation's following sections.

5.2.1 Timiskaming

A. Socio-demographic portrait

The community of Timiskaming is located in the Health region of Abitibi-Témiscamingue and is adjacent to the municipality of Notre-Dame-du-Nord (1250 inhabitants). It is serviced by the *CSSS du Lac-Témiscamingue*, in Ville-Marie. Timiskaming First Nation is located 30 km away from Ville-Marie and 105 km away from Rouyn-Noranda. Based on AANDC's classification¹⁷, this community is located in a geographical isolation zone 1, which means that it is located within 50 km of the nearest service centre with year-round road access. Established in 1849, Timiskaming is one of the oldest communities of Quebec. At the time of its creation, the community covered over 40,500 hectares. But following the numerous partial concessions, often against the will of the community, the community's total area now covers 1,852 hectares.

Based on the statistics compiled by AANDC (2010), the community of Timiskaming has a population of 1,675 people. Of this number, 610 people live in the community and 1,065 live outside the territory. According to the data provided by the Band Council as of 2006 (total population: 1,624 people), women represent 53% of the population. As well, the group aged 0 to 14 represents 17% of the population, the 15-24 age group 15%, the 25-44 age group 34%, the 45-64 age group 24 % and, finally, the group aged 65 and over represents 10% of the population.

The Algonquin language is spoken mostly amongst a few elders and community members. The most common language spoken in the community is English, although French is understood by many. Concerning the schooling level, based on the 2001 census, nearly 53% of the active population in Timiskaming (15 years old and over) does not have a high school diploma. On the community's territory there is a school, Kiwetin School, which offers pre-kindergarten to secondary II. During the 2008-2009 school year, 65 children attended the school (AANDC, 2010). At the beginning of 2010 school year, a total of 90 children were enrolled in the school including the Head Start Program.

The average individual income of the community members in 2001 was approximately \$19,000. There are about thirteen businesses on the community's territory: convenience

¹⁷ According to the classification manual developed by AANDC, the First Nations communities are divided into four zones of geographic isolation. The communities that are located less than 50 km from a service centre with year-round road access are part of **zone 1**. The communities that are located between 50 and 350 km from a service centre with year-round road access are part of **zone 2**. The communities that are located more than 350 km away from a service centre with year-round road access are part of **zone 3**. The communities that do not have year-round road access to a service centre are part of **zone 4** (Aboriginal Affairs and Northern Development Canada, 2000).



stores, gas station, heavy duty machinery and wear parts distributor and transportation enterprise.

B. First-line health services offered in the community

The community of Timiskaming has a Health Centre which mainly offers health prevention and promotion services. Its medical team is comprised of three nurses, one full-time and two part-time. The team also consist of a health director, one community health representative (CHR), one Community Diabetes Prevention Worker, two addictions workers (NNADAP), one Mental Health, one Brighter Future, one oral hygienist, a medical transportation worker, a medical secretary and a receptionist.

The Timiskaming First Nation Band Office is in charge of the Health Centre administration. For health problems, patients are referred to their family practitioner or to the hospital. A majority of patients go to the hospital in New Liskeard (Ontario) for two reasons, their physician practises in Ontario and the language issue. Others go to the CSSS in Ville-Marie and Timiskaming, Quebec, where services are limited due to mostly French speaking personnel. Hence, despite the fact that accessing health services is not easier by crossing the provincial border, several members prefer receiving services without the language barrier.

The CSSS mandated to provide services to the community members includes a CLSC, a general hospital and a residence for long-term care. Furthermore, two pharmacies and a "COOP Santé" can be accessed in Ville-Marie and one physician from the CSSS has a consultation office on a monthly basis in Notre-Dame-du-Nord. A physician from Ontario provides limited services to some community members. He visits the Health Centre monthly and sees from 12 to 15 of his patients. He also cares for the patients at the local Nursing Home, Anishnabe Long Term Care Centre. Patients have access to three pharmacies and a hospital in Ontario.

The members of Timiskaming also have access to a physical instructor and to other health professionals such as a speech language therapist, nutritionist or dietician from New Liskeard (located 27 km away from Notre-Dame-du-Nord) or from Kirkland Lake (50 kilometres away). Physicians have been invited to give conferences on a number of subjects. A nutritionist from Health Canada has been involved with the CHR in organizing health prevention and promotion activities in the community.

C. Second- and third-line health services offered

The *CSSS du Lac-Témiscamingue* only offers first-line services. To receive more specialized care, the members of Timiskaming must travel to Rouyn-Noranda, Amos, Val-d'Or or Montreal. However, a few specialists from Montreal do offer consultations in Rouyn-Noranda and Amos.

When patients are seen by their Ontario physician, they are usually referred to Ontario centres for further testing and treatment. Patients need to travel to Sudbury hospitals, in



Ontario, nearly 250 km away from Notre-Dame-du-Nord. Waiting periods are generally shorter in Ontario than in Quebec, further enticing the population to obtain services from Ontario. Overtime, some Ontario specialists have been requesting money upfront for tests and some treatment due to the difference in fees and length of time before receiving compensation for services rendered.

Patient's appointments with specialists are usually arranged by the physician's office and often booked by the nursing staff at the Health Centre. After a consultation, the report is sent to the requesting physician. The Health Centre may receive a copy of the results if requested by the patient or if follow-up is required from the Health Centre nursing staff. Other places where it is possible for patients from Timiskaming to consult a specialist (ophthalmology, internal medicine, nephrology, cardiology and neurology) are the hospitals of North Bay, New Liskeard or Ottawa, which are all located in Ontario. It is to be noted that specialists can be accessed in the other CSSSs of the Abitibi-Témiscamingue region (*Eskers of Abitibi, Vallée-de-L'Or and Rouyn-Noranda*).

D. Diabetes related prevention and promotion activities

In Timiskaming, diabetes is one of the three priorities identified in the community's health plan. There are about 70 diabetics and glucose intolerant in the population living on the territory. Furthermore, gestational diabetes is present at 10% among pregnant women. Of course, this data corresponds to the people that have been diagnosed by or get their follow-up at the community Health Centre. However, a lack of motivation and participation is noted in the population when it comes to diabetes. The Health Centre wishes to improve the prevention and promotion in relation to this disease, but the resources and time are limited.

The members of Timiskaming are informed of health prevention and promotion through consults with nurses during walk-in clinics. Other tools such as, cooking workshops, newsletter articles, conferences, radio announcements, community electronic board are used to convey health related information or messages. A Health Day fair is a yearly event in which different community organisation, for example, the police force, Kiwetin School, Pidaben daycare, Anishnabe Long Term Care Centre, join forces in distributing their message on promotion and prevention.

Nutrition-related activities are organized by the community health representative (CHR). A nutritionist from Health Canada or adjoining town has on occasions collaborated with these activities, which may include, for example, cooking classes or grocery store visits. Physical activities are also offered by the CHR on a regular basis. Physical activity challenges have attracted as many as 30 to 45 participants per sessions. They have been well attended. To promote these activities, an electronic billboard has been installed outside the Health Centre and the information is also published through newsletters and distributed in the community.



E. Diabetes screening and follow-up of diagnosed patients

Mass screening sessions are offered in the community but not on a systematic basis. Once a year, during the National Health Day held in May, screening is done with the population. Anyone participating to the fair is encouraged to have their blood pressure or blood sugar tested. However, when there are obesity or predisposing genetic factors, screening is also done with younger individuals. When abnormal results are obtained, clients are informed of the result, are encouraged to seek health teaching and referred to their family practitioner.

The community members also have access to individual screening on a regular basis during walk-in clinics held every week morning. Screening for gestational diabetes is part of the routine evaluation conducted during the pregnancy. Blood tests are done using a blood glucose monitor and when abnormal results are obtained, patients are referred to their physician or the emergency department. Statistics that identify the individuals with diabetes are compiled by the Health Centre. This list includes only the individuals who visit the health centre. There are concerns that many may not be aware of their condition.

Blood pressure can be monitored according to the patient's needs. Blood work clinics are held every Tuesday. Samples obtained are taken a local lab, either in Ontario or Quebec, depending on where the request originated from. Once analysed the result are forwarded to the physician and to the Health Centre, if it is indicated on the requisition.

The Timiskaming Health Centre performs yearly physical school exams. Parents are informed if any concerns arise from the evaluation, so appropriate measures can be taken. The nurse takes advantage of this activity to promote healthy eating, safety issues and the importance of physical activity along with verifying each student's vaccination record.

F. Trajectory of the diabetic people for the screening of diabetic retinopathy before the implementation of the pilot project

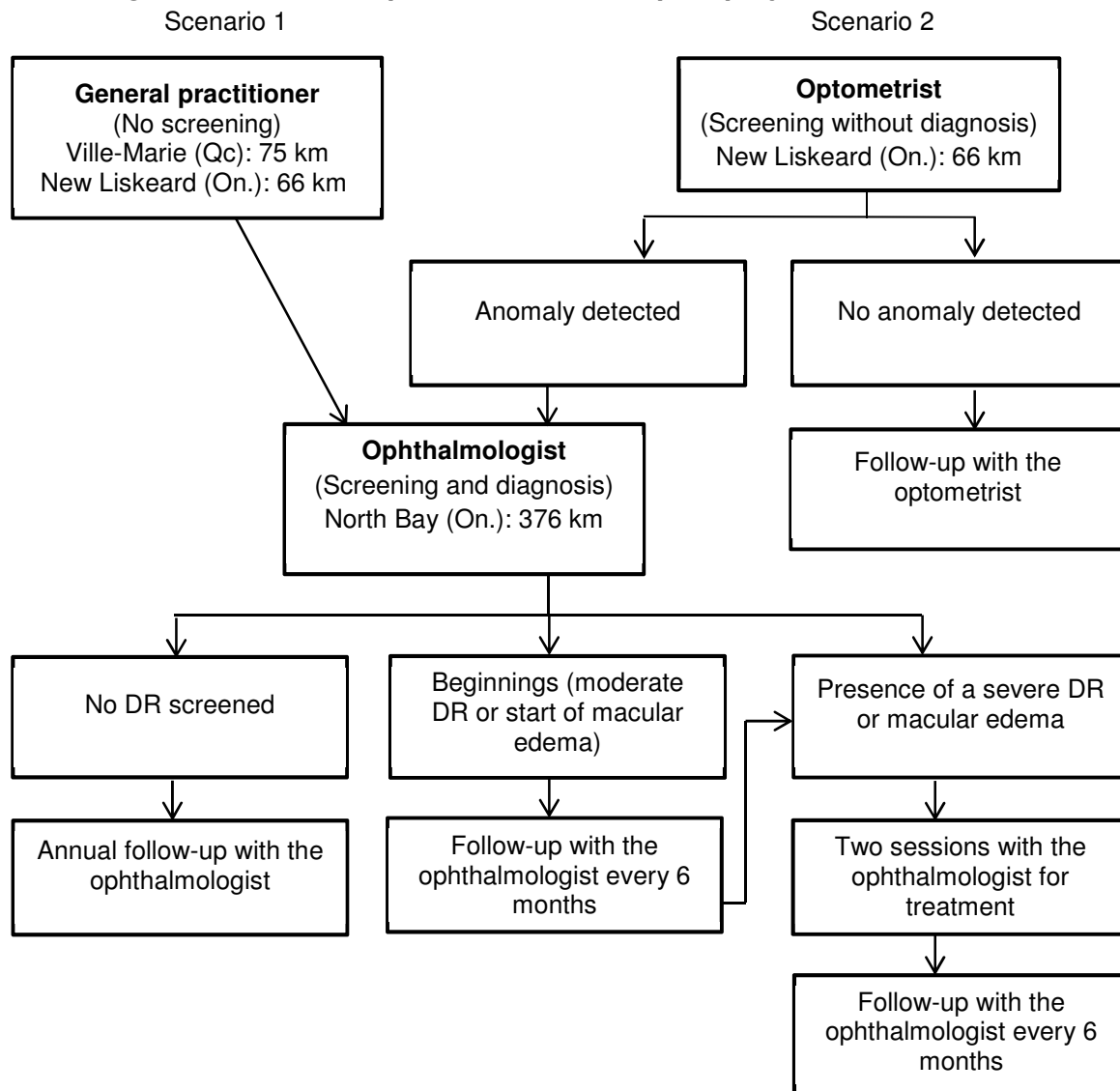
Before the implementation of the DR remote screening pilot project, no well-defined service corridor had been created in order to allow diabetic individuals from Timiskaming to access DR screening tests. Two scenarios were then possible for the patients wishing to obtain this service: either obtaining a referral for an ophthalmology consultation from their general practitioner, or obtaining a referral for an ophthalmology consultation following a first screening test provided by an optometrist. It should be noted that an optometrist cannot make this diagnosis, but he/she can nonetheless identify an anomaly requiring a consultation with an ophthalmologist.

The following figure (5.1) illustrates the possible trajectories for the patients from Timiskaming before the implementation of the pilot project. It outlines the locations of the professionals and the distance (return trip) that must be travelled in order to consult a general practitioner, optometrist or ophthalmologist. It is important to note that the



trajectories outlined in this flowchart reflect the service corridors that were frequently used by the members of the community. These trajectories were reported by the health centre personnel and supported by information provided by the users of the service in the satisfaction questionnaire. Thus, other professionals may also have been consulted by diabetic individuals from Timiskaming before the arrival of the service within the community. No empirical data was available in order to accurately determine the number of diabetic people from Timiskaming who had already been screened for DR, nor the exact trajectory taken by these patients.

Figure 5.1. Trajectories of the patients from Timiskaming for a diabetic retinopathy screening test before the implementation of the pilot project*



* The distances presented in this figure are for a return trip.

This diagram indicates that the offices of the general practitioners of the members of Timiskaming are located, for the majority of the cases, either in Ville-Marie which is



located in Quebec, or in New Liskeard which is located in Ontario. As for the optometrists and ophthalmologists that are frequently consulted, they are located in New Liskeard and North Bay respectively.

5.2.2 Eagle Village

A. Socio-demographic portrait

The community of Eagle Village, which originally was called Kebaowek, is located a dozen kilometres away from Témiscaming, on the shores of the Lake Kipawa, in the Abitibi-Témiscamingue region. The community of Eagle Village, also known as Kipawa, covers an area of 50.6 hectares and can be accessed year-round by road 101, thus classifying itself in a geographical isolation zone 2, based on Aboriginal Affairs and Northern Development Canada (AANDC).

The Eagle Village-Kipawa Band was officially formed in 1965 and the community built in 1974. The community's economic activities are mainly related to business and services, arts and crafts, forestry, trapping, outfitting operations and transportation. The community offers various services to its residents such as a fire protection service, a police force, a Health Centre as well as a daycare centre. But there is no school on the community's territory.

Based on the statistics compiled by the Band Council in 2006, the community has 781 members, of which 268 live in the community and 513 live off reserve. Based on the same data, women represent 49.7% of the population and men represent 50.3% of the population. It should also be noted that 19.5% of the members are aged 15 and under while 3% are aged over 65. English and Algonquin are the languages used by the members.

The *Centre de santé et de services sociaux (CSSS) de Témiscaming-et-de-Kipawa* is mandated to offer health services to the members of Eagle Village. This way the community members have access to a local community service centre (CLSC), a hospital, a long-term care centre, a family medicine group (GMF) and a pharmacy; all located 15 km away from the community.

Based on the data from the Health Centre as of 2009, 34 members of the population residing on the territory had been diagnosed as diabetics. At the beginning of the implementation phase of the diabetic retinopathy screening project, this number was 40. It is to be noted that this data only takes into account the cases diagnosed at the Health Centre or followed-up there.

B. First-line health services offered in the community

The Health Centre team is comprised of a health director, two nurses - one in community health and one in homecare – one community health representative trained as diabetes officer at Yellowquill College (Community Diabetes Worker Program), one sports and leisure officer trained in intervention with youth, one addictions officer (NNADAP) who



was also trained at Yellowquill College, one environmental health technician and one mental health officer. All the team members work full-time. One support and care officer from the homecare program works two half days per week. Youth programs are also offered and coordinated by the Migizi Odenaw Day Centre.

There is no nutritionist working in the community and the workload of the person in this position at the CLSC does not allow for a regular support in the community. Also, the services that used to be offered by an optometrist are no longer available because of equipment and license attribution problems.

Three general practitioners from the *CSSS de Témiscaming-et-de-Kipawa* visit the Health Centre half a day three times a month. However, no formal agreement has been reached between the two entities. The community members can consult another physician through appointments and the emergency services at the hospital, but never on the community.

Usually, patients can get an appointment at the Health Centre within a month, whereas it is often months before they can get one at the hospital. The sharing of information between the Health Centre and the hospital seems inefficient: when patients are seen at the hospital and the physician enters notes and test results in the file, the Health Centre does not necessarily receive a copy of them. The names of the patients are sent to the hospital before the clinics are held at the Health Centre and the physicians bring the patients' files with them when doing the visits. Finally, medicine students from McGill University go in the community on a regular basis in the context of their family medicine residency, but there is no formal agreement between the university and the community of Eagle Village.

C. Second- and third-line health services offered

Since the Health Centre and the *CSSS de Témiscaming-et-de-Kipawa* only provide first-line care, patients are either referred to the North Bay general hospital or the Sudbury regional hospital, both located in Ontario, or in Rouyn-Noranda. For several years now, connections have developed between the *CSSS de Témiscamingue-et-de-Kipawa* and the North Bay general hospital because of the proximity and the language of communication. Indeed, North Bay is located 81 km away from the community and offers services in English while Rouyn-Noranda is 2 hours 50 minutes away, or 230 km from Eagle Village and located on French-speaking Quebec territory. Therefore, the CSSS refers its patients there and the North Bay hospital takes them in and accepts being paid based on the rates in effect in Quebec. Eagle Village benefits from such an agreement between both provinces. Members of the community have access to a DR specialist at North Bay.

D. Diabetes related prevention and promotion activities

Articles are published monthly in the community newspaper and health promotion and prevention workshops allow patients to be well-informed on diabetes, its symptoms and



complications. Information is also provided during walk-in clinics. Once every second year a person with diabetes is invited to give a personal account during a discussion group on the consequences of diabetes. Overall, diabetes related workshops gather a lot of people.

The staff's lack of availability has resulted in a reduction of nutrition related activities such as nutrition, grocery and cooking workshops. Generally speaking, the community health representative (CHR) is responsible for organizing health prevention and promotion activities in collaboration with the other members of the Health Centre team. The CHR is also responsible for the promotional material, the preparation of screening activities and breakfasts organized four times a year for the community members with diabetes. During these breakfasts, people are invited to show up without having eaten in order to be able to measure their blood glucose and cholesterol levels. Once the tests are done, participants share a meal and information is given to them. The services of a nutritionist would allow holding this activity more frequently. The promotion of physical activity (weight loss challenge, walking challenge and exercise program) is done through mouth-to-ear, but also through the monthly community newspaper.

E. Diabetes screening and follow-up of diagnosed patients

Diabetes screening activities have been held for the past five years. Diabetes, blood pressure and cholesterol mass screening is conducted twice a year: in the spring during the Health Fair and in autumn at the Health Centre. The capillary glucose and cholesterol levels are checked with an *Acutrend* type monitor. On average, 75 to 85 adults aged over thirty are screened this way. When abnormal results are obtained, a second test is done in a fasting state and a letter is sent to the family practitioner with the results of both tests. Usually, patients are able to get a consultation at the Health Centre within a month whereas it takes several months for a consultation at the CLSC or the hospital.

Individual screening is also done for people aged between 7 and 75 years old, and it is planned to conduct screening at school with the parents' permission. Pregnant women are screened by a general practitioner and referred to an obstetrician in case of a positive test result. A database created by the nurses allows for a follow-up of people with diabetes. A collective prescription for the follow-up of diabetes was developed in collaboration with the Office of Nursing Services of Health Canada's FNIHB-QC and approved by the council of physicians, dentists and pharmacists of the region.

F. Trajectory of the diabetic people for the screening of diabetic retinopathy before the implementation of the pilot project

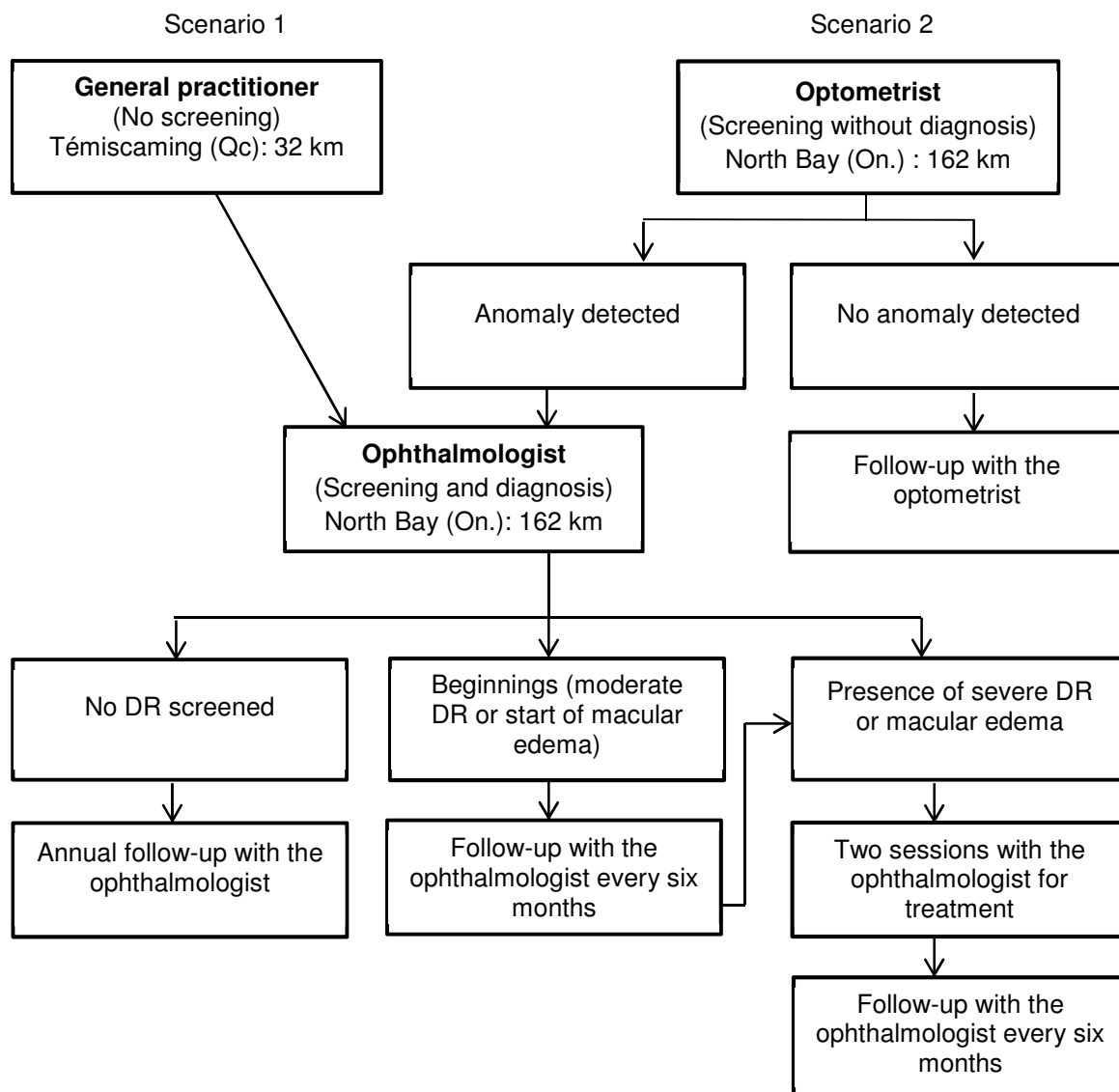
Before the implementation of the DR remote screening pilot project, no well-defined service corridor had been created in order to allow diabetic individuals from Eagle Village to access DR screening tests. Like for the diabetic individuals from Timiskaming, two scenarios were then possible for the patients wishing to obtain this service: either



obtaining a referral for an ophthalmology consultation from their general practitioner, or obtaining a referral from an optometrist.

The following diagram (figure 5.2) illustrates the possible trajectories for the patients from Eagle Village before the implementation of the pilot project. The trajectories presented reflect the service corridors that are frequently used by the members of the community.

Figure 5.2. Trajectories of the patients from Eagle Village for a diabetic retinopathy screening test before the implementation of the pilot project*



* The distances presented in this figure are for a return trip.



The previous figure demonstrates that the diabetic patients from Eagle Village generally visit their family physicians in Témiscaming which is located in Quebec not far away from their community. For more specialised services in the fields of ophthalmology or optometry, generally-speaking, the patients travel to North Bay which is located 81 km from their place of residence.

5.2.3 Winneway

A. Socio-demographic portrait

The community of Winneway (Long Point First Nation) settled at its current location, on the shore of the Winneway River, in the 1950s. It is located in Abitibi-Témiscamingue slightly over 100 km from Ville-Marie. Long Point-Winneway is therefore a community classified as being in a geographical isolation zone 2 according to Aboriginal Affairs and Northern Development Canada (AANDC). Until the end of the 19th century the community was named Long Point, which, in fact, was the name of the trading post built at that place. The members now use the name Winneway for their community, which means “white water” in Algonquin. The community’s territory covers an area of approximately 38 hectares.

A special feature of this community is the fact that it is not considered as a reserve but rather as an Indian settlement. An Indian settlement is a census area defined by AANDC where at least ten individuals live on a permanent basis. This area is usually located on Federal or Provincial land that has not been put aside for the use or profit of an Indian Band, as it is the case for reserves.

The community of Winneway has 751 members of which 405 live on the territory and 346 live off reserve (2009). Based on the statistics compiled by the Band Council as of 2006, 53% of the population is composed of women. As well, 39% are aged between 0 and 19, and only 3% of the members are aged over 65. The community members speak both Algonquin and English.

Concerning the services available in the community, there is a school, the Amo Ososwan School, which offers pre-kindergarten to the last year of secondary school and was attended by 85 students in 2010-2011. A gas station, a convenience store, a community radio station, a fire station, a nursing station¹⁸, a police force and craft workshops are the facilities that can be found on the territory of Winneway.

Concerning the presence of diabetes in Winneway, the Health Centre estimates that approximately 40 diabetics would have been diagnosed among the population living on the territory. This data corresponds only to the people that have been diagnosed or get their follow-up at the nursing Station.

¹⁸ As previously mentioned, certain aspects of nursing stations are different from health centres. However, for the purpose of brevity, the nursing station is included in the term “health centre”.



B. First-line health services offered in the community

The *CSSS du Lac-Témiscamingue*, located in Ville-Marie, is mandated to provide health services to the members of Winneway; the CSSS includes a CLSC, a general hospital and a hospital offering long-term care. There are no specialists affiliated to this CSSS. The members of Winneway have access to two pharmacies and to one private medical clinic in Ville-Marie. Also, a new medical cooperative has been implemented in Ville-Marie and all the members of the community are registered there.

The staff at the nursing station in the community of Winneway is comprised of a health director, three full-time nurses¹⁹, one community health representative and one diabetes officer trained at Yellowquill College. The nurses working in Winneway all come from a private agency and are employed by Health Canada²⁰.

A number of specialists visit the community on a regular basis: a nurse specialized in foot care (once every six weeks), a dentist (once a week) and a psychologist. No nutritionist offers services in the community and no general practitioner comes to the community on a regular basis. The members do have access to teleconsultation with a physician associated to the *CSSS du Lac-Témiscamingue*, but the physician not being available very much and the technology related difficulties result in the service being offered only sporadically and the patients having to travel great distances to consult a physician at the emergency services of the CSSS. As almost all residents of Winneway have no family practitioner, an application has been made to have a physician visit the community on a regular basis.

C. Second- and third-line health services offered

As the *CSSS du Lac-Témiscamingue* provides only first-line services, the members of Winneway must travel to Rouyn-Noranda (216 km), Amos (166 km), Val-d'Or (115 km) or Montreal (630 km) to consult specialists. A number of specialists from Montreal also offer consultations in Rouyn-Noranda and Amos. It is difficult for patients to get an appointment with a specialist and the waiting time can extend to several years. With a referral from a family practitioner, the waiting time is reduced but can nevertheless reach a month. All appointments with physicians are organized by the medical transportation service coordinator.

Concerning the diabetes complications related care, the results of the tests conducted by general practitioners or specialists are sent to the nursing station, which in turn

¹⁹ As will be explained in the following chapter (chapter 6), nurses working in the nursing station of the community of Winneway left their positions over the course of the project's implementation. Therefore, staff turnover during the implementation of the project had the effect of varying the number of nurses in position.

²⁰ The management of the health services within the First Nations communities can be performed, according to the signed transfer agreements, by the actual communities or by Health Canada – FNIHB. The nursing station in Winneway is one of the community health facilities for which health service management has yet to be transferred.



carries out the appropriate follow-up. Concerning the screening for diabetes related retinopathy, no screening is carried out, except when a referral to the ophthalmologist in Rouyn-Noranda is requested. However, the waiting time to consult this specialist can reach several months since only one ophthalmologist is available for the whole region. Therefore, the average waiting time for screening is two years.

D. Diabetes related prevention and promotion activities

Diabetes is one of the three health priorities identified by the community. The community members are informed of health prevention and promotion at workshops organized during the Diabetes Week held every fall. Other workshops are also offered on nutrition and physical activity. Walks are also organized during the Diabetes Week and the Aboriginal diabetes Day. According to the workers in Winneway, the population looks forward to these workshops and activities.

The community's diabetes officer is responsible for organizing promotion and prevention activities in collaboration with the nursing station staff. To promote these activities, the community radio, interpersonal communication channels and memos are used. Despite these activities, the nursing station staff estimates that individual consultations would be necessary. Moreover, the staff would like to organize other various activities in order to increase the information transmitted to the community youth adults, such as a walking club, an exercise program, cooking classes or even a dance club.

E. Diabetes screening and follow-up of diagnosed patients

Mass screening activities are held every year during the Aboriginal Diabetes Day in May and during the Aboriginal Diabetes Week in the fall. Also, one morning is dedicated to diabetes screening among the community youth. This event is held at school and allows reaching over 90% of the youth. It is estimated that the community members participate more when food is served during the event. Finally, concerning children, they are screened with their parents' approval when they enter daycare or during their first school year. Over 50% of the children are screened this way and it is hoped that all the community members aged 12 and over will also be screened in the future.

The screening results are noted in the patient's file. If the results are considered abnormal, the patient's family practitioner is informed. When other tests are requested by the physician, they are done at the nursing station, which also ensures the necessary follow-up.

Pregnant women are screened for diabetes during their 14th and 28th week of pregnancy. Close follow-up is ensured when a pregnant woman is already diagnosed as diabetic.

The follow-up of individuals with diabetes or high blood pressure is ensured by the nurses at the nursing station twice a week. Only 20% of the people who require a follow-up show up at these clinics. However, other follow-ups are offered during home visits by



nurses or when a patient comes to the nursing station. Blood samples are sent to the *CSSS du Lac-Témiscamingue* on a regular basis and copies of the results are sent to the patient's family practitioner and to the nursing station.

There used to be a support group for diabetics, but it ended several years ago. The community plans to start a new support group.

Finally, no collective prescription has been given to the community of Winneway.

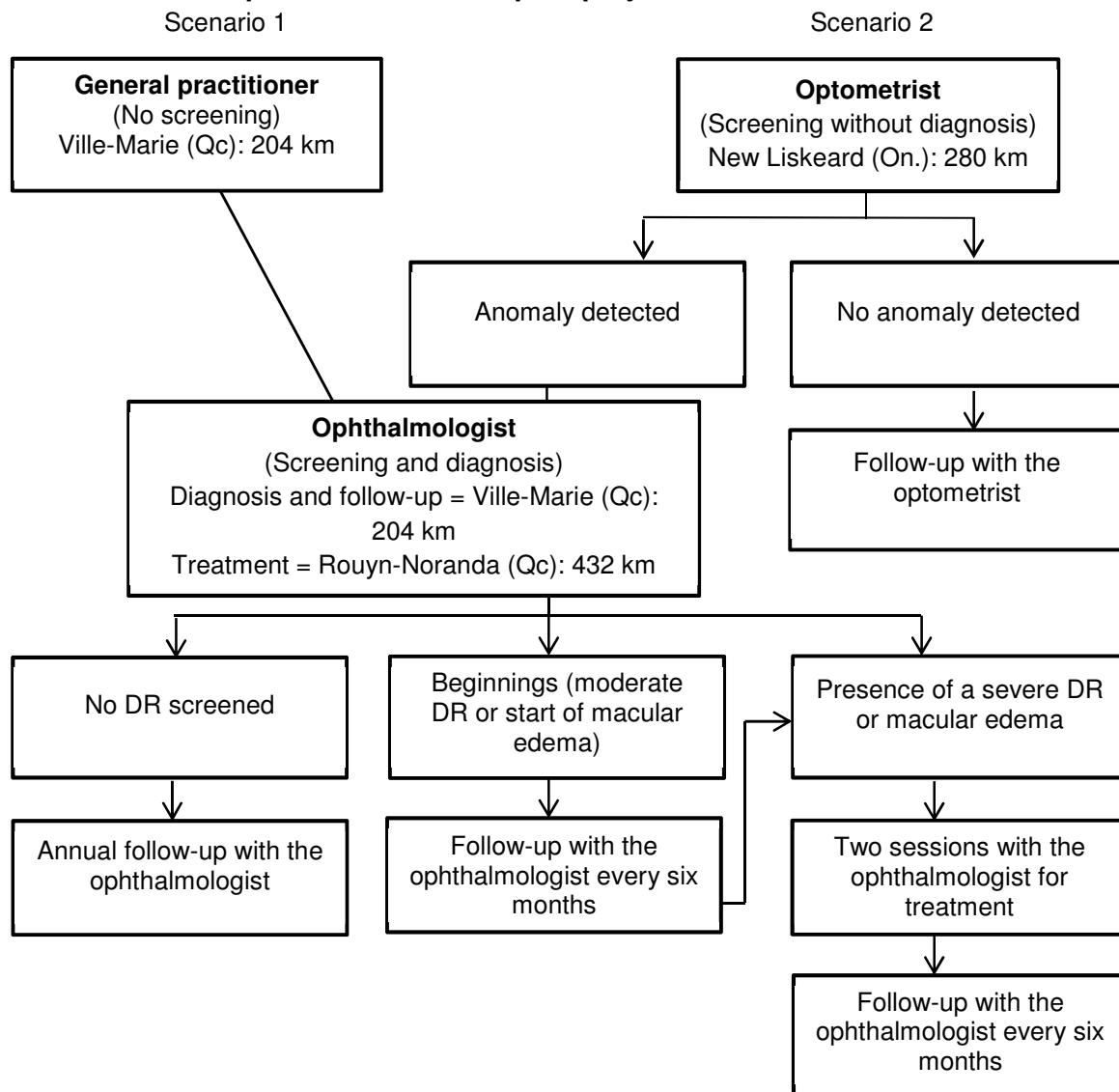
F. Trajectory of the diabetic people for the screening of diabetic retinopathy before the implementation of the pilot project

Before the implementation of the DR remote screening pilot project, no well-defined service corridor had been created in order to allow diabetic individuals from Winneway to access DR screening tests. As for the other communities involved in the pilot project, two scenarios were possible for the patients: either obtaining a referral for an ophthalmology consultation from their general practitioner or from an optometrist.

The following figure (5.3) illustrates the possible trajectories (frequently used) for the patients from Winneway before the implementation of the pilot project.



Figure 5.3. Trajectories of the patients from Winneway for a diabetic screening test before the implementation of the pilot project*



* The distances presented in this figure are for a return trip.

Contrarily to the other communities participating in the pilot project, the diabetic individuals from Winneway that needed to consult an ophthalmologist either went to Ville-Marie or Rouyn-Noranda, both of which are located in Quebec. However, for an optometry consultation, the patients went to New Liskeard in Ontario.

5.2.4 Wolf Lake

A. Socio-demographic portrait

The community of Wolf Lake covers an area of 4 hectares and is located 37 kilometres northeast of Témiscaming, at Hunter's Point Lake, in the Abitibi-Témiscamingue region. Based on AANDC's classification, Wolf Lake is located in a geographical isolation zone 2. As with the community of Winneway, Wolf Lake is not considered as a community but rather as an Indian settlement. The community's territory is occupied mainly during the summer season.

The Wolf Lake Band has over 200 members, but only a dozen of them live on the community's ancestral territory. Most of the other members live in Témiscaming, Eagle Village or elsewhere in southern Abitibi. Algonquin and English are the languages used by the community members.

Wolf Lake's economy is mainly related to tourism activities such as hunting and fishing. As such, the Band Council owns a non-profit corporation - very active with regards to tourism - whose mission is to identify and develop local and regional economic development opportunities. There are no public services offered on the community's territory, whether fire protection, police force or educational institution.

B. Health Services Offered in the Community

Wolf Lake does not have a Health Centre and several of its members use the one in Eagle Village or the hospital in Témiscaming to receive health services. However, a number of diabetes related activities are organized such as walks and healthy snacks. Information sessions are also organized with neighboring communities, such as workshops in collaboration with the Yellowquill College.

5.3 SUMMARY OF THE EVALUATION OF THE RELEVANCE

As indicated in the scans of the communities, the four communities that were selected had already targeted the fight against diabetes as one of their priorities before the implementation of the remote screening project. Furthermore, for the four communities, 15% of the members were diagnosed with diabetes.

Prior to the implementation of the project, the communities had already developed awareness and prevention activities intended for their members in order to inform them regarding the possible complications associated with diabetes and the ways that type 2 diabetes can be prevented. The following are some examples: discussions held in the context of National Diabetes Day, annual health fairs, messages broadcasted by community radio stations, cooking workshops, etc. Already, mass diabetes screening sessions (blood pressure and blood sugar testing) were being performed once or twice per year in the community health centres and in some schools, with the exception of Wolf Lake which has no health centre or school. People from Wolf Lake could however



benefit from the health services and educational services provided by the community of Eagle Village.

The communities participating in phase 1 of the project are located in geographic zone 1 or 2 according to the classification system developed by AANDC, meaning that they are located between 50 and 350 km from a service centre with year-round road access. Also, the members of the communities participating in phase 1 speak English as their primary official language which may cause them to choose to travel to Ontario (North Bay or New Liskeard) to receive services in English.

As for the personnel working in the communities, the communities of Timiskaming and Eagle Village possess a health centre that employs nurses, a community diabetes prevention agent, a medical transportation coordinator as well as other employees working in the area of health care and prevention. The community of Winneway has a nursing station offering many services and providing various human resources to the population such as nurses, a community health representative and a diabetes agent.

In order to benefit from a DR screening service, the patients from the communities had to travel either to Rouyn-Noranda, Ville-Marie, North Bay or New Liskeard. To receive medical follow-up for DR, the patients were required to travel either to Rouyn-Noranda, North Bay or Montreal (see the map in the appendices). This means that no predefined service corridor had been created in order to enable the diabetic individuals from these communities to have access to this test. The arrival of the new locally-provided screening service, in addition to the corridors created with the second-line services, will undoubtedly allow for facilitating and simplifying the trajectory of the patients wishing to receive this screening test.

These communities therefore possess the characteristics that are conducive to the implementation of the DR remote screening service: they have a program to fight against diabetes and they demonstrate a certain willingness to implement activities to combat this disease; they possess human resources that are available to ensure the operation of the service; by offering the service, the communities therefore ensure that the screening service is available locally for their members thereby avoiding the need to travel to urban centres and the project allows them to develop their local competencies and autonomy. The community scans also highlighted the fact that each of them present unique demographic, geographic and organisational characteristics that must be taken into consideration during the analysis of the information collected.



CHAPTER 6 - THE EVALUATION OF THE IMPLEMENTATION

An evaluation of the implementation allows for describing the main characteristics and how the project actually unfolds as well as understanding and comprehending how and why it evolves, determining the factors influencing its results and making the necessary corrections, if necessary. This type of evaluation allows for guiding the decision-making process in order to facilitate and render the project or program more adequate.

First of all, this chapter presents various data on the number of diabetic individuals among the communities participating in the pilot project who participated in the screening as well as the referrals that were made following the analysis of the images. Then, the quality of the collaborative relationship between the various partners of the project that all had a role to play in the success of the pilot project, as well as the training provided to the workers responsible for offering the screening service to the members of their communities, will be addressed. This chapter will also discuss the integration of the new screening service as well as the changes that this service made to the human and material organisation of the community health centres. Finally, this evaluation will allow for determining the adequacy of the training provided to the community workers as well as facilitating factors and difficulties encountered by the community technicians in terms of the use and handling of the camera.

6.1 STATISTICS ON THE PARTICIPATION OF THE DIABETIC INDIVIDUALS OF THE COMMUNITIES PARTICIPATING IN THE PILOT PROJECT

6.1.1 Anticipated participants and screenings performed

Table 6.1 presented the number of diabetic individuals known by the community health centres, the anticipated number of participants as well as the actual number of participants for the two years that the service was provided.



Table 6.1. Number of anticipated and actual participants for each of the communities participating in the pilot project

Communities	Population ages 30 years and up living on the community territory*	Known number of diabetic people at the beginning of the pilot project**	Number of participants		
			Expected*	Actual in 2010**	Actual in 2011**
Eagle Village	164	48	25	25	20
Timiskaming	277	66	42	33	34
Winneway	149	49	22	23	0
Wolf Lake	n/d	12	n/d	1	1
Total	590	175	89	82	55

* This data stems from the document entitled *Diabetic Retinopathy: First Nations of Quebec Distance Screening Project* (2008) developed by the various partners and presented to Canada Health Infoway in order to obtain the funding required for the project's deployment.

** The data regarding the number of diabetic individuals known by the health centres and the number of invited and actual participants stems from those responsible for the service in each of the health centres. This data indicates that 15% of the population of these communities is indeed suffering from diabetes.

Table 6.1 demonstrates that the number of people who benefitted from the new screening service in 2010 is close to the expected number of participants (15% of the population ages 30 years and up). However, a decrease in participation is observed for the year 2011. This significant decrease is mainly due to the fact that only a single wave was performed in Winneway because of a lack of human resources.

6.1.2. Participation of the diabetic population of Timiskaming

For the years 2010 and 2011, a total of 71 remote screening tests were performed in the community of Timiskaming (33 tests in 2010 and 38 in 2011). The number of diabetic people known by the health centre personnel in Timiskaming is 66. In total, 33 people participated in the first wave of screening performed in 2010 and 34 people participated in the second wave of screening performed in 2011. The screening service therefore reached half of the diabetic people known by the health centre²¹. It is important to keep in mind that according to the recommendations, all diabetic patients should be screened on an annual basis for diabetic retinopathy (DR). The colligated data does not enable us to identify the patients who were screened for the first time in 2011 and those who were screened for follow-up purposes.

²¹ Note that different reasons can explain the fact that certain diabetic patients in a community do not receive the DR remote screening test. Besides personal reasons, the fact that a person is already being followed by an ophthalmologist can explain a person's non-participation.



6.1.3 Participation of the diabetic population of Eagle Village and Wolf Lake

In the case of the community of Eagle Village, it was possible to colligate much more information. In fact, the health centre has a database allowing, among other things, to access information on the number of patients who were invited to receive the screening test and the number of new patients who participated in the second wave of screening.

It can therefore be noted that for the communities of Eagle Village and Wolf Lake, a total of 60 people are known to be suffering from diabetes. In 2010, 40 people were invited to receive screening and 26 people attended. In total, 30 screening tests were performed in 2010. In 2011, 43 people were invited while 21 people benefitted from the service (22 screening tests were performed). This data tells us that just under half of the known diabetic individuals from these two communities accessed this service and that a slight decrease can be observed for the second wave of screening. However, the data collected by the Eagle Village health centre indicates that among the 21 individuals who were screened in 2011, seven were being screened for the first time. According to the workers responsible for offering the service in Eagle Village, participation on behalf of diabetic individuals is good and some of the diabetic patients who were not screened at the health centre are already being followed by an ophthalmologist. Also, according to the workers, some patients are unable to visit the health centre due to their poor state of health (local players, May 4, 2011).

As mentioned in chapter 3, a screening slip was developed and sent to the health centres of the communities participating in the pilot project. This slip had to be filled out by the nurse and the technician for each of the screenings performed (see the appendices for a copy of the screening slip). Only the community of Eagle Village returned the slips that were filled out and only for the second year of screening.

The information collected in these slips informs us that for the 22 screening tests that were performed during the second wave of screening, 13 men and 9 women were screened. These users were between the ages of 33 and 71 years and the average age was 55 years. Also, the colligated data indicates that 18 patients were suffering from type 2 diabetes while the type of diabetes was not specified for the four other patients.

6.1.4 Participation of the diabetic population of Winneway

According to the information held by the nursing station in the community of Winneway, 49 community members are diabetic. Without knowing the exact number of people who were invited to take part in the screening, the number obtained indicates to us that 23 people received a screening test and that a total of 26 screening tests were performed in 2010. As previously mentioned, the community of Winneway did not perform screening sessions in 2011.

The following table (6.2) sums up in a detailed manner the number of individuals screened, the number of tests performed and the various recommendations made by the *Laboratoires de la rétine RD* following the analysis of the photographs taken in the



communities. The data it presents was provided by the *Laboratoires de la rétine RD*. It should be noted that these numbers differ slightly from those compiled by the communities and by the E-Health Agent of the First Nations of Quebec and Labrador Health and Social Services Commission (FNQLHSSC) (statistics derived from the invoices paid by the FNQLHSSC). These slight differences can be explained by the fact that, up until now, no common information management system has been established for data collection ensuring that all of the players have the same information.



Table 6.2. Number of participants, screening tests and referrals made in the context of the pilot project

Community	2010	2011	Total
Eagle Village and Wolf Lake*			
Participants	25 (+1)	20 (+ 1)	47
Number of new participants	-	7	7
Screenings performed	29 (+1)	21 (+1)	50 (+2)
Normal tests (reimaging in a year)	17	18	35
Reimaging in four or six months	7	1	8
Ophthalmology referrals	5 (+1)	3	8 (+1)
Timiskaming			
Participants	33	34	67
Number of new participants	-	n/d	n/d
Screenings performed	33	38	71
Normal tests (reimaging in a year)	25	27	52
Reimaging in four or six months	0	4	4
Ophthalmology referrals	8	7	15
Winneway			
Participants	23	-	23
Number of new participants	-	-	-
Screenings performed	26	-	26
Normal tests (reimaging in a year)	15	-	15
Reimaging in four or six months	1	-	1
Ophthalmology referrals	10	-	10
All of the pilot project communities			
Participants	82	55	137
Number of new participants	-	n/a	n/d
Screenings performed	89	60	149
Normal tests (reimaging in a year)	57	45	102
Reimaging in four or six months	8	5	13
Ophthalmology referrals	24	10	34

* The numbers in parentheses refer to the patients from the community of Wolf Lake.

In the previous table, regarding the number of participants and the number of screenings performed, the differences are due to the fact that certain individuals were obligated to receive a second test in the same year according to the recommendations of the *Laboratoires de la rétine RD*. As previously mentioned, following a first DR screening test, the ophthalmologist from the *Laboratoires de la rétine RD* can recommend reimaging in the following four or six months to perform better patient follow-up.

Table 6.2 also presents the ophthalmology referrals suggested by the ophthalmologist responsible for analysing the images. These referrals can indicate that an advanced diabetic retinopathy was detected, that another eye anomaly was observed or even that the images were of insufficient quality and that a consultation with an ophthalmologist is



therefore required. Depending on the urgency of the situation, the ophthalmologist from the *Laboratoires de la rétine RD* can make a referral ensuring that a patient is seen in one or two months for immediate treatment or for treatment in the following year. The statistics regarding the ophthalmology referrals tell us that approximately 23% of the screenings performed (34 referrals out of 149 screenings) among the three communities led to a consultation with an ophthalmologist. This data demonstrates the legitimacy of this newly implemented service.

It should be noted that the numbers presented in table 6.2 regarding the number of screenings, normal tests, reimaging and ophthalmology referrals stem from the statistics compiled by the *Laboratoires de la rétine RD*. It is therefore impossible to determine if the patients actually followed through with the prescribed recommendations. Furthermore, the logistics surrounding the relocation of the camera between the communities may have made it impossible for a patient to undergo reimaging within the prescribed period of time.

6.2 EVOLUTION OF THE ROLES AND RESPONSIBILITIES AND THE COLLABORATIVE RELATIONSHIP BETWEEN THE PARTNERS

This section describes the roles and responsibilities of the partners as well as their collaborative relationship. It also describes the evolution of the partnership over the course of the project.

6.2.1 The participating First Nations communities

This DR remote screening pilot project would not have been possible without the active participation of the First Nations communities of Eagle Village, Timiskaming, Winneway and Wolf Lake. In fact, one of this project's specific objectives was to foster collaboration and mutual aid between the communities.

It is with the objective of fostering exchanges between the participating communities and developing a spirit of collaboration and mutual aid that a local working group, uniting various workers, was set up as of the very first steps related to the project's implementation. This working group brought together the nurses, technicians and health directors of the communities, representatives from the Algonquin Nation Programs and Services Secretariat (ANPSS), representatives of the First Nations and Inuit Health Branch, Quebec Region (FNIHB-QC) and the E-Health Agent of the FNQLHSSC. The local working group meetings were organised as needed. In the first year of the pilot project, three meetings were held. As of 2011, only one meeting per year was planned. These meetings allowed for consolidating the linkages between the communities while discussing their needs between each other and with the other players involved in the project (local player, October 25, 2010).

In the context of the project, it was indeed important for the communities to maintain good communication between each other in order to ensure the proper planning and unfolding of the screening tests (local player, June 23, 2011). Various reasons brought



the workers to communicate amongst each other during the pilot project. Discussions also took place in order to ensure the proper handling of the equipment or when the material was malfunctioning (local player, June 23, 2011). The workers also communicated with each other from time to time in order to keep each other informed, for example, regarding the camera's movements, medication or when problems of a technical nature were encountered with the material or computer network.

During the first wave of screening that was carried out in 2010, the communities did not share a calendar to assist them in the planning of appointment setting and equipment transportation. According to one worker, the planning of the camera's movements between communities took place by telephone at the time. The workers were therefore required to locate where the camera was situated at that particular time and ensure that the camera would be present in their community at the right time (local player, March 12, 2012). This could generate certain hazards related to the planning of the screening tests. In order to facilitate the transportation of the camera and the setting of the appointments for the tests, a calendar was developed by the communities in the spring of 2011. This calendar allowed for overcoming the disadvantages related to the planning of the meetings during the first wave of screening (regional player, March 7, 2011). Another calendar for camera relocation was developed in the following year.

6.2.2 The regional and local partners

Besides the participation of the communities, the smooth unfolding of the project was based on the work and collaboration of various regional and local players that evolved over time. Moreover, the communities were able to count on the support and assistance of the ANPSS in addition to the major contributions throughout the entire duration of the project of the FNQLHSSC and the FNIHB-QC. McGill University's *Réseau universitaire intégré en santé* (RUIS McGill) played an important role at the start of the project during its design phase. Finally, as for the *Laboratoires de la rétine RD*, they were responsible for the analysis and interpretation of the images throughout the entire project. From a financial perspective, a major portion of the budget required for the operation of the service was provided by Canada Health Infoway.

A. The First Nations of Quebec and Labrador Health and Social Services Commission

At the beginning of the implementation phase for the screening service, the FNQLHSSC contacted the communities in order to reconfirm their interest with respect to the project and obtain band council resolutions from each of the communities thereby making their involvement official (regional player, August 25, 2010). In January 2009, the E-Health Agent of the FNQLHSSC met with the health directors, nurses and workers from each of the participating communities in order to explain the project to them in detail: the screening process, referrals, job description, promotional tools and the various forms used. The community workers then provided feedback regarding the adjustments to be made so that the project would be in line with their realities. That is how the project



developed over the course of the meetings with the communities (regional player, August 25, 2010).

The FNQLHSSC contributed to the purchasing of the necessary equipment, establishes the connections between certain partners, clarifies the organisation of the services and transmits the deliverables to the funding agencies (regional player, August 25, 2010). Like FNIHB-QC, the FNQLHSSC also took care of coordinating the training and providing technical support to the communities (regional player, November 1, 2010). At the beginning of the project, the FNQLHSSC also called upon the First Nations Education Council (FNEC) which shared its expertise in connection with the telecommunications networks.

B. The Algonquin Nation Programs and Services Secretariat

Before undertaking the implementation process for the DR remote screening project, the FNIHB-QC and the FNQLHSSC initiated dialogue with the ANPSS in order to secure its support with respect to the project. The ANPSS then contacted the communities that were identified in order to inform them of the project and discuss the training with them that would eventually be provided to their personnel in order to develop their competencies in the execution of their new tasks (regional player, October 25, 2010). It was also the ANPSS that recommended a trainer from Yellowquill College to provide the training offered to the workers in the community of Eagle Village (regional player, November 1, 2010).

C. Health Canada's First Nations and Inuit Health Branch, Quebec Region

The FNIHB-QC participated in the process of selecting the communities that would participate in the project and worked with the communities and the *Agence de santé et services sociaux (ASSS) de l'Abitibi-Témiscamingue* in order to secure collective prescriptions for the nurses from certain health centres. The FNIHB-QC also worked on developing the clinical procedures and the training to be provided to the community nurses and technicians (regional player, August 25, 2010). Several information elements are missing however in order to properly understand the development processes of these components.

The FNIHB-QC remained available all throughout the project's implementation in order to support the communities in providing the service.

During the implementation of the pilot project for the new screening service, the community workers mentioned that they mainly called upon the FNIHB-QC for problems of a technical nature such as poor connectivity to the computer network (local player, June 23, 2011; local player, May 4, 2011).



D. McGill University's Réseau universitaire intégré en santé

During the project's pre-implementation phase, RUIS McGill participated in the coordination of the project. RUIS McGill already had experience in this type of project in collaboration with Aboriginal communities (Cree and Inuit). Furthermore, RUIS McGill provides its services in both French and English, thereby making it possible to address the needs of the English-speaking communities of Quebec.

The original idea behind the DR remote screening project was first of all developed by RUIS McGill which established connections with the FNQLHSSC and FNIHB-QC in order to present their telehealth project. At the beginning of the project, RUIS McGill also facilitated contacts with the *ASSS de l'Abitibi-Témiscamingue* (regional player, August 25, 2010). It in fact participated in the development of the project's first presentation document in addition to the selection of the participating communities:

We were looking for a place where a positive telehealth experience had already occurred. A physician or physicians were needed who believed, who knew what we were talking about, who believed that telehealth was possible. A certain infrastructure needed to be already established (regional player, November 24, 2010).

E. The Laboratoires de la rétine RD

In the context of the pilot project, the participating communities were communicating on a regular basis with the *Laboratoires de la rétine RD* with respect to the transmission of the images and the reception of the reports following the interpretation of the images. The FNQLHSSC also communicated with the *Laboratoires de la rétine RD* on a regular basis during the development of the project and for the interpretation of the images taken in the communities.

Communication between the communities and *Laboratoires de la rétine RD* was even more important when the communities performed a screening session for the first time. These more frequent contacts allowed for quickly resolving any technical issues that occurred when sending the images. For example, the communities do not all use the same network connection and sometimes there can be problems with the firewall that blocks access to the server. Furthermore, there seems to be confusion regarding the email management software used for the transmission of the information (local player, June 23, 2011).

According to those responsible for the *Laboratoires de la rétine RD*, communication with the communities is going smoothly when a problem arises related to the taking or transmission of the images and the forwarding of the results to the health centres. On certain occasions, FNIHB-QC played an intermediary role between the communities and the *Laboratoires de la rétine RD* which caused "the communications to not take place as directly as they could have" (free translation) (regional player, February 10, 2012). According to the *Laboratoires de la rétine RD*, good communication with the



communities is essential to consolidating partnerships and establishing relationships of “collegiality” (regional player, February 10, 2012).

The workers from the various communities maintained that they had positive relationships with the *Laboratoires de la rétine RD*. They are also very grateful with respect to the *Laboratoires de la rétine RD* which helped them to resolve problems when they were faced with technical difficulties:

I would like to let you know – I am still in the process of praising [...] the Laboratoires de la rétinoopathie... This person is very understanding and it is a genuine pleasure to work with him. I only have good things to say about him because he helped us a lot in the month of April. We were experiencing technical difficulties [...] and this person was very patient and understanding [...] (free translation) (local player, May 4, 2011.

The professionals from the *Laboratoires de la rétine RD* were not in direct contact, during the pilot project, with the regional ophthalmologists who had to meet the patients that were referred for particular medical follow-up. According to the *Laboratoires de la rétine RD*, in the context of the project, it could be beneficial for them to be in direct contact with the ophthalmologists so that they can explain the complications they observe without going through an intermediary (regional player, February 10, 2012).

6.2.3 The problems related to defining the roles and responsibilities of each

Collaboration between the three players that worked on the development of the DR screening project, the FNQLHSSC, RUIS McGill and FNIHB-QC, all of which have their own ways of doing things and their own vision of the project, was not always easy. Therefore, it was observed, as of the very beginning of the work performed in connection with the project, that each of these partners wanted to be the project leader. There was confusion related to the roles and responsibilities of each and no common vision for the pursuit of the project was established. Furthermore, each of the main partners, including the *Laboratoires de la rétine RD*, had different interests in this project. For example, the priority of the FNQLHSSC was to make the service available to the First Nations while adapting it to their needs. The priority of RUIS McGill was to develop a telehealth system in connection with the public health system that would be extended geographically (regional player, August 25, 2010). In other words, without being irreconcilable, the distinct missions of these organisations impeded proper collaboration between the partners. A more in-depth process to merge the visions and better define the conditions related to the project's realisations and next steps would have facilitated a good collaborative relationship between the partners.

Furthermore, at the start of the project, all of the partners were attempting to facilitate the process so that the project could move forward and the service implemented. A lot of compromises were made and the defining of the roles and responsibilities of each was not performed in an optimal fashion.



Progressively, a redefining of the roles between RUIS McGill, FNIHB-QC and the FNQLHSSC for the coordination of the project was performed (regional player, November 24, 2010). Over the course of the project's pre-implementation, the decision-making powers and those in charge at RUIS McGill became less important. The coordination of the project was therefore shared between the E-Health Agent of the FNQLHSSC and the Special Project Coordinator of the FNIHB-QC. However, certain confusion between the roles of the two coordinators was experienced until a clear defining of the responsibilities was performed.

From RUIS McGill's perspective, they find it unfortunate that their expertise was not sufficiently recognised and integrated into the project. According to RUIS McGill, to ensure the project's sustainability, it would have been beneficial to integrate this telehealth service into Quebec's public health system instead of relying on a private clinic for image analysis purposes (regional player, November 24, 2010). Since the service was not yet developed within the public health network and despite efforts aiming to identify service providers and the parameters surrounding the remuneration of the specialists who are able to perform image analysis, FNIHB-QC and the FNQLHSSC made the decision to call upon, in an interim fashion, private analysis services (regional player, August 25, 2010).

6.3 THE TRAINING PROVIDED TO THE TECHNICIANS AND NURSES

6.3.1 The unfolding of the training

A preparatory training was provided to the nurse from Eagle Village, the E-Health Agent of the FNQLHSSC and two members of the FNIHB-QC personnel. This training, which took place on December 4, 2009, in the FNIHB offices in Montreal, served to validate the context of the training that was subsequently provided to the community nurses. The nurses from the communities of Timiskaming, Winneway and Eagle Village therefore participated in a training session on February 25, 2010, allowing them to acquire knowledge on DR and to have the tools needed to perform the pupil dilation that is part of the screening process.

Another two-day preparatory training was provided in Montreal on December 17-18, 2009, to those entrusted with the mandate to handle the camera and perform the photography. In the context of this project, these people are referred to as technicians for the DR remote screening test. This training was provided by the same trainer who facilitated the training intended for the nurses. This preparatory training offered in Montreal allowed the project management team to make the necessary modifications to the contents in preparation for the training to be provided to the community technicians.

In the spring of 2010, three-day training sessions were provided to the workers directly in the participating communities. In the context of the pilot project, three workers per community participated in the training (a nurse and two technicians) and the health directors were also invited to participate but only one health director attended the entire training. This training included a theoretical component (one day), a practical component



related to the handling of the camera (one day) and a component related to preparation for a screening session (one day). This training was facilitated by FNIHB-QC nurses or by a trainer from Yellowquill College in Manitoba who works directly among the First Nations. A representative from Innova (distributor of the camera) and the E-Health Agent of the FNQLHSSC were also in attendance for the training sessions (regional player, November 1, 2010; January 13, 2011). A draft of the training manual was prepared by RUIS McGill and reworked by the clinical committee and the FNQLHSSC with the help of a consultant who expanded and adapted it according to the comments received during the preparatory training sessions.

The training days that were held within each of the communities allowed the workers to enhance their knowledge and skills so that they would be able to perform the DR remote screening test correctly. The workers of the Eagle Village health centre were the first to receive the training focused on the use of the technology and the photography process, but contrarily to the other communities, without having access to the camera at the very beginning of the training. It was identified in the comments from the workers that it would have been better to be able to visualise the screening process directly with the camera (regional player, November 1, 2010). This aspect was therefore taken into consideration during the subsequent training sessions that were held in the other communities.

The community of Winneway was the last one to receive the training intended for the nurses and technicians. Following the previous experiences, the trainer from Yellowquill College adapted the training in order to make it as accessible and easy to understand as possible. The trainer also left materials (flash drives, games, objects to be handled (eye)) at the nursing station so that the workers can use them during their meetings with the service users. Personnel from FNIHB-QC were also on site to demonstrate how to proceed with pupil dilation, measure ocular pressure, camera operation and photograph identification and recording. The community workers were then able to practice with the camera to simulate screening tests.

6.3.2 General satisfaction related to the training

In the month of October 2010, those who participated in the training provided in each of the communities were invited to fill out a satisfaction questionnaire. In total, nine workers representing the three communities offering the service filled out the questionnaire: six technicians, two nurses and one health director.

According to the responses provided, most of the respondents stated that they had found the training to be either “very satisfactory” (six respondents) or “satisfactory” (2 respondents). One of the respondents provided an explanation for the response by emphasising the clarity of the explanations given during the training while another mentioned having learned a lot from the training and that he is now able to support the DR remote screening project in his community. For two respondents, the main reason for their appreciation comes from the fact that they believe that the training offered the time needed for the practical component. However, one of the nine respondents deemed the training to be “unsatisfactory” because the explanations were given too quickly.



All of the respondents qualified the theoretical portion of the training as being either “very adequate” (eight respondents) or “adequate” (one respondent): some of them (four respondents) for the quality of the explanations and one for the trainer’s skills. The practical component of the training was deemed to be “very adequate” by five respondents, “adequate” by three respondents and “inadequate” by one respondent. According to a comment that was made, the manner in which the photographs must be transmitted should have been explained more clearly. A second respondent would have liked the trainer to be present for one of the first meetings with a user in order to provide assistance. A third stated that the time dedicated to handling the camera was appreciated.

The visual support used during the training was deemed to be “excellent” by seven respondents and “good” by the two others. One of the two latter respondents believes that too much information was provided in a small amount of time. Another respondent said that it was easy to understand the elements being presented. The contents of the manual were qualified as being “very relevant” by eight respondents and “relevant” by one respondent. Two respondents appreciated that the steps for the recording and transmission of the images are clear and well indicated, while four other respondents believe that more explanations and instructions could be provided regarding the assembly of the equipment.

Five respondents mentioned having used the training manual in their work, either for the material assembly or for the transmission of the images to the server. Several respondents (four respondents) stated that they did not use the training manual in the context of their work. The information obtained indicates that the workers mainly used the training manual during the screening sessions that were performed during later screenings rather than during those performed immediately after the training. The training manual was therefore used more to refresh the memory of the workers.

All of the respondents (one person did not answer the question) consider that the time allocated during the training in order to practice the various tasks is sufficient. Certain tasks, such as the use of the camera and the taking, recording and transmission of the images could nonetheless benefit from more practice time. One respondent believed that two additional training days would be necessary.

Eight of the nine respondents are of the opinion that the training did in fact meet their expectations. They mainly referred to the improvement of the knowledge related to the photography and diagnosis process. According to the respondents, the training is adapted and relevant for the nurses, technicians and diabetes human resources. One of the respondents had no expectations regarding the training.

Eight of the nine respondents believed that they had the prerequisite knowledge in order to properly understand the training and that they now have the skills required in order to apply what they learned during the training to their work. These eight respondents consider that the training is in line with the realities of the tasks to be accomplished in the context of their work. However, six respondents believe that additional training would



be necessary in order to refresh their memory and improve image quality. One respondent explained that the amount of time between the screening waves causes him to forget certain things. One respondent believes that he would have needed more knowledge since he was unable to attend the first information session provided in Montreal. One respondent never performed a screening test in the context of his work and does not believe that the training is relevant to address his professional duties that are more in line with direction and management in the context of the project.

The analysis of the responses compiled from the satisfaction questionnaire for the three-day training provided to the community respondents allowed for identifying certain general observations that are listed in the following table (table 6.3).



Table 6.3. Observations based on the analysis of the satisfaction questionnaires for the training sessions provided to the pilot project community workers (n=9)

General satisfaction for the training
❖ All of the respondents found the theoretical component of the training to be either “adequate” or “very adequate”; ❖ Eight respondents deemed the practical component to be “adequate” or “very adequate”. One respondent emphasised that he would have liked more support during the meetings with the patients and another wanted the information regarding the transmission of the images to be clearer; ❖ According to the respondents from two communities, the time allocated to practice the various tasks is “sufficient”, while it is considered “insufficient” by the respondents from the other community. Several respondents emphasised that more practice is needed for camera use and photography; ❖ Eight respondents maintain that the information transmitted during the training is in line with the realities of their job. One respondent confided that the delays between each patient visit were too long, causing him to need to review the manual each time.
Relevance of the training manual
❖ The contents of the training manual are considered “very relevant” or “relevant”. One respondent emphasises that more explanations are needed related to the assembly of the equipment; ❖ A little over half of the respondents mentioned having consulted the training manual in the context of their work. Most of them underlined having consulted the manual to help them assemble the material, use the camera or transmit the images. Three of the four respondents who did not use the training manual come from the community that performed only a single screening session; ❖ Four respondents believe that some information is missing in the training manual such as the assembly of the material or a section indicating the various problems that could be encountered (inadequate photography, actions to be taken when an uncommon situation arises, examples of unsatisfactory material assembly, etc.).
Recommendations/suggestions
❖ Five respondents maintain that another training session would be appropriate. According to these respondents, an additional training would allow for refreshing memory or improving image quality; ❖ Two respondents suggest that, when providing the training, more time should be allocated to the practical component and the handling of the camera; ❖ One respondent suggested that, when providing the training, each participant should have the opportunity to handle the equipment on their own. This respondent stated that it was difficult to manipulate the camera in a group.



6.3.3 DIFFERENCES BETWEEN THE PERCEPTIONS OF THE NURSES AND THE TECHNICIANS WITH RESPECT TO THE TRAINING PROVIDED

The analysis of the questionnaires reveals that there are few notable differences that exist between the perceptions of the technicians and the nurses regarding the training provided in the communities. However, the observation has been made that more technicians raised negative points such as the fact that certain information is missing in the training manual and that they found the time dedicated to practicing insufficient.

6.4 UTILISATION OF THE CAMERA

6.4.1 The quality of the images

According to the *Laboratoires de la rétine RD*, all of the images, with the exception of two, were of sufficient quality for the screening tests that were performed in the communities between March 2010 and February 2012 (regional player, February 10, 2012). Images of insufficient quality are usually due to the presence of pathologies of the retina or cataracts. In the event of images of insufficient quality, the patients are referred to an ophthalmologist. According to the *Laboratoires de la rétine RD*, the insufficient quality of the images is not connected to the poor use of the camera or the transmission of the images by the technicians of the communities. The professionals of the *Laboratoires de la rétine RD* believe that the community workers are doing good work with respect to the taking and transmission of the images (regional player, February 10, 2012).

With time and practice, technicians stated that they have become increasingly comfortable with the equipment, and have also learned to get to know the users and are now aware of the ones who have greater difficulty opening their eyes properly or those who have less patience during the tests (local player, May 4, 2011). According to the 22 screening slips filled out by the workers from a community during the second wave of screening, the difficulties associated with the proper dilation of the pupils and taking good quality images is often related to ocular particularities among the users. For example, one of the user's eyes were sensitive to the light being projected by the camera, some of them had cataracts, another had a damaged eye due to an accident, another had an artificial eye, etc. (screening slips, May 12, 2011). Due to various ocular characteristics or complications during photography, sometimes a technician may not be able to access one or two parts of the eye (screening slips, May 12, 2011). Therefore, in these cases, the *Laboratoires de la rétine RD* must make their diagnosis using fewer photographs.

6.4.2 The difficulties related to the utilisation of the equipment

Workers from two communities stated that they experienced problems with the power source for which the switch was seemingly defective. Due to this defect, the camera was changed in the month of February 2010. There were also seemingly problems related to



the downloading of the images caused by network connection problems (local player, June 23, 2011).

The *Laboratoires de la rétine RD* believes that it could be beneficial to modernise and standardise the computer applications in the communities in order to facilitate the work in the health centres for the transmission of the images, for example. This could avoid problems related to the firewall and therefore improve the effectiveness of the services. Also, the *Laboratoires de la rétine RD* has made the suggestion that the communities should ensure, the day before a first screening day, that the Internet network is currently operational in order to avoid last minute surprises as much as possible (regional player, February 10, 2010).

Several workers said that between the two waves of screening, they had time to somewhat forget how to operate the device. One of the technicians believes that when the material has not been used for six months, it is difficult to remember how to use it properly. He said that he therefore refers to the training manual, but that it would be preferable to handle the material on a more regular basis (local player, May 4, 2011). Another technician mentioned that there is a difference between the images taken at the beginning of a screening wave and those taken at the end of a screening wave. At the end of a screening wave, the technician has become accustomed to the equipment and needs to take fewer photographs because of the improved quality of the images. Several believe that it would be desirable, during the next wave of screening in their communities, to take a day or two before performing the tests with the patients in order to practice and become comfortable with camera operation once again (local player, June 23, 2011; May 4, 2011).

6.5 THE REORGANISATION OF THE SERVICES AND HUMAN RESOURCES OF THE HEALTH CENTRES

The DR remote screening pilot project requires that the health centres of the communities provide adequate human resources in order to offer the services to the population, even though no additional budget is provided to the health centres in order to compensate for these additional needs. The human resources – the nurses and technicians assigned to the DR screening testing – are identified by the health directors of the health centres (regional player, May 7, 2011).

The integration of the DR remote screening service therefore requires a reorganisation of the schedules and an increased workload for the workers. In the context of this evaluation, it was not possible to estimate this workload. However, according to the information collected, the tasks to be performed in connection with the offering of the new service represent a periodical and intensive workload among workers who already have many duties and responsibilities to fulfil.

Before the camera's arrival in the community, the workers must therefore ensure that the users will show up for their appointments. They must therefore prepare invitations and provide reminders over the telephone among the users. During the screening days, a



nurse must free herself from her usual duties for complete days in order to perform the screening tests.

The personnel hired by the health centres is limited and during the screening tests, the number of users who go to the health centres increases considerably. A readjustment of the schedule and room occupation for the nurses is therefore necessary.

Despite these readjustments, the comments collected among the workers regarding the new service are very positive. In fact, all of the workers stated that they are either “very satisfied” (5 respondents) or “satisfied” with the new tasks that they have been assigned to. Some respondents have underlined the fact that the diabetic rates in the communities are high and that the prevention of the complications related to diabetes remains a priority for them and for their health centres. Six workers consider the new service as being “easy to integrate” into their job descriptions, even if this forces them to work more. Some workers maintain that the project allows them to better coordinate their interventions and ensure improved follow-up among the community members with diabetes. One nurse however deemed the new service as being “difficult to integrate” into her job description considering the workload it entails:

The health centre does not have a lot of employees and it is difficult to distribute the tasks. This causes us to be faced with a workload that is a little larger (local player).

According to one of the respondents, the technicians are now becoming autonomous and can take turns using the camera. The fact that two technicians are trained allows for greater flexibility in the planning of the screening tests. He also mentioned that the project’s sustainability is dependent upon the stability of the personnel in place (local player). For that matter, for one community, the person responsible for pupil dilation was a nurse from a private agency hired by Health Canada. She participated in performing the tests in 2010, but she left her position over the course of the winter of 2010-2011, which prevented the remote screening testing for the year 2011. This nurse was not a member of the community and was only present periodically depending on the needs. According to one community worker, the fact that the nurse was not on site in a permanent fashion at the community health centre could also cause difficulties related to performing the tests. For example, it could be difficult to plan the appointments while ensuring that the nurse, camera and patient were united (local player, March 12, 2012). It should be noted that during the first wave of screening performed in 2010, the camera sharing calendar had yet to be developed. It was later created at the beginning of 2012, precisely to assist in improving the planning process for the screening tests.

In addition to the nurse, note that there was also a change in the health director position in this same community. These two departures had the effect of delaying the second wave of screening and decreasing the amount of time, effort and resources devoted to the screening service. Furthermore, at the beginning of the implementation, two technicians received the training required for the taking and transmission of the images.



However, it seems that only one of these two people actively participated in offering the service.

In order to compensate for the lack of human resources following the nurse's departure, Health Canada hired a new nurse during the winter of 2011-2012. The date of the second wave of screening for the community is not yet known, but should take place over the course of the year 2012.

6.6 THE ADOPTION OF THE PROJECT BY THE WORKERS AND THE MOBILISATION OF THE MEMBERS OF THE PARTICIPATING COMMUNITIES

The adoption of a project by the workers responsible for offering the new service is a determining element in the optimal implementation of a project. In fact, among other things, it is important for the workers to perceive an advantage to adopting the project and for it to be seen as something that is easy to integrate on a daily basis (Rogers, 1983).

In the context of this pilot project, both the health directors and the nurses and technicians quickly adopted the new screening project and invested time and effort in order to offer a quality service to their community members. As observed in the questionnaires and the interviews performed with the interveners, many benefits have been perceived with respect to the pilot project's implementation and most of them consider that the new DR screening service can easily be integrated into their usual duties despite the increased workload.

In terms of the adoption of the new service by the population, for some communities, it was more difficult to rally the people at the beginning of the project to get them to participate in the screening. There also apparently several patients who did not show up for their appointments (local player, June 23, 2011). According to one nurse responsible for the service, approximately 10 patients did not show up for their appointments, either due to a lack of time, work-related issues or for another reason:

There are people who do not realise, their work is more important than everything else [...]. I have a patient who missed her appointment three times. After the third time, I told myself: look, she's a worker like you and me [...] if she forgets to come, it's because it isn't important to her, and we gave her the opportunity... (free translation) (local player, June 23, 2011)

According to one of the respondents, the difficulty related to mobilising the patients during the implementation of the service is also due to a lack of knowledge and skepticism among the patients of the community with respect to a screening program. Over time, the patients come to realise that the service being provided is of good quality and they then begin to trust it.



According to one regional player, the fact that all of the diabetic patients did not take part in the screening process could be due to the fact that the nurses are not well-known by the members of the community, particularly those provided by an agency or under Health Canada's responsibility.

These indications reinforce the idea that it is necessary to continue to promote the project among the communities. Furthermore, the results related to user satisfaction related to the service received, as presented in the next chapter, demonstrate that the service addresses a need and that people appreciate being able to benefit from this specialised service directly within their communities.

6.7 SUMMARY OF THE EVALUATION OF THE IMPLEMENTATION

The DR remote screening project has brought together many players such as the communities of Eagle Village, Timiskaming, Winneway and Wolf Lake, the FNQLHSSC, the FNIHB-QC, the *Laboratoires de la rétine RD*, Canada Health Infoway and RUIS McGill.

As a whole, the relationships between these various players led to the project's success in the field. The communities receive quality support, which allowed the project to gain momentum and unfold smoothly. However, it seems that the relationships that were maintained between FNIHB-QC, the FNQLHSSC and RUIS McGill were sometimes tense during the pre-implementation phase of the project. These players each had their own visions and ways of doing things. Fortunately, the few misunderstandings do not appear to have had repercussions on the project's success among the communities. The activities and services provided in the context of the implementation of the project took place as anticipated without any problems.

The support and assistance activities performed among the communities offering the service were deemed important to the project's success. The FNIHB-QC was highly involved in the development of the training provided to the workers in the communities in order to provide them with the tools they needed to take charge of the DR remote screening process. As a whole, the training sessions provided to the community workers were highly appreciated and deemed adequate. The practical component of the training was highly appreciated and deemed important for the acquisition of the knowledge and skills related to the handling of the camera and the transmission of the images.

When problems occurred with the camera and the network connection, the technicians called upon technicians from the other communities, the technical support of the FNIHB-QC, the *Laboratoires de la rétine RD* or the E-Health Agent of the FNQLHSSC. Therefore, the project follow-up mechanisms among the communities and the various partners were deemed adequate and important to the project's success.

A more negative element of the project that was raised by the technicians is the fact that a lot of time passes between the screening waves and that they need a certain amount of time to reacquaint themselves with the camera's operation. For the future screening



waves, the technicians hope to have time to practice with the equipment before proceeding with the tests among the users. It has been noted however that most of the workers perceived an improvement in their work since the beginning of the project.

For the First Nations communities, the DR remote screening project demands a reorganisation of the schedule and increased workloads for the workers (nurses and technicians). However, the workers who responded to the implementation evaluation questionnaire stated that they are very satisfied or satisfied with their new tasks and responsibilities. Several workers maintain that the project is important for the members of their communities and display a genuine interest in getting involved. In light of the observations made through this evaluation of the implementation, factors that both facilitated and impeded the implementation of the pilot project were identified and are presented in the following table (6.4).

Table 6.4. Summary of the factors that facilitated or hindered the implementation of the project

Facilitating factors	Impeding factors
❖ Support and assistance provided to the First Nations communities participating in the project by all of the partners ❖ Collaboration and mutual aid between the First Nations communities ❖ Quality of the training provided to the workers of the First Nations communities ❖ Interest and motivation of the health centre personnel of the First Nations communities with respect to implementing the project ❖ Easy to use technology	❖ Disagreement regarding the definition of the roles and responsibilities of the project's partners ❖ Increased workload for the workers of the First Nations communities participating in the project ❖ Important delays between the waves causing the workers to require a certain amount of time to reacquaint themselves with the equipment ❖ Difficulties encountered while using the equipment due to its sporadic use over time ❖ Difficulties associated with rallying the diabetic individuals to take part in the screening tests



CHAPTER 7 - THE EVALUATION OF THE SHORT-TERM EFFECTS

This chapter addresses the evaluation of the short-term effects of the diabetic retinopathy (DR) remote screening pilot project both in terms of the organisation of the services and practices of the workers and the prevention and treatment of the complications related to diabetes. This type of evaluation aims to verify the achievement of the short-term objectives of the project and better understand and comprehend the influential factors. First of all, this chapter addresses the changes in the capacities that the community health centres possess in terms of taking charge of the service, raising awareness among the local population regarding the effects of diabetes and transmitting the knowledge related to the DR screening test. Furthermore, it deals with the manner in which the follow-up with an ophthalmologist is performed when deemed necessary following a screening test. Finally, this chapter addresses user satisfaction with respect to the new service being offered in their communities and the factors explaining this satisfaction.

7.1 COMMUNITY CONTROL OVER THE SERVICE AND LOCAL CAPACITY-BUILDING

As was mentioned in the previous chapter (evaluation of the implementation), the remote screening service involved an additional workload for the workers of the community health centres. However, the workers are proud to have participated in the project since they understand its importance for the members of the communities and because they appreciate the new knowledge they are acquiring. They have also asserted that the project allows them to create linkages with other health players while allowing them to develop their abilities and autonomy. Furthermore, the new service allows the workers to intervene in a more complete manner among their patients in the areas of health promotion and prevention as well as curative intervention among the patients.

According to one health director, the staff members feel more concerned by the effects and consequences of diabetes among their patients. The same observation was made on behalf of the technicians who say that they now have a better understanding of type 2 diabetes.

The workers also affirmed that they felt a lot more confident during the second wave of screening than during the first wave due to the experience they had acquired:

I definitely found that things went more smoothly this year. It was less stressful because we knew what we were doing (free translation, local player, June 23, 2011).

I enjoyed it this year. I was more comfortable and I was even looking forward to starting another day with six appointments lined up (free translation, local player, June 23, 2011).



The credibility of the workers is an important stake in the project's success. It is important for the personnel selected as those responsible for the project to be known and recognised by the population:

[...] the selected individuals [the workers] must have credibility among the clientele and be interested in the project (free translation, regional player, March 7, 2011).

According to the workers of one health centre, the screening service acquired positive credibility due to their professionalism. Furthermore, the patients are aware that more photographs of the back of the eye are taken in the context of this service than when the test is performed at an optometrist for an annual or occasional examination.

Another positive effect of the pilot project that was observed is the increase in the number of diabetic people known by one community's health centre. In fact, for example, this health centre saw its number of known diabetic individuals increase when two people showed up at the health centre and stated that they were diabetic and that they wanted to take advantage of the new DR screening service. However, the current data does not allow for obtaining precise numbers. Continuing to provide this service over the course of the subsequent years will undoubtedly lead to the discovery of new cases of diabetes by the health centres.

7.2 DIABETES AWARENESS AND KNOWLEDGE TRANSMISSION

The new remote screening service offers another opportunity for the workers of the health centres of the First Nations communities to raise awareness among their diabetic patients regarding the complications associated with diabetes and the ways to prevent them. First of all, the new service being offered encourages the population of the community to pass a DR screening test. According to the workers who are responsible for the service, passing the DR screening test allows the diabetic individuals to be informed regarding the harmful consequences of diabetes on their retinas, which is generally a complication that the patients are less aware of.

In the context of the project, memorandums were distributed to the diabetic individuals so that they could learn about the consequences associated with DR and to encourage them to participate in the screening being provided in their communities. Community-based events such as healthy breakfasts also allow the health professionals to promote the project and talk about the stakes related to diabetes.

Contrarily to what was hoped during the project's design process, when performing the screening test, some workers stated that the transferring of knowledge to the patients is minimal. In fact, explaining the various steps related to the test such as the pupil dilations, taking the pictures and the transmission of the results is very time consuming for the nurse and the technicians. Therefore, some of the workers try not to provide too much additional information when performing the testing, particularly for patients receiving their first screenings. The workers instead encourage the patients to return to



the health centre if they wish to consult with the objective of discussing their health with a staff member:

I had the impression that they [the patients] want their meeting to be as simple and quick as possible and that is what we try to offer them (free translation, local player, May 4, 2011).

There were discussions... they [the patients] talk about certain particularities in connection with diabetes, etc. We [the workers] answer their questions, or we leave the door open so that they [the patients] can return later on to discuss it (free translation, local player, May 4, 2011).

7.3 THE POST-SCREENING FOLLOW-UP WITH AN OPHTHALMOLOGIST

The results of the DR screening sessions performed in the communities indicate that a significant number of users (n=34) were referred to an ophthalmologist for follow-up due to complications. Ensuring that the follow-up is provided by an ophthalmologist is taken care of by the nurse responsible for the screening service. When this nurse receives the results of the analysis of the images from the *Laboratoires de la rétine RD*, she transmits by fax a request for a consultation to a coordinator at the hospital or clinic. When the patients are referred to an ophthalmologist practicing in Ontario, the community health centres must fill out an additional form.

When the hospitals or clinics receive the consultation request, they must contact the patients in order to set an appointment within the amount of time prescribed by the *Laboratoires de la rétine RD*. The health centres are therefore not necessarily informed of when the appointment will be held and therefore they cannot ensure that the patient is seen within the period of time prescribed by the *Laboratoires de la rétine RD*. Discussions were held with Health Canada's First Nations and Inuit Health Branch, Quebec Region (FNIHB-QC) in order to modify the patient referral process and enable the health centres to be better informed.

Note that the workers from one community stated that the referral delays prescribed by the *Laboratoires de la rétine RD* are not always respected and the community personnel feel powerless with respect to this situation. Moreover, the workers report that certain referred patients were not seen by a specialist. According to them, the agreements reached with certain ophthalmologists before the implementation do not always seem to be respected (local player, June 23, 2011).

During the first wave of screening, still in this same community, a patient was recommended to see an ophthalmologist. Following complications related to the patient's treatment and the required trip to Montreal, this ophthalmologist lost credibility among the patients of the community. Those requiring follow-up or treatment with an ophthalmologist now prefer to travel to Ontario.



Despite the few difficulties that were encountered during the patient referral process, the fact that many users consulted an ophthalmologist is a direct positive impact of the implementation of the new service within the communities. It is possible to estimate that without the implementation of the remote screening service, many of these patients would not have been referred to an ophthalmologist or would not have been treated within the same delays for complications that could eventually lead to blindness. However, the limitations of this evaluation do not allow us to determine the number of patients for whom the screening test provided in their community represents their first DR screening experience.

7.4 SATISFACTION OF THE USERS OF THE DIABETIC RETINOPATHY REMOTE SCREENING SERVICE

7.4.1 Participation of the service users in the evaluation

As mentioned earlier, a total of 82 diabetic individuals participated in the first year of screening and 55 people participated in the second year of screening among the communities participating in the pilot project. Of these, 57 people filled out the satisfaction questionnaire following the first year of screening and 38 people filled out the questionnaire following the second year of screening. The rate of participation in the evaluation is very high for two of the communities, exceeding 83%. It was however more difficult to reach the users of the two other communities for which we received the filled out questionnaires from nine users who were screened in 2010 and from six users who were screened in 2011. The rate of participation for these two communities is situated at a little over 33%²². Therefore, the results collected and analysed in this section represent in a more accurate fashion the perceptions of the respondents from two of the four communities.

The analysis of the satisfaction questionnaires is presented in such a way as to differentiate the characteristics observed for each community. However, the general satisfaction and certain general comments are basically the same regardless of which community the respondent belongs to. Therefore, a fair portion of the analysis is presented in a general fashion without identifying the communities that the respondents come from.

²² The health centre workers from a community targeted two main reasons that could potentially explain this low rate of participation. First of all, the amount of time between the first wave of screening and the reception of the questionnaire may have been far too long (over a year) which caused users to not remember their experiences very clearly. This may have influenced their decisions regarding whether or not they would participate in the evaluation for the first year of screening. As for the second year of screening, the questionnaire was received between one and four months following the screening testing. This relatively short delay should not be an influential factor in the rate of participation with respect to the second questionnaire that was administered. A second factor mentioned by the health centre personnel is related to the fact that the members of their community are already highly solicited and they may be tired of participating in surveys and filling out forms and questionnaires. These health centre workers also mentioned that it would be preferable to administer the questionnaire among the users immediately after the screening test while they are still at the health centre. The users could then be assisted by an employee of the health centre who is not directly involved in the screening.



7.4.2 General satisfaction regarding the service

According to the comments received, generally-speaking, the service was appreciated by the users. Out of the 95 respondents, 93 deemed the service to be either “very satisfactory” (48 respondents) or “satisfactory” (45 respondents). A single respondent stated that they were “unsatisfied” with the service without providing justification for this position. Even if they were “satisfied” with the service, another respondent believes that the service would have been quicker if the retina specialist had been on location for the test.

According to the collected data, in order of priority, the following are benefits identified by the respondents:

- The proximity of the service;
- The quality of the service;
- The development of the knowledge related to health;
- The relationship based on trust with the health centre personnel;
- The health centre’s flexibility with respect to setting appointments.

Following the first year of screening, nearly all of the people (51/52 respondents²³) stated that they agreed with the idea of receiving another screening test in the same manner. Unfortunately, the information collected does not allow us to determine whether or not an equally large proportion of the users actually received the screening test during the second year of screening. In the same questionnaire, 51 respondents (51/53 respondents) mentioned that they were willing to use other telehealth services provided by their health centre.

7.4.3 Proximity of the service

The proximity of the screening service was the element that was the most frequently mentioned by the users and workers of the communities as being the primary benefit of the project (39/46 respondents). Note for example that the members of these communities, situated in the rural region of Témiscamingue in Quebec, were required to travel distances varying between 95 and 188 kilometres in order to access a screening test performed by an ophthalmologist. Therefore, the DR remote screening service provided within each of the communities saves the community members from many issues related to travelling (transportation, escort assistance, meals, lost work hours, etc.) even though these vary from one community to the next.

7.4.4 Development of the diabetes-related knowledge

The implementation of the screening service in the participating communities had significant impacts from an awareness perspective with respect to the diabetes-related

²³ It is important to note that the number of respondents for each of the questions differs from the total number of the questionnaire’s respondents due to the fact that some people did not answer all of the questions.



problems. The results obtained following the first year of screening indicate that more than half of the respondents (28/53) had never even heard of DR screening testing before the service was available within their communities.

Still after the first year of screening, more than half of the respondents (32/55) reported having acquired new knowledge related to diabetes, either in terms of ocular health or blood sugar control in connection with nutrition or diabetes in general. Also, in the questionnaire following the second year of screening, over half of the respondents (27/36) stated that they had the chance to discuss with the health centre workers and acquire new knowledge related to diabetes, ocular health, nutrition, physical activity or medication. In the recommendations made by the participants, one of them emphasised the value of repeated testing in the community. This person believes that the project will improve awareness among community members with respect to diabetes. Two other respondents underlined that, in parallel to the screening test, the health centres should organise diabetes awareness and demystification workshops in order to, once again, improve the knowledge of the community members regarding the causes and consequences of diabetes.

These observations made by the users stemming from all of the communities of the pilot project differ from the perceptions reported by the workers. In fact, the workers consider that they do not have the time required for raising awareness and transmitting knowledge among the users. This means that, despite the short amount of time spent with the users and the small amount of information provided, the users nonetheless acquired knowledge that will be useful to them in improving their state of health.

7.4.5 Local competencies

Following the first year of screening, 51 respondents maintain that it is “completely acceptable” (35 respondents) or “acceptable” (16 respondents) that it is a technician from their health centre who is responsible for providing the service. According to the comments collected, the patients know the technicians and nurses from their health centres and have developed a sense of trust in them. Many also believe that the technicians and nurses are qualified and that they have received adequate training to provide the service.

Two respondents stated that they are indifferent and two respondents believe that it is “unacceptable” (one respondent) or even “completely unacceptable” (one respondent) that the person responsible for providing the service is a technician from their health centre. Their reasons for this position were unfortunately not explained.

Following the second wave of screening, the 36 respondents from the communities involved believe that the nurses and technicians from their health centres possess the expertise required in order to take charge of the DR remote screening service. In their opinion, the technicians and nurses are well trained (three respondents), do quality work (one respondent) and can quickly obtain the information that they need (one respondent).



The vast majority of the respondents stated that it is “acceptable” (31 respondents) or “completely acceptable” (16 respondents) that the ophthalmologist is not on location during the screening tests that are performed at the community health centre. Three of these respondents believe that the workers from their health centres possess the necessary expertise and that they are able to answer their questions properly. Another respondent pointed out that the images are still verified by an ophthalmologist who can make a diagnosis. However, another respondent stated that he is concerned with the delay between the photography performed by the health centre and the delivery of the results following the analysis of the images by the ophthalmologist. Four respondents stated that they are “indifferent” and another maintained that it is “unacceptable” that the screening test is performed without the presence of an ophthalmologist. They did not provide reasons for their opinions.

Following the second wave of screening, 13 respondents out of 25 believe that the remote screening service offered in their community has improved since the first wave of screening. According to these respondents, the improvement of the service is primarily due to the experience accumulated by the health professionals (four respondents). Secondly, three respondents emphasised that the service is quicker and better planned. The 12 other respondents did not note any changes with respect to the service provided and no respondent believes that the service deteriorated during the second year of screening compared to the first year.

7.4.6 Follow-up with an ophthalmologist

For the two waves of screening performed in the communities participating in the pilot project, a total of 34 ophthalmology referrals were made. In the satisfaction questionnaire that was filled out by the users, only nine respondents commented on their follow-up and appointment setting with an ophthalmologist following the diagnosis made by the *Laboratoires de la rétine RD*. These respondents said that they were “satisfied” with the follow-up performed and the appointment setting process with an ophthalmologist.

Two of these nine respondents emphasised that they were already being monitored on a regular basis for their vision before the implementation of the remote screening service in their community. One mentioned that he was receiving follow-up from an ophthalmologist while the other did not specify whether he was consulting an ophthalmologist or an optometrist for follow-up purposes.

For most of the respondents, it was the nurses from their health centres who informed them regarding the results of their test and let them know that they required medical follow-up with an ophthalmologist. One respondent actually stated that this process (regular follow-up with an ophthalmologist) would not have been initiated without the assistance of the health centre workers.



7.4 SUMMARY OF THE EVALUATION OF THE SHORT-TERM EFFECTS

As of the emergence of the project, community control over the project was encouraged through capacity-building and the development of their autonomy. As pointed out by various players, the credibility of the trained workers is an important stake in the project's success. It is important for the staff members selected as those responsible for the service to be recognised by the population.

Despite the fact that the nurses and technicians of the health centres claim that they do not have enough time while performing the screening to provide information on diabetes to the users, the fact remains that the service offered by the health centres allows for increasing awareness among the community members regarding diabetes and its potential complications. A significant portion of the users who filled out the satisfaction questionnaire maintain that the remote screening service offered in their communities enabled them to increase their knowledge on diabetes and the consequences that the disease can have on their health. For example, the photography process performed in the presence of the patient allows this person to see the disease and be more aware of it (regional player). Also, in the letter of invitation that is sent out to the diabetic individuals asking them to participate in the testing, a wealth of information on diabetes and DR is provided to them.

In light of all of the satisfaction questionnaires filled out by the users of the service in the context of the pilot project, very little divergence with respect to the opinions transmitted have been observed. In fact, despite certain particularities, similar points of view were emitted by the users regardless of which community they belong to. We have also noted that almost all of the diabetic individuals who passed a DR screening test within their health centres stated that they were satisfied with the service received. Many advantages were raised in the questionnaires: the proximity of the service, its quality, quickness and flexibility and the development of the knowledge in connection with ocular health and diabetes. The majority of the respondents maintain that the workers are credible due to the experience they have developed and the sense of trust that the population has in them.

It has also been noted that, generally-speaking, the DR screening test is not well-known by the patients. This information leads us to believe that a significant number of diabetic patients may have never been screened in the past and that the project genuinely fostered taking control and follow-up related to the evolution of the disease.

Finally, approximately half of those who filled out the satisfaction questionnaire consider that the service offered by the personnel from their health centres has improved between the first and second waves of screening and no respondent believes that the service has deteriorated. This information is in line with the comments of the health centre workers who felt more confident during the second year of screening. It will be interesting to see if the perceptions of the users regarding the improvement of the service will have an effect on the number of participants in the project's subsequent years.



CHAPTER 8 - ECONOMIC ANALYSIS

8.1 INTRODUCTION

This economic analysis allows for identifying the resources used in order to accomplish the activities carried out in the context of the diabetic retinopathy (DR) remote screening pilot project among the communities of Timiskaming, Eagle Village, Winneway and Wolf Lake. This analysis of the costs and benefits presents estimates regarding all of the costs (societal and economic) and benefits related to the project.

The cost-benefit ratio is generally estimated by comparing the project costs with the expected benefits of a project. During the implementation of a new project, it is essential that the scenario of reference, meaning the scenario in the project's absence, is optimised before the costs and benefits are calculated. In other words, it is not the situation before or after the implementation that is important, but rather the optimal situation with or without the project.

The complexity of this pilot project presents certain challenges with respect to the realisation of an economic analysis such as the number of activities, the number of partners, the possible benefits and the lack of time that has passed since its implementation. This chapter therefore proposes the beginnings of an evaluation of the efficiency that will eventually allow for determining the return on investment, meaning the moment when the project will be considered profitable. This economic analysis is also associated with the development of new expertise at the FNQLHSSC.

This component of the evaluation therefore allows for presenting the amounts allocated to the activities carried out in the context of the pilot project. The calculations are made based on the costs in human, material and financial resources related to the addition of the service. However, this analysis does not take into consideration the costs related to the time invested by the health centre personnel and the other partners of the project.

The first part of this chapter presents the costs associated with the project, meaning the estimate of the costs emanating from its design and implementation. The second part compares the costs generated by the DR screening among the diabetic patients of the targeted communities without the implementation of the project and the cost of screening with the new service. These calculations are determined based on the number of service users, the number of ophthalmology referrals and the number of reimaging. The data used is the data from 2010 and comes from the centre tasked with analysing the back of the eye images, the *Laboratoires de la rétine RD*. This exercise allows for observing the difference in costs related to transportation, examination fees and societal costs for the communities with and without the implementation of the project.



8.2 CHALLENGES OF THE ECONOMIC ANALYSIS

In addition to the limitations of the evaluation presented in chapter 4, challenges that affect more specifically the economic analysis of the pilot project were encountered. However, as addressed in the introduction, the economic analysis of the project was initiated and allows for the establishment of conditions that will be able to enrich the process progressively as the project evolves.

The significant challenges of the economic analysis are particularly related to the collected data. This data often stems from diversified sources and most of it is not standardised or systematically entered locally or regionally.

The variability of the model trajectories

For each patient and for each community, there are differences between the trajectories that are normally taken by the patients between the screening step and the post-treatment follow-up step, when necessary. It is therefore important to consider the fact that the screening costs were calculated based on model trajectories. Other possible trajectories would generate costs that are perceptibly different from those presented.

The variability of the medical acts practiced

The evaluation also suffered due to the difficulty related to contacting the ophthalmologists and receiving information on the medical acts related to DR screening and follow-up. The nurses and sometimes the secretaries of the ophthalmology departments were able to provide some information. The *Régie de l'assurance maladie du Québec* (RAMQ) and the Ontario Health Insurance Plan (OHIP) also provided information related to the ophthalmology care covered by the provincial governments. However, during the collection process, the various sources consulted offered noticeably different proposals with respect to the medical acts practiced.

The costs covered by the Non-Insured Health Benefits (NIHB) Program

An important difference has been observed between the fees covered by the NIHB Program and the actual costs of the optometry services. These fees are left to the discretion of the optometrists and if they charge more than the amount reimbursed by NIHB, the patient must cover a portion of the invoice. Ideally, it would have been interesting to determine the portion of the fees that must be covered by the patient. To that end, it would have been necessary to be able to determine the individual trajectories of each user, which was not possible in the context of this evaluation.

The optometry fee schedules and the actual fees

The rates used for the optometric examinations stem from the optometry honorarium guides suggested by the Ontario Association of Optometrists (OAO) and the *Association des optométristes du Québec* (AOQ). It is important to mention that these fee schedules were used as an indication and that each optometry clinic sets its own prices. It is



therefore probable that the patients from the targeted communities go to clinics charging fees that are different from those identified for calculation purposes.

The difficulty related to determining the fees for ophthalmology care

Contrarily to the costs for optometric care, ophthalmology services are covered by the RAMQ. Fixed rates, for each examination, are established in the manuals for the specialists from each of the provinces. However, the costs presented in the context of this evaluation for ophthalmology services are also estimates due to the fact that these vary according to the type of facility the care is provided in. Therefore, the costs for a given examination performed in an external clinic, short-term hospital or physician's office will be different. With the available data, it was impossible to find out the place where each individual was screened and treated. The calculations were therefore made based on the average costs in effect among the three types of establishments where a patient could potentially consult. The use of this method was justified from a statistical perspective.

The cost of treatment according to the pathology and its severity

The analysis focuses on the cost of treatment for proliferative DR affecting a single eye. This rate was applied to all patients who were referred to an ophthalmologist. In reality, certain patients may have been referred for other conditions such as macular edema, the presence of cataracts or the presence of a DR affecting both eyes.

The reasons for the ophthalmology referral and the severity of the pathology cause the treatment costs to vary. In the context of the evaluation, it was impossible to account for this information, therefore it was not possible to take this variation in the cost of treatment into consideration.

The limited information on the trajectories of the patients before the implementation of the service

The data related to the DR consultations is limited for the years preceding the implementation of the project since the ophthalmologists and optometrists do not share the files with the community health centres. In most cases, they do not have a registry that can provide us with information on the proportion of diabetic patients who were already receiving care from either an ophthalmologist or an optometrist. Furthermore, there is no information on the number of diabetic patients who have already received treatment.

The incompatible sources of information and the divergence in the compilation of the data

The project's partners, which include the *Laboratoires de la rétine RD*, the FNQLHSSC, the FNIHB-QC and those responsible for the service among the community health centres, each kept a registry of the number of patients screened, the screenings performed and the ophthalmology referrals made. However, significant differences between these registries were observed. There are therefore noticeable differences in



the number of participants and the number of screenings performed for each year, due to the fact that no clear distinction was established between these two statistics. To ensure that the presented data is coherent, it was agreed to perform the analyses according to the database provided by the *Laboratoires de la rétine RD*. The advantage of this database is that it systematically provides the details on the type of referral assigned to each patient, which is necessary to calculate the costs of the various trajectories.

Access to the data of the FNIHB-QC

The difficulty in terms of obtaining information from FNIHB-QC represents one of the important limitations that the evaluation team was forced to deal with. This partner holds a database regarding the number of screenings, reimaging and users per year. The team responsible for the evaluation was unable to obtain access to this information. It was also necessary to estimate the costs related to travelling for the FNIHB-QC personnel since the organisation did not provide this information.

The insufficient data on the number of new patients

There is little available data to identify the number of new users among the patients for the second year of screening. However, one community collected data from the screening slips during the second year of screening. This data allowed for a first estimate of the evolution of the participation with respect to the number of new cases and the number of patients screened for the second time. The pursuit of the collection of this type of data will allow for determining if the number of users will increase or decrease over the course of the subsequent years and how large this variation will be, if such is the case.

All of these challenges must be taken into consideration when looking at the tables that are presented in this chapter. The presented data therefore represents estimates that must be interpreted with caution. Despite the limitations of this economic analysis, the observations made will allow for guiding informed decision-making for the continuation and deployment of the project among the First Nations communities of Quebec.

8.3 PRESENTATION OF THE PROJECT COSTS

Table 8.1 presents the expenses related to the implementation of the pilot project. The costs are presented by fiscal year and according to the source of funding. The global cost of the pilot project corresponds to the contributions provided by FNIHB-QC and Canada Health Infoway to the FNQLHSSC and the actual operating expenditures of FNIHB-QC.



Table 8.1. Contributions allocated to the FNQLHSSC and actual operating expenditures of FNIHB-QC for the pilot project

	Fiscal years		
	2008-2009	2009-2010	2010-2011
Contribution from Canada Health Infoway	\$16 430.00	\$111 056.00	\$78 746.00
Contribution from FNIHB-QC*	\$101 614.00	\$70 100.00	\$60 714.00
Actual operating expenditures of FNIHB-QC	\$167 988.00	\$145 501.00	\$168 973.00
Cost of the project per year	\$286 032.00	\$326 657.00	\$308 433.00
Global cost of the pilot project	\$921 122.00		

* The budget for the E-Health Agent of the FNQLHSSC is included in the contribution of the FNIHB-QC. The calculation was made according to a portion of this person's total salary representing the percentage of time allocated for the coordination and development of the DR screening project. The costs related to the evaluation of the pilot project are excluded from the project's economic analysis.

It must be mentioned that, at the beginning, there was no distinct budget for each of the project's phases. Therefore, a portion of the costs associated with the second and third years of the project was used for service deployment activities among other communities.

Furthermore, other partners, such as the community health centres, provided financial and human resources that cannot be accounted for in the previous table because they have not been assigned values in the context of this evaluation. It is also important to take into consideration that certain costs associated with patient screening are covered by the RAMQ, the NIHB Program or the patient. These other costs were not calculated.

8.3.1 Definition of the project's start-up, pre-implementation, implementation and operational costs

Four different types of project costs must be taken into consideration: start-up, pre-implementation, implementation and operating costs.

A. Start-up costs

The start-up costs are the non-recurring costs associated with the activities required in order to start the project that are not directly related to the implementation of the service. Eventually, these start-up activities will benefit all of the First Nations communities of Quebec which will have access to DR remote screening services. These activities



namely include the creation of the collective prescriptions and training materials as well as the training provided to the personnel of FNIHB-QC. The activities associated with the start-up costs are described in table 8.2.

Globally-speaking, for the four types of project costs, it was impossible to estimate the costs of certain activities. This observation results from the lack of access to the information and the fact that it is impossible to sufficiently break down the amounts invested.

Note that a portion of the costs that are not broken down are nonetheless included in the global cost presented in table 8.1. There were also other not estimated costs that were not taken into consideration in the global budget: indirect and incalculable costs (human resources of the various mobilised First Nations organisations) and costs related to upcoming activities (recertification of the nurses, repeated training for personnel replacement, replacement of equipment).

Some of the costs that could not be estimated are addressed in section 8.3.3.

Table 8.2. Estimated and not estimated costs

	Project start-up costs (non-recurring*)
Estimated**	❖ Creation of the training material ❖ Training of the FNIHB-QC personnel ❖ Preparatory training ❖ Creation of the service contract ❖ Detailed architecture ❖ Translation and revision ❖ Evaluation of the privacy factors
Not estimated	❖ Development of the project ❖ Development of the collective prescriptions ❖ Punctual services provided by the <i>Laboratoires de la rétine RD</i> ❖ Meetings of the various committees

*Even if the start-up costs are considered to be non-recurring costs, it is possible that some of these activities may require an update (training materials, service contracts, training of the FNIHB-QC personnel, etc.).

** When they were accessible, the actual costs related to the activities were taken into consideration for the calculations. For certain activities for which the cost was inaccessible, it was nonetheless possible to estimate the cost based on various known data.



B. Pre-implementation costs

Before the implementation of the service among each group of communities²⁴, pre-implementation is necessary. This step includes activities such as the signing of collective prescriptions and contracts, equipment purchasing and meetings with health professionals. The pre-implementation must be repeated during the deployment of the service to a new group of communities.

C. Implementation costs

The implementation costs are associated with the activities related to the implementation of the screening service among the health centres of a same group of communities. In the context of this evaluation, this phase corresponds to the period when the nurses and technicians of the communities were training and the first screening tests were performed.

D. Operating costs

The operating costs are defined here as being all of the costs required in order to operate the project on a regular basis within the health centres. These costs are therefore related to the population's access to the services. All of the operating costs are recurring in nature.

The activities associated with the pre-implementation, implementation and operating costs are described in table 8.3.

²⁴ A "group of communities" refers to a set of communities that share the same camera.



Table 8.3. Estimated and not estimated pre-implementation, implementation and operating costs

	Pre-implementation costs	Implementation costs	Operating costs
Estimated*	❖ Presentation of the project to the communities and the regional physicians, ophthalmologists and pharmacists ❖ Configuration fees per access point for the <i>Laboratoires de la rétine RD</i> ❖ Equipment purchasing ❖ Office supplies	❖ Training of the technicians and nurses of the communities	❖ Operating fees of the <i>Laboratoires de la rétine RD</i> ❖ User fees per access point ❖ Equipment transportation ❖ Fees for the analysis of the images ❖ Meeting of the local working group ❖ Technical support after the implementation
Not estimated	❖ Technical support for start-up ❖ Meetings of the various committees ❖ Securing of the band council resolutions ❖ Signing of the collective prescriptions and contracts	❖ Technical support during the implementation	❖ Quality insurance ❖ Recertification of the nurses ❖ Repeating training for personnel replacements among the health centres and FNIHB-QC ❖ Indirect costs connected to the human resources involved among the participating communities and the ANPSS ❖ Equipment repairs and/or replacement ❖ Connectivity fees

* When they were accessible, the actual costs related to the activities were taken into consideration for the calculations. For certain activities for which the cost was inaccessible, it was nonetheless possible to estimate the cost based on various known data.

8.3.2 Estimated start-up, pre-implementation, implementation and operating costs

Tables 8.4 to 8.7 provide details on the project costs associated with the start-up, pre-implementation, implementation and operating costs that were estimated in the context of this economic analysis.

As previously explained, certain costs related to the salaries of the personnel of the FNQLHSSC, the FNIHB-QC and the community workers are not included, but are nonetheless included in the global costs presented in table 8.1.



Table 8.4. Estimated start-up costs

Activities	Cost explanations	Estimated cost
Creation of the training material	Costs related to the development, revision, translation and editing of the training manuals used in the context of the training sessions offered to the community nurses and technicians.	\$68 602.00
Training of the FNIHB-QC personnel	Costs related to the training of the nurses and technicians of the FNIHB-QC who were then responsible for offering training to the community nurses and technicians.	\$3 246.00
Preparatory training in Montreal	Two meetings for which the goal was to validate the contents, duration and educational approach of the training sessions to be provided to the technicians and nurses. The costs are associated with the travel and accommodations fees of the people attending these meetings.	Training of the technicians: \$4 539.30 Training of the nurses: \$2 987.88 \$7 527.18
Creation of the service contracts	The costs are related to the hiring of a legal firm in order to create service contracts between the FNQLHSSC and the communities and between the communities and the <i>Laboratoires de la rétine RD</i> .	\$12 244.20
Detailed architecture	The costs are related to the work on the evaluation and the computer architecture used for the DR screening.	\$14 967.27
Translation and revision	The costs are related to the translation and revision of the documents in connection with the project for the years 2008 to 2011.	\$7 545.87
Evaluation of the privacy factors	This evaluation allowed for verifying the legal and legislative foundations of the project.	\$9 600.00
Total		\$123 732.52
Cost per community* (estimated cost/4)		\$30 933.14
Cost per known diabetic person** (estimated cost /175)		\$707.04

* The costs related to these activities can be divided among the four communities of the pilot project. Since the products resulting from these activities will also benefit the other communities that will integrate the project, these costs will eventually be divisible among a greater number of communities.

** For the time being, these costs can be divided among the 175 diabetic individuals who are known by the health centres of the four communities of the pilot project. These costs will eventually be divisible among a greater number of diabetic people.



Table 8.5. Estimated pre-implementation costs

Activities	Cost explanations	Estimated cost
Presentation of the project to the communities and health professionals	The costs associated with travelling for one FNQLHSSC employee and one FNIHB-Quebec Region employee for the presentation of the project to the regional communities, physicians and ophthalmologists.	Presentation to the communities: \$3 179.64 Presentation to the professionals: \$2 875.30 \$6 054.94
Set-up fees per access point	Connection charges that apply for each access point (communities sharing the same camera constitute one access point).	\$1 000.00
Equipment purchasing	Includes the purchasing of a camera, a computer and a Tono-Pen. In order to amortize the annual cost, the equipment cost was divided over its life span (camera: 17.5 years, Tono-Pen: 6.5 years).	Camera: $\$38\,264.63 / 17.5 = \$2\,186.55$ Tono-Pen: $\$4\,018.38 / 6.5 = \618.21 \$2 804.76
Office supplies	Cost established according to the list of transactions of the FNQLHSSC.	\$828.88
Total		\$10 688.58
Cost per community (estimated cost /4)		\$2 672.15
Cost per known diabetic person (estimated cost /175)		\$61.08



Table 8.6. Estimated implementation costs

Activities	Cost explanations	Estimated cost
Training of the nurses in Montreal	The costs include travelling and accommodations for the trainers and trainees. For those who work in Montreal, an amount of \$24.50 was established for travelling and meals.	Timiskaming: \$1 137.84 Eagle Village: \$1 099.34 Wolf Lake: -- Winneway: \$1 137.84 FNQLHSSC: \$343.00 FNIHB-QC: \$73.50 \$3 791.52
Training of the technicians in the communities	The costs include travelling for the FNIHB-QC and FNQLHSSC personnel. The same travel fees were estimated for the personnel from these two organisations.	Timiskaming: \$11 708.46 Eagle Village: \$9 263.00 Wolf Lake: \$0 Winneway: \$12 189.91 \$33 161.37
Total		\$36 952.89
Cost per community (estimated cost /4)		\$9 238.22
Cost per known diabetic person (estimated cost /175)		\$211.16



Table 8.7. Estimated operating costs (year of reference: 2010)

Activities	Cost explanations	Estimated cost
Operating fees of the Laboratoires de la rétine RD	These annual costs ensure the operation of the project regardless of the number of communities using the service.	Server, fiber optic, security and archiving: \$10 200.00 Retina-Lab license: \$24 000.00 Telecommunications: \$900.00 \$35 100.00
User fees per access point	Set rates of \$50.00 are payable on a monthly basis.	\$600.00
Equipment transportation*	The calculation includes two screening sessions per year per community. The costs are calculated based on travel from Eagle Village using the medical transportation rate.	Eagle Village (Wolf Lake): \$0 Timiskaming: \$338.00 Winneway: \$566.00 \$904.00
Image analysis	Set rates of \$115.00 are charged for the analysis of images related to each screening test performed (89 tests in 2010).	\$10 235.00
Meeting of the local working group	The costs were determined for all those who attended the local working group based on a meeting that took place in Timiskaming (travelling and accommodations).	Winneway: \$175.52 Timiskaming: \$73.50 Eagle Village: \$210.26 Wolf Lake: \$173.26 FNQLHSSC/FNIHB: \$3 078.00 \$3 710.54
Technical support offered to the communities	Costs related to the technical support provided by FNIHB-QC to the communities after the implementation of the service.	\$3 207.00
Total		\$53 756.54
Cost per community (estimated cost /4)		\$13 439.14
Cost per known diabetic person (estimated cost /175)		\$307.18

*The costs related to transporting the equipment from one community to another are costs that are covered by Eagle Village's medical transportation program. Since they are not covered by Canada Health Infoway or Health Canada, these costs were not included in the global costs of the project presented in table 8.1.



Table 8.8 presents a summary of the costs of the project as estimated within the context of this economic analysis.

Table 8.8. Summary of the estimated project costs

Types of costs	Global estimated cost	Cost per pilot project community (estimated cost/4)	Cost per known diabetic person (estimated cost /175)
Start-up costs	\$123 732.52	\$30 933.13	\$707.04
Pre-implementation costs	\$10 688.58	\$2 672.15	\$61.08
Implementation costs	\$36 952.89	\$9 238.22	\$211.16
Operating costs	\$53 756.54	\$13 439.14	\$307.18
Total	\$225 130.53	\$56 282.64	\$1 286.46

The global estimated cost is therefore \$225 130.53 which comes out to an amount of \$56 282.63 per community and \$1 286.46 per diabetic person known by the health centres of these four communities. As indicated in table 8.1, a total amount of \$921 122.00 was invested by the various partners in order to carry out the first three years of the project. A cost breakdown was therefore performed for approximately a quarter of the amount allocated.

For the continuation of the project consisting of maintaining the service in the four pilot project communities and deploying the service among the other First Nations communities of Quebec, only the costs associated with pre-implementation, implementation and operation need to be invested again. Therefore, as mentioned previously, the start-up costs, which represent a significant portion of the project's costs, will not need to be reinvested.

8.3.3 Not estimated project costs

It was impossible to assign a numerical value to many costs associated with the start-up, pre-implementation, implementation and operation of the DR remote screening pilot project. It was impossible to estimate these costs due to the fact that the team responsible for the evaluation was unable to access certain information or determine if the costs were related to upcoming activities or if the costs were indirect costs namely connected to the mobilisation of human resources. Two of these not estimated costs are outlined here.



A. The recertification of the nurses and technicians and repeated training to address staff turnover among the health centres

It was anticipated that the workers responsible for the service in the communities would receive recertification every two years. Since these sessions have yet to be provided, the costs that they will involve are still unknown. Also, certain training costs will be added depending on the rate of staff turnover among the health centres or the needs expressed by the teams in place.

B. Indirect costs related to the time invested by the human resources of the health centres

Considerable work must be carried out by the health centres and it is important to take into consideration the impacts of all the time devoted to personnel training, recruitment, appointment setting, screening sessions and follow-up for the cases screened with the ophthalmologists. Globally-speaking, the employees devote a significant amount of time that can therefore not be invested towards the accomplishment of their other usual tasks. Furthermore, the health centres are required to provide work space which impedes the duties of the other workers.

In the context of this pilot project, no budget was allocated to the health centres in order to compensate for this additional workload. The health centres are also required to cover on their own the costs related to the time invested by their personnel in order to perform the various tasks associated with DR screening. They must also cover the costs related to the transportation of the equipment between the communities as well as the insurance premiums for the camera.

8.3.4 Projection of the costs for the upcoming years

Certain costs related to implementation and operations will be lower when deploying the service among other communities and for the subsequent years of operation for the four communities of the pilot project. This factor must be examined in order to evaluate the costs of the project for the upcoming years.

A. The costs of the training for the technicians

For the training of the technicians in Timiskaming and Winneway, the presented cost includes expenses related to travel and accommodations for a trainer from Yellowquill College located in Manitoba. These expenses (\$3270.52 for the community of Winneway and \$3197.46 for Timiskaming) will no longer be necessary, since the training will be provided by the FNIHB-QC for the new communities that will be added to the project.



B. The costs of the training for the nurses

For the communities that will subsequently integrate the remote screening service into the services they provide, the training of the nurses will take place directly within the health centres on the same week as the training intended for the technicians. Since the training will be offered in the communities, the nurses will not be required to travel.

C. Technical support offered to the communities after the implementation of the service

Another cost that is likely to be lower in subsequent years is the cost related to the technical support offered by FNIHB-QC to the communities following the implementation of the service. In fact, we can estimate that the more the technicians handle the equipment, the more comfortable they will become with it and the less technical support they will require.

8.4 COSTS ASSOCIATED WITH THE PATIENT TRAJECTORIES

An important component of the project's operating costs is related to the travelling and examination fees for the patients receiving the screening services and DR follow-up. As mentioned, a comparison of the costs "without" the implementation and "with" the implementation of the service in the communities will be presented.

8.4.1 Definition of the costs associated with screening and follow-up for the patients

The costs associated with screening and follow-up for the patients which are presented here are the direct costs stemming from the trajectory of a person requiring a screening test and follow-up for a DR. It is necessary to note that, included in the trajectory costs, are all of the fees with monetary value, whether these are reimbursed by the federal government through the NIIHB program, the provincial government through the RAMQ or even covered by the patient.

A. The transportation costs

The first cost associated with DR screening, follow-up and treatment is the cost related to patient transportation for each step of the trajectory. The calculation of the transportation cost was established according to the cities indicated by the personnel of the health centres as being the destinations where the patients most often consult a specialist.

When seeking medical consultation outside of the community the patient resides in, several choices are available to the patient with respect to transportation. In the context of this evaluation, a single type of transportation that is normally used by the patients was selected, which is the community medical transportation service. Furthermore, the



calculations were based on the fact that the patient is accompanied by a person of his/her choice as stipulated in each community's medical transportation policy.

The transportation expenses were therefore calculated while taking into account the number of kilometres travelled for a round trip (\$0.50 per kilometre) as well as the salary of the medical transportation driver according to the rates in effect in the communities. Furthermore, meal expenses (\$10.00) were also calculated for the patient and his/her escort when the estimated time for the transportation and medical consultation exceeds four hours, which is the equivalent of half a day.

B. The examination fees

For each step of the trajectory, the fees associated with the examinations and medical acts that are typically performed by an optometrist or ophthalmologist were calculated. For the examinations performed by optometrists, the costs were based on the fee schedule of the *Association des optométristes du Québec* (AOQ) or the information provided by the personnel of the Ontario Association of Optometrists (OAO). For the examinations performed by the ophthalmologists, the costs reported are those established in the *Manuel des médecins spécialistes* of the RAMQ and OHIP.

C. The societal costs

The societal costs stemming from the patient trajectories are the costs associated with the loss of productivity caused by the work hours lost by the patient or the person accompanying him/her. These costs were calculated based on a minimum hourly wage of \$9.65 (the minimum hourly wage in effect for the period of May 2011 to April 2012). The calculation of the number of hours of work lost includes the time required for travelling, waiting at the clinic and consulting with the specialist as well as the blurred vision time caused by pupil dilation (only for the patient). These calculations were made based on the information transmitted by the hospitals and clinics where the ophthalmology or optometric care is usually provided to the patients from the four communities of the pilot project. For the patient, the time lost due to blurred vision is estimated to be four hours, from which was subtracted the number of hours required to return to the community.

Table 8.9 outlines the wait times, consultation and blurred vision durations that were taken into consideration for the calculation of the societal costs.



Table 8.9. Time taken into consideration for the calculation of the societal costs

		Ophthalmologist	Optometrist
Screening and follow-up	Wait time at the clinic	90 minutes	30 minutes
	Duration of the consultation	1 hour	30 minutes
	Blurred vision time	4 hours	4 hours
Treatment	Wait time at the clinic	30 minutes	-
	Duration of the consultation	1 hour	-
	Blurred vision time	4 hours	-

8.4.2 Costs associated with the model trajectories of the diabetic patients without the implementation of the DR remote screening pilot project

As explained in chapter 5, two possible scenarios were identified for the trajectories of diabetic people between the screening and post-treatment follow-up steps before the remote screening project is implemented. The first scenario involves the patient receiving a referral from their family physician for consultation and DR screening by an ophthalmologist. The second scenario involves an ophthalmology referral being made by an optometrist following a first screening indicating the presence of an anomaly.

Tables 8.10 and 8.11 outline the costs that would have been generated by the provision of care for the users of the screening service without the implementation of the pilot project for scenario 1 and scenario 2. For each of the steps of the trajectories, the cost presented is the sum of the costs related to travelling, examination fees and the societal costs.

These costs were determined according to the three types of referrals that can possibly be made by the specialists of the *Laboratoires de la rétine RD* following a screening test performed by way of telehealth: 1) normal test and reimaging in one year; 2) beginning of a pathology and reimaging in four or six months; 3) ophthalmology referral.

In these tables, the global costs of the trajectories are presented for each of the communities. Furthermore, this amount was divided by the number of diabetic individuals known by the health centres. Detailed tables for each community of the pilot project presenting the costs associated with travelling, examination fees and the societal costs for each of the steps of the trajectories are appended to this document.



Table 8.10. Operating costs associated with the trajectories of the patients without the implementation of the pilot project, per community, for scenario 1 (referral for ophthalmology made by a general practitioner)*

	Timiskaming			Eagle Village			Wolf Lake			Winneway		
Steps of the trajectory	Normal test	Reimaging 4/6 months	Treatment**	Normal test	Reimaging 4/6 months	Treatment	Normal test	Reimaging 4/6 months	Treatment	Normal test	Reimaging 4/6 months	Treatment
Screening and diagnosis by the ophthalmologist	\$629.69	\$629.69	\$629.69	\$424.38	\$424.38	\$424.38	\$395.14	\$395.14	\$395.14	\$407.74	\$407.74	\$407.74
Follow-up or treatment if necessary	\$0	\$609.59	\$1 376.08	\$0	\$404.28	\$933.45	\$0	\$375.04	\$874.98	\$0	\$383.50	\$1 873.95
Total for one user	\$629.69	\$1 239.28	\$2 005.77	\$424.38	\$828.66	\$1 357.83	\$395.14	\$770.18	\$1 270.12	\$407.74	\$791.24	\$2 281.69
Number of users	25	0	8	17	7	5	0	0	1	15	1	10
Total cost per trajectory	\$15 742.25	\$0	\$16 046.16	\$7 214.46	\$5 800.62	\$6 789.15	\$0	\$0	\$1 270.12	\$6 116.10	\$791.24	\$22 816.90
Total for all the trajectories	\$31 788.41			\$19 804.23			\$1 270.12			\$29 724. 24		
Grand total for all of the communities	\$82 587.00											
Average cost per diabetic person (175)	\$471.93											

* According to the number of users who benefitted from the screening service in 2010.

** As previously explained, an ophthalmology referral can indicate different situations (DR requiring treatment, presence of another eye anomaly or an image of insufficient quality). In the context of this economic analysis, all the ophthalmology referral cases are considered as leading to treatment for proliferative DR in one eye.



Table 8.11. Operating costs associated with the trajectories of the patients without the implementation of the pilot project, per community, for scenario 2 (referral for ophthalmology made by an optometrist following a first screening indicating an anomaly)*

	Timiskaming			Eagle Village			Wolf Lake			Winneway		
Steps of the trajectory	Normal test	Reimaging 4/6 months	Treatment**	Normal test	Reimaging 4/6 months	Treatment	Normal test	Reimaging 4/6 months	Treatment	Normal test	Reimaging 4/6 months	Treatment
Screening by the optometrist	\$371.65	\$371.65	\$371.65	\$499.26	\$499.26	\$499.26	\$470.02	\$470.02	\$470.02	\$617.94	\$617.94	\$617.94
Diagnosis by the ophthalmologist	\$0	\$660.89	\$660.89	\$0	\$455.58	\$455.58	\$0	\$426.34	\$426.34	\$0	\$418.94	\$418.94
Follow-up or treatment by the ophthalmologist if necessary	\$0	\$609.59	\$1 376.08	\$0	\$404.28	\$933.45	\$0	\$375.04	\$874.98	\$0	\$383.50	\$1 873.95
Total for one user	\$371.65	\$1 642.13	\$2 408.62	\$499.26	\$1 359.12	\$1 888.29	\$470.02	\$1 271.40	\$1 771.34	\$617.94	\$1 420.38	\$2 910.83
Number of users	25	0	8	17	7	5	0	0	1	15	1	10
Total cost per trajectory	\$9 291.25	\$0	\$19 268.96	\$8 487.42	\$9 513.84	\$9 441.45	\$0	\$0	\$1 771.34	\$9 269.10	\$1 420.38	\$29 108.30
Total for all the trajectories	\$28 560.21			\$27 442.71			\$1 771.34			\$39 797.78		
Grand total for all of the communities	\$97 572.04											
Average cost per diabetic person (175)	\$557.55											

* According to the number of users who benefitted from the screening service in 2010.

** As previously explained, an ophthalmology referral can indicate different situations (DR requiring treatment, presence of another eye anomaly or an image of insufficient quality). In the context of this economic analysis, all the ophthalmology referral cases are considered as leading to treatment for proliferative DR in one eye.



These two tables demonstrate a difference in cost between scenario 1 and scenario 2, and this applies to all of the communities of the pilot project. The cost per known diabetic patient is therefore higher for scenario 2 except for the community of Timiskaming. The tables detailing the costs appended to this document demonstrate that the costs associated with travelling account for a significant portion of the costs related to each of the steps of the trajectories and have a large impact on the screening costs for each community.

8.4.3 Costs associated with the model trajectories of the diabetic patients with the implementation of the remote screening pilot project

The following table (8.12) presents the costs associated with the diabetic patient trajectories for DR screening and follow-up following the implementation of the remote screening pilot project. The costs presented are established according to the number of users for the first year of operation of the pilot project. One cost was calculated for each trajectory step as described in chapter 5.

These costs were determined according to the three types of referrals that can possibly be made by the specialists of the *Laboratoires de la rétine RD* following a screening test performed through telehealth: 1) normal test and reimaging in one year; 2) beginning of a pathology and reimaging in four or six months; 3) ophthalmology referral. By multiplying the costs of each of the trajectories by the number of users of the pilot project having received this diagnosis, it is possible to determine the cost generated by the screening and follow-up provided to the users for each of the communities. The total cost of the trajectories can also be lessened by the number of diabetic individuals known by the health centres of each community.

The calculations used were the same calculations that were applied to determine the costs without the implementation of the pilot project in the communities. The screening examination cost is the amount charged by the *Laboratoires de la rétine RD* for image analysis purposes. When a patient receives an ophthalmology referral, the fees related to follow-up and treatment are based on the rates in effect in the public health network that are covered by the health insurance plans of Quebec and Ontario.

The following table (8.12) outlines, for each of the communities of the pilot project, the costs related to the possible trajectories for the diabetic patients receiving a first screening test from their health centres. Detailed tables focusing on the costs for each of the communities are also appended to this document.



Table 8.12. Operating costs associated with the patient trajectories with the implementation of the pilot project, per community*

	Timiskaming			Eagle Village			Wolf Lake			Winneway		
Steps of the trajectory	Normal test	Reimaging 4/6 months	Treatment **	Normal test	Reimaging 4/6 months	Treatment	Normal test	Reimaging 4/6 months	Treatment	Normal test	Reimaging 4/6 months	Treatment
Screening	\$172.90	\$172.90	\$172.90	\$172.90	\$172.90	\$172.90	\$235.38	\$235.38	\$235.38	\$172.90	\$172.90	\$172.90
Follow-up	\$0	\$172.90	\$660.89	\$0	\$172.90	\$455.58	\$0	\$235.38	\$426.34	\$0	\$172.90	\$418.94
Treatment	\$0	\$0	\$1 376.08	\$0	\$0	\$933.45	\$0	\$0	\$874.98	\$0	\$0	\$1 873.95
Total for one user	\$172.90	\$345.80	\$2 209.87	\$172.90	\$345.80	\$1 561.93	\$235.38	\$470.76	\$1 536.70	\$172.90	\$345.80	\$2 465.79
Number of users	25	0	8	17	7	5	0	0	1	15	1	10
Total cost per trajectory	\$4 322.50	\$0	\$17 678.96	\$2 939.30	\$2 420.60	\$7 809.65	\$0	\$0	\$1 536.70	\$2 593.50	\$345.80	\$24 657.90
Total for all the trajectories	\$22 001.46			\$13 169.55			\$1 536.70			\$27 597.20		
Grand total for all of the communities	\$64 304.91											
Average cost per diabetic person (175)	\$367.46											

* According to the number of users who benefitted from the screening service in 2010.

** As previously explained, an ophthalmology referral can indicate different situations (DR requiring treatment, presence of another eye anomaly or an image of insufficient quality). In the context of this economic analysis, all the ophthalmology referral cases are considered as leading to treatment for proliferative DR in one eye.



Tables 8.13 and 8.14 offer a summary of the costs generated by the trajectories of the diabetic patients “with” and “without” the implementation of the pilot project for each of the four communities.

Table 8.13. Total cost of the patient trajectories with and without the implementation of the pilot project, per community

	Without the project		With the project
	Scenario 1 (patients referred by a physician)	Scenario 2 (patients referred by an optometrist)	
Eagle Village	\$19 804.23	\$27 442.71	\$13 169.50
Timiskaming	\$31 788.41	\$28 560.21	\$22 001.46
Winneway	\$29 724.24	\$39 797.78	\$27 597.20
Wolf Lake	\$1 270.12	\$1 771.34	\$1 536.70
Total	\$82 587.00	\$97 572.04	\$64 304.86

Table 8.14. Costs of the patient trajectories with and without the implementation of the pilot project by diabetic patient known by the health centres

	Without the project		With the project
	Scenario 1 (patients referred by a physician)	Scenario 2 (patients referred by an optometrist)	
Average cost per known diabetic person (175)	\$471.93	\$557.55	\$367.46

In light of the amounts presented in the previous tables, it appears that the costs of the patient trajectories following the implementation of the service in the communities are lower than the costs without the implementation. For all of the patients screened in the context of the pilot project, a difference of nearly \$20 000 can be observed between the costs related to scenario 1 without the implementation and the costs with the implementation. In terms of the scenario 2 comparison, over \$30 000 were saved thanks to the implementation of the remote screening service.



The savings achieved through the pilot project are mainly related to a decrease in travel fees as well as a significant number of ophthalmology consultations that were avoided for patients who do not have a pathology requiring treatment.

8.5 AMORTIZATION OF THE COSTS AND PROFITABILITY OF THE PROJECT

When examining the tables presenting the project costs related to the patient trajectories, several analyses can be made.

First of all, a decrease in the costs of the trajectories following the implementation of the remote screening service must be considered. By being able to estimate the expenses involved in order to develop and implement the project and the expenses avoided thanks to the implementation of the remote screening project, it would be interesting to establish a projection of the costs allowing to estimate the number of years needed for the project to become profitable. Certain limitations of this economic analysis explain the fact that at the end of phase 1 of the project, it is too early for this exercise to be possible. Indeed, it is impossible to estimate the number of users who will benefit from the service in the upcoming years and dampen the project's costs due to the fact that certain data is missing. Furthermore, knowing the number of users would allow for estimating the costs that could be avoided thanks to the new trajectories of the patients.

Another limitation preventing the calculation of the amortization of the project's costs is the fact that the number of patients receiving ophthalmology referrals who will resume receiving remote screening services following treatment remains unknown. For the time being, there are no clear directives from the *Laboratoires de la rétine RD* or the treating ophthalmologists allowing to determine if the patients referred to an ophthalmologist can resume being monitored remotely and, if so, starting when.

Finally, it would be difficult to make an exact projection of the time needed in order to render the project cost-effective. In fact, many costs related to the project could change over the course of the upcoming years (see point 8.3.4) and several costs related to pre-implementation, implementation and operation have not been estimated in the context of this evaluation.

Despite this limitation, when comparing the costs saved for each of the patients screened remotely with the amounts invested into the project, it seems possible to anticipate that the project will become cost-effective in the more or less long-term. Therefore, the calculations made demonstrate that the implementation of the project allowed for saving at least \$20 000 in 2010 for screening and follow-up services among diabetic patients. The calculations presented also demonstrate that, regardless of the number of patients that will be screened each year by the health centres, the costs of their trajectories will be lower than when DR remote screening services are not provided to them. Each year, an additional amount corresponding to the costs avoided could be subtracted from the global amount invested.



Furthermore, various other factors must be considered in order to establish the amount of time required to offset the costs.

A. Offsetting of the start-up costs

The start-up costs represent a significant portion of the pilot project's budget. First of all, it must be noted that these expenses are non-recurring and can be lessened by a greater number of communities and users as they join the project. In fact, the remote screening service will be offered on a voluntary basis to all of the First Nations communities of Quebec and the pre-implementation costs could eventually be offset by 25 communities.

B. Offsetting the operating costs of the *Laboratoires de la rétine RD*

While certain recurring costs go up with the addition of points of service or an increase in the number of users such as image analysis fees and connection fees per point of service, certain recurring fees are fixed fees. They can therefore be offset with a greater number of communities as new points of service are added. This is actually the case for the operating fees of the *Laboratoires de la rétine RD* which include costs related to server renting, fibre optic connection, living archiving security, Retina-lab licensing and telecommunication fees. In total, these costs come out to \$35 100.00 and are payable on an annual basis, irrespective of the number of communities that are benefitting from the service.

According to the statistics compiled by the *Laboratoires de la rétine RD*, during the first year of screening in which only the four communities of the pilot project participated, the sum of the operating costs (\$35 100.00) and the total cost for image analysis ($89 \times \$115.00 = \$10\,235.00$) divided by the number of users (82) comes out to a cost of \$552.87 per patient. Performing the same calculation for the following year, during which three new communities were added to the project (Kitigan Zibi, Lac Simon and Pikogan), comes out to a per patient cost of \$340.80. This demonstrates that the recurring costs will decrease in proportion to the increase in the volume of users.

8.6 SOCIETAL ADVANTAGES OF DR REMOTE SCREENING

In the context of this economic analysis, it is important to balance the costs of the project with all of the societal costs avoided and the benefits obtained thanks to the new service provided. Furthermore, many of these advantages are incalculable and focus more on the well-being of the First Nations people.

By improving DR screening, this project contributes to decreasing the number of patients suffering from complications associated with late diagnosis or inadequate medical follow-up. Consequently, the implementation of this service in all of the First Nations communities would enable the public health system to achieve substantial savings.



8.6.1 Travelling avoided by the patients

The reduction of the travelling costs represents the main financial benefit of the DR remote screening pilot project. This service represents a significant decrease in the distances travelled by the diabetic patients from the communities. In fact, each examination that was once performed at an ophthalmologist or optometrist can henceforth be performed in the patient's community of residence. This only leaves travelling for treatment and post-treatment follow-up examinations. Furthermore, the time required for travelling can be one of the main reasons why some diabetic people were not receiving DR follow-up as often as recommended.

Based on the tables of the trajectory costs without the implementation of the pilot project appended to this document, the observation can be made that the costs related to travelling exceed the treatment costs. The time required for travelling entails societal costs corresponding to work time lost by the patient and their escort.

8.6.2 Systematic screening and possible increase in the number of diabetic people screened

Before the implementation of the remote service, travel time may have been one of the reasons why the recommended DR screening examinations and follow-up were not being performed. Therefore, it is possible to estimate that the number of patients screened through the pilot project is higher than the number of patients who travelled in the past.

The conclusions of this analysis will not allow for emphasising an important benefit of the project, which involves going from opportunistic screening to systematic screening of all the diabetic patients. It is in fact believed that access to annual screening, in proximity to the place of residence, fosters regular or systematic screening which, in the long-term, provides economic and social benefits when compared to punctual or opportunistic screening (Jones & Edwards, 2010).

The information derived from the satisfaction questionnaires completed by the users allows for making the observation that the remote screening services provided enabled many diabetic people to receive DR screening for the first time. According to the recommendations, these people should have been monitored many years ago. This is underlined by the referrals for ophthalmology treatment and consultation on an urgent basis or during the same year.

According to a study by Jones and Edwards (2010), the implementation of a remote screening program causes an increase in the number of follow-ups performed and therefore a probable increase in costs in the short-term. However, it allows for a significant decrease in costs in the long-term, which is mainly the result of a decreased number of cases with complications.



8.6.3 Regular and more frequent follow-up of the patients

By comparing the trajectory of a diabetic patient with the implementation of the pilot project to the trajectory of a patient without the implementation, as suggested by scenario 2 (referral made by an optometrist), the observation can be made that remote screening allows for more frequent follow-up. While sessions are held on a regular basis and provided free-of-charge for all of the diabetic people in the community, the optometry examination for diabetic people is only covered once every two years by the NIHB program. Furthermore, offering remote screening services among the health centres eliminates certain barriers that may have been hindering certain patients such as travel time, linguistic barriers and wait times related to receiving services.

8.6.4 Decrease in treatment complexity

DR remote screening allows for ensuring that treatment is provided to diabetic people more quickly. This is important since early diagnosis allows for simple and inexpensive treatment, while late diagnosis often involves more specialised treatment that is provided in the large urban centres.

8.6.5 Decrease in the costs associated with blindness

Blindness is a major consequence of DR if it has not been adequately treated and monitored. In fact, several economic analyses have concluded that decreasing the societal costs associated with blindness is an important factor in achieving a cost-effective remote screening program. In this regard, a study conducted by Malberly et al. (2003) documenting a remote screening project among the Cree Nation in Ontario demonstrates that the screening service allowed for reaching more individuals thereby increasing the number of years of sight saved.

8.6.6 Decrease in the costs related to wait times

Each step of a patient's trajectory is associated with a delay in order to obtain an appointment and this wait time can aggravate the disease, which generates additional societal costs. In the context of the pilot project, it is the ophthalmologists of the *Laboratoires de la rétine RD* who provide ophthalmology referrals to the patients and prescribe a maximum delay in order to obtain a follow-up appointment according to the identified degree of urgency. According to the health centre personnel of one community targeted by the project, this procedure has the effect of decreasing wait times from a period of three to twelve months before the implementation to a period of two weeks to six months after the implementation. Moreover, it is also important to note that the project completely eliminated the wait times for a screening test, while with an ophthalmologist, this delay is the same as for follow-up or treatment.



8.6.7 Relief for the public health system

The remote screening service allows for offering follow-up to all of the patients while only providing ophthalmology referrals for cases that require them. This project therefore provides relief to the public health system while decreasing the costs associated with unnecessary ophthalmology consultations.

8.6.8 Local capacity-building

The implementation of the remote screening service fosters the development of local capacity-building, autonomy and First Nations control over the services. Indeed, increasing the training provided to the workers of the health centres and creating collective prescriptions are part of a local capacity-building perspective. Moreover, these prescriptions also represent an additional connection between the First Nations communities and the Quebec health network through the *Conseils des médecins, dentistes et pharmaciens* (CMDP) of the CSSS concerned.

8.7 FOOD FOR THOUGHT TO INCREASE THE COST-EFFECTIVENESS OF THE SERVICE

In order to increase the cost-effectiveness of the DR remote screening service and offset the amounts invested more quickly, various measures could be studied.

8.7.1 Systematic screening of the entire population

Certain screening programs have targeted not only diabetic individuals but the entire at-risk population. In the communities where these programs were implemented, pathologies were detected among many people who had never been diagnosed with diabetes. With respect to the implementation of the pilot project, this procedure could be considered in order to ensure better follow-up for diabetes and its complications.

8.7.2 The integration of the remote screening service into the provincial health network

A significant portion of the recurring costs for the pilot project stems from the fees associated with image analysis. The current organisation of the service could be reviewed in order to find a less expensive way of performing image analysis. Eventually, the integration of the project into the Quebec network would generate a considerable decrease in cost. From this perspective, the service could also be offered to non-Aboriginal people residing in proximity to the communities being served. The operating costs would therefore be offset by a greater number of users.

8.7.3 Improving calendar management for equipment sharing

In the context of the pilot project, the purchasing and maintenance of the equipment is divided between four communities. Through an improved management of the sharing of the camera, more communities can have access to the equipment, which has the effect



of dividing the costs. A camera must be available twice per year in each community and, depending on the number of patients to be screened, the duration of the camera's stay can vary from a few days to four weeks. Therefore, a camera can be shared by more than three points of service.

Since October 2011, the communities that have participated in the pilot project have been sharing their camera with an additional community (Kitigan Zibi). The community of Rapid Lake will also be using the same camera for screening purposes starting in December 2012. Therefore, several costs will be divided among six communities instead of four.

8.8 SUMMARY OF THE EFFICIENCY EVALUATION

The costs generated by the remote screening service are clearly lower than those associated with screening in person with an ophthalmologist or optometrist the way it was performed before the project's implementation.

As previously mentioned, the evaluation revealed that many users had never been screened before. Therefore, by offering screening tests to all of the diabetic people in the communities, this pilot project allows for addressing the recommendations suggested by the associations of optometrists and the Canadian Diabetes Association. Consequently, increasing the number of tests amplifies the costs associated with screening, but the evaluation of all of the financial and societal costs indicates a decrease in the costs associated with care and treatment for diabetic individuals.

This chapter demonstrates that the amount of time required in order to offset the costs of the project will decrease as the number of points of service and users increase. The changes made to certain costs (8.3.4) also indicate that operating the project will be less expensive after the two first years.



CHAPTER 9 - SUMMARY AND RECOMMENDATIONS

9.1 THE DIABETIC RETINOPATHY REMOTE SCREENING PILOT PROJECT

Diabetes and its complications are a major cause for concern in the First Nations communities of Quebec and Canada. The studies performed demonstrate that more than 15% of the First Nations population of Canada has been diagnosed with diabetes, while among the Canadian general population, this proportion varies between 7 and 10% (Harris and coll., 1997; Health Canada, 2000; Young and coll., 2000).

Diabetic retinopathy (DR) is one of the major consequences of diabetes and represents the main cause of blindness in many First Nations communities. An effective way of decreasing the prevalence and consequences of DR is early screening and regular monitoring of the state of the retina, more specifically the macula.

In order to decrease the costs associated with the DR screening test and to make it more accessible, various partners worked together in order to set up a DR remote screening pilot project, through the use of telehealth, in the First Nations communities. A pilot project, coordinated by the First Nations of Quebec and Labrador Health and Social Services Commission (FNQLHSSC), Health Canada's First Nations and Inuit Health Branch, Quebec Region (FNIHB-QC), the First Nations communities of Eagle Village, Timiskaming, Winneway and Wolf Lake and McGill University's *Réseau universitaire intégré en santé* (RUIS McGill), was implemented in the fall of 2009. The main objectives of the pilot project were as follows:

- ❖ Ensuring access to DR screening tests closer to the patient's place of residence;
- ❖ Ensuring access to competent specialists in order to analyse and interpret the images taken during the screening in the community;
- ❖ Ensuring follow-up for those afflicted with DR;
- ❖ Decreasing travelling associated with DR screening;
- ❖ Raising awareness among the First Nations communities regarding the benefits associated with the use of telehealth;
- ❖ Fostering collaboration and mutual aid between the communities;
- ❖ Fostering First Nations capacity-building;
- ❖ Improving the services offered in connection with diabetes in the communities;
- ❖ Allowing for an improved collaborative relationship with the provincial network (sharing of information with the health centres, access to a general practitioner, etc.).

Furthermore, DR screening can constitute an additional opportunity for raising awareness among diabetic patients and those close to them regarding the complications associated with diabetes and the prevention activities in connection with diabetes offered in their communities.



The objectives of this pilot project are in line with the priority actions outlined in the 2007-2017 First Nations of Quebec and Labrador Health and Social Services Blueprint and the 2007-2010 Telehealth Strategic Plan.

9.2 THE OBJECTIVES OF THE EVALUATION OF THE PILOT PROJECT

This evaluation should allow for determining if the objectives of the pilot project have been achieved, evaluating the relevance, implementation, short-term effects and efficiency of the project and identifying the factors that influenced its implementation.

The objectives of this evaluation were as follows:

- ❖ Identifying the conditions associated with the emergence of the DR remote screening pilot project;
- ❖ Evaluating the establishment and implementation of the pilot project and identifying the factors facilitating and limiting its implementation and the establishment of the services;
- ❖ Evaluating the short-term effects of the DR remote screening pilot project;
- ❖ Documenting the mechanisms established in order to ensure the adoption of the pilot project by the workers in the four communities (health directors, nurses and technicians) and the sustainability of the project.

Furthermore, this evaluation was conducted with the objective of estimating the economic impact of the pilot project as accurately as possible.

In the context of this evaluation, it was not possible to completely achieve all of the objectives defined in the beginning. As explained in the section on the limitations of the evaluation in chapter 4 and the section on the limitations and challenges related to the economic analysis of the project presented in chapter 8, it was not possible to obtain certain data as anticipated. Therefore, certain relevant information could not be collected regarding, for example, the technical support provided to the communities and other elements related to the deployment conditions and project sustainability. Furthermore, the economic analysis of the pilot project was carried out in a descriptive manner and could not be performed in a deep enough fashion to fully determine the efficiency of the project.

The results of this evaluation will nonetheless allow for the sharing and dissemination of the lessons learned that are useful to the promotion and improvement of the projects developed among the First Nations. The evaluation is therefore considered to be a strategy that allows for contribution to project and research team decision-making and evaluation capacity and culture.

9.3 DISCUSSION ON THE RESULTS OF THE EVALUATION

The evaluation of the DR remote screening pilot project allowed for identifying various key stakes related to the implementation of this new service. This evaluation allowed for



performing an analysis of the various stakes involved and highlighting the differences and similarities between the communities that can be taken into consideration when deploying the service among the other First Nations communities of Quebec. However, the results of this evaluation demonstrate, similarly to other evaluations of projects that are implemented in First Nations communities, the difficulty or impossibility related to standardising actions and the importance of taking into consideration the local adaptation and implementation conditions, the organisational contexts, the pre-existing services and the local and regional socio-political realities.

The analysis of the information collected in the context of this evaluation allowed for identifying the major stakes of the set up and implementation of this pilot project. These stakes refer to the participation of the diabetic population, the organisation of the services, the partnerships created and maintained, the utilisation of new technologies and the establishment of project management and follow-up mechanisms.

Participation of the diabetic population

The participation of the diabetic patients who are known by the health centres is a major stake of the project. In fact, the recruitment and retention of the patients constitutes a significant portion of the work of the community workers. The data obtained indicates that nearly half of the diabetic people who are known by the health centres were screened in the context of the pilot project during the first year (82 out of 175 known diabetic people) and nearly one-third during the second year (55 diabetic patients). These proportions demonstrate that the service addresses a need among the community members who are afflicted with diabetes. In addition, note that 34 people obtained ophthalmology referrals in the context of the pilot project, which is nearly 25% of the patients who were screened. This high number of referrals confirms the legitimacy of the new service and the poor retinal states of many diabetic patients living in these communities.

Certain conditions such as relationships based on trust between workers, and between the workers and the patients, were emphasised as being elements playing a key role in the participation of the patients. The literature confirms the importance of this trusting relationship as well as the time required for this relationship to develop. The experiences of one of the health centres demonstrate the additional difficulty related to developing this relationship based on trust when the workers do not come from the community or work full-time for the health facility.

In terms of the users, the high level of satisfaction expressed constitutes irrefutable support for the project's continuation. Many benefits are perceived by the users: the proximity, flexibility and quality of the service, the development of their knowledge contributing to an enhanced ability to take control of their disease as well as a maintained sense of trust in the workers.



Organisation of the services

The integration of the screening service demands a reorganisation of the work schedule and a temporary increase in the workload of the workers. Several strategies that were adopted by the workers in order to organise the work and compensate for a lack of time and resources were described. The establishment of an equipment sharing calendar was of considerable help for the community workers in terms of being organised better and planning their interventions.

The integration of the new service into the usual activities of the health centre and the program focused on fighting diabetes sometimes seemed difficult at the beginning of the implementation. It is actually still a challenge, since the health centres must consider the follow-up to be performed with the patients referred to an ophthalmologist. Furthermore, they must bank on the development of service corridors in connection with diabetes and DR for both general and specialised services that are ideally available in the region.

Despite the increased workload, the workers appreciate their new responsibilities and are proud to be participating in the project. In fact, through this pilot project, these workers are learning, creating linkages between this new service and the other activities that they offer to their patients and developing their autonomy as well as the autonomy of their community health centres.

One aspect of the service that created more problems for the workers is the follow-up to be provided to the patients when they receive ophthalmology referrals following the screening. The problems raised seem to be magnified by the fact that the members of the communities of the pilot project, due to the geographic location and spoken language, usually seek to access specialised services in Ontario. A referral process involving a province other than the residential province is often more complicated and requires a different procedure. Furthermore, the delays prescribed by the *Laboratoires de la rétine RD* for follow-up with a specialist are not necessarily respected by the ophthalmologists and the health centre workers do not receive details regarding the appointments involving the patients and the specialists.

Finally, the reorganisation of the services and work in the health centres is being carried out without additional financial support. Each of the health centres must identify the resources required in order to offer quality services to its clientele. In order to optimise the implementation of the service, an examination of the organisational context of the communities must also be taken into consideration during the planning and implementation of the services.

Partnerships

The active participation of the communities was another key factor in the project's success. It allowed for developing approaches, solutions and strategies that take the realities of the settings into consideration. This strategy is moreover increasingly recognised in the literature as one of the main conditions for success among innovative



projects. It indeed allows for sharing experiences and ensuring effective and efficient planning of the services.

Many partners collaborated in order to provide access to a quality service to the populations of the four communities of the pilot project. Therefore, collaboration between the various players is a key element of the implementation of the service. The evaluation allowed for observing the good relationships that have been maintained between the First Nations communities and the regional players. However, the lack of precision with respect to the roles and responsibilities of the organisations that are associated with the project at the regional level (FNIHB-QC, FNQLHSSC, and RUIS McGill) led to problems related to redefining the mandates while the project was underway.

Good collaboration between the regional and local partners is essential in order to carry out this type of project. Indeed, the DR remote screening project is highly complex when you consider not only the technological components of its operation, but also the impacts that it has on the practices and the organisation of the clinical services of a great many workers who must work in an interdisciplinary and complementary manner.

The contributions of the various partners varied according to their own specific mandates and interests, which even though they are often different, all include one or more functions required for the smooth operation of a health system. This project highlighted the importance of properly identifying the respective visions, roles and responsibilities of these organisations from a project continuation perspective.

The FNQLHSSC played an important role in rallying the communities and keeping them involved all throughout the project. It performed a major coordination role for the entire duration of the pilot project, but also worked towards ensuring its deployment among the other First Nations communities. Furthermore, the Research Sector of the FNQLHSSC assumed responsibility for conducting the evaluation and set up a working group for this purpose. The FNIHB-QC also played a frontline role in the implementation of the pilot project by providing the training to the community workers in addition to the necessary support during the implementation of the service.

The *Laboratoires de la rétine RD* was retained as the analysis centre in order to facilitate a quicker start for the project. This company's contribution was important in many respects and generally appreciated by the community workers. The *Laboratoires de la rétine RD* therefore performed the analysis of the images and supported the communities. The fact that the image analysis was performed in parallel to the public health system sometimes complicated the patient follow-up process. In terms of the project's continuation, special attention will have to be paid to this situation so that patient follow-up is always ensured according to the prescribed delays.

Technological stakes

The equipment and supplies used for photography and image transmission purposes were appreciated for both image quality and user-friendliness. A few problems surfaced



over the course of the pilot project, but they were resolved. However, questions remain regarding the need to standardise the computer applications of the communities in order to facilitate the task of the workers who are required to transmit the images to the analysis centre. Another issue is the need for solutions facilitating data entry, organisation and sharing. Particular attention must be paid to the needs assessment process in the area of technology and applications in order to avoid the need for frequent upgrading and to ensure conditions fostering interoperability – the exchange of electronic data – with the other existing systems.

Project management and follow-up mechanism

The implementation of an information management system designed for and by the communities and shared between the partners appeared to be a missing element for the project in order to allow for effective follow-up, management and evaluation. In the subsequent service implementation phases, it will be important to be much better informed regarding patient follow-up (trajectories and treatment) in order to ensure the management of the services in partnership with the patients being screened. Without this information management system, it was not possible to recognise all of the project's added value, particularly in terms of care, services provided and diabetes control. This balanced system would be a major asset to monitor the progress of the patients between the first-, second- and third-lines.

Likewise, the realisation of the community scans revealed the importance of having more information regarding the diabetic patients from each of the communities. That is to say, the importance of knowing the total numbers of diabetic people, screening test participants and new participants as well as the status of these individuals (type of diabetes, whether or not a DR is present, whether or not a patient is already being followed for a DR, etc.).

As previously explained, the information collected among the users and workers demonstrated that many of the diabetic patients who were screened by the health centres had not received the recommended follow-up when an ophthalmology referral was requested or that this follow-up had not taken place in an optimal fashion. This demonstrates once again the relevance of implementing an information management mechanism.

9.4 LESSONS LEARNED AND RECOMMENDATIONS

In light of the results obtained through the evaluation of the DR remote screening pilot project, certain elements emerge as being essential to the success and continuation of the project. These lessons learned result from the analysis of all of the information collected in the context of this evaluation. These factors fostering the implementation and success of the remote screening service should be taken into consideration for the subsequent implementation phases targeting all of the First Nations communities of Quebec. These lessons learned deal with the key stakes previously explained and the



resulting recommendations can be grouped according to the players they are intended for.

9.4.1 Recommendations intended for the workers of the First Nations communities (nurses, technicians and health directors)

❖ Continuing to promote the screening service among the community members

The comparison between the number of diabetic people who benefited from the service in the pilot project communities and the number of diabetic people known by the health centres demonstrates the importance of continuing to promote the screening service among diabetic patients. Various methods must be used in order to reach out to and encourage the diabetic individuals to benefit from the service. As demonstrated by the results of the satisfaction questionnaires filled out by the users, the patients who use the service experience many benefits and are satisfied with the service they receive. Therefore, when promoting the service, the emphasis should be placed on the positive impacts associated with the service.

❖ Increased focus on awareness and the transmission of knowledge among diabetic patients who receive the screening test

One of the objectives of the pilot project is to improve the way in which diabetic people take responsibility for their health. The pilot project also aims to reinforce the activities related to awareness and prevention for diabetes and its complications. The workers who offered the service emphasised the lack of time for having discussions with their patients during the testing except to provide explanations related to the screening service. It would be beneficial to ensure that the workers have more time to devote to the patients so that their visits for the screening test can become additional opportunities to increase awareness.

❖ Taking time before each screening session begins in order to allow the workers to handle the equipment

Since the camera only goes to each community a few times per year, the workers can experience a certain apprehension related to using it. Offering them the opportunity to handle the material before the first screening sessions to be performed with the patients can increase confidence among the workers and, by the same token, increase trust among the patients among their health centre personnel.

❖ From the beginning, ensuring that a camera transportation calendar is established

The difficulties encountered during the first year of screening in 2010, related to the transportation of the camera between the communities, underscore the need for the communities to establish an equipment transportation calendar. This actually allows each community to anticipate the human resources and work space needed and to proceed with the promotion of the service among its diabetic population. The other



partners involved in the project such as the *Laboratoires de la rétine RD* and the FNQLHSSC could also take advantage of this calendar in order to streamline their activities with those of the communities.

9.4.2 Recommendations for the coordinators of the DR remote screening project

- ❖ *From the beginning, ensuring that all of the partners have a clear definition of their roles and responsibilities and that they have the capacity to respect their commitments*

As previously mentioned, the disagreements that occurred between the regional partners seem to stem from a lack of clarity with respect to the definition of the roles and responsibilities to be undertaken by each of the players. To ensure the project's success, it is very important for the roles and responsibilities to be clearly defined and connected to the capacities and resources of each. This exercise should be performed from the beginning and should avoid complications from an organisational perspective.

It is therefore important to continue the work leading to the establishment of a common vision and the definition of the roles of the primary partners according to their respective places in the health system. This work must also include the roles of the other partners required for a more integrated health system operating within a network and capitalising on the resources of the setting.

- ❖ *Clearly defining the long-term trajectory of the diabetic patients when they are referred to an ophthalmologist for follow-up or treatment*

Certain issues continued to remain among the community workers following the training sessions and the meetings of the local working group. There were also questions related to the follow-up to be offered within the community to the diabetic patients who consult with an ophthalmologist for follow-up or treatment. Certain users are wondering if follow-up should be provided by both the ophthalmologist and their community health centre. It would be advisable that the trajectory of the patient receiving follow-up for a DR from an ophthalmologist be defined and that all of the workers be informed of the procedures retained.

- ❖ *Implementing a data collection method in each of the health centres offering the screening service*

All throughout the evaluation, it was difficult to obtain information regarding, for example, the number of screening tests performed, the number of diabetic individuals invited to take part in the testing or the socio-demographic characteristics of the users of the service. The establishment of a registry documenting the interventions performed, addressing the needs of the communities and the various partners involved and not representing an additional workload for the workers could allow for monitoring the evolution of the service. The development of this type of system at the onset of the



implementation would assist the workers in centralising the information and avoiding the need to repeat the note-taking process.

The implementation of this management and follow-up system corroborates the importance of strengthening the alliances for an interdisciplinary and inter-organisational approach from an integrated service network perspective. This integration must take into consideration the local first-line, regional (in connection with the action plans of the *Agences de la santé et des services sociaux* (ASSS)) and superregional characteristics. In this regard, the arrival of the information system on the clientele and services of the *Centres locaux de services communautaires* (I-CLSC) in the First Nations communities could be an interesting avenue in order to support the communities in terms of data collection and sharing.

- ❖ *Ensuring that protocols are established between the community health centres and the hospitals and clinics providing second- and third-line health care in connection with DR*

Patient follow-up planning with an ophthalmologist, when required, is the step that caused the most problems among nurses in the community health centres. Even though agreements were already reached before the beginning of the implementation, updating and officialising these could simplify the work of the nurses.

- ❖ *Ensuring adequate training for the workers who will eventually be called upon to provide the services and offering an update of the knowledge of the workers who have already been trained and feel the need for it*

The information collected regarding the training sessions provided to the nurses and technicians of the communities revealed that these were appreciated but a few changes should be made in terms of the content and structure of the training. It would also be a good idea to ensure that refresher training is provided on a regular basis to the workers who feel the need for it.

- ❖ *Ensuring that the communities possess adequate computer resources*

In the context of the implementation of the remote screening service, it is necessary to ensure that the health centres possess computer infrastructures, such as a reliable Internet connection, enabling them to easily transmit the images to the analysis centre.

9.4.3 Recommendations for the project's funding organisations and partners

- ❖ *Fostering First Nations capacity-building and self-determination*

According to the wishes of the First Nations political players, the projects implemented in the communities must foster First Nations capacity-building and self-determination. These wishes, as expressed in the 2007-2017 First Nations of Quebec Health and



Social Services Blueprint, are in line with the objective of improving the quality of life and the local control over the services provided for and by the First Nations.

The fact that it is the community workers who are responsible for the remote screening tests, equipment transportation and appointment setting with the diabetic patients contributes to local capacity-building and autonomy among the First Nations. Other aspects of the project could be developed in this regard, such as the establishment of a First Nations clinical committee that would be responsible for organising and providing the training intended for the community workers. health

❖ *Anticipating financial resources allowing to make adjustments among the human resources in place in the communities*

As was often mentioned by the workers when they were asked, providing the new screening service generates an additional workload for the personnel in place. Since the human resources available in the health centres are already limited, it is important for the workers to have the possibility to free themselves from certain tasks or reorganise their work schedules in order to provide the new service.

❖ *Ensuring the optimal involvement of all of the partners in the project's realisation and evaluation process*

One of the main partners refused to participate in a major portion of the evaluation process of the project. This had repercussions on the compilation of the information related to all of the processes associated with the development, pre-implementation and implementation of the project. Therefore, information regarding the number of screenings, reimaging instances and users per year are either missing or could not be validated. Moreover, this lack of information means that the perceptions of the members of FNHB-QC regarding the general coordination of the project, the relationships maintained between the various players and certain activities such as the training provided to the community workers and the collective prescription securing process could not be taken into consideration in the context of this evaluation. When a project is initiated, it is thus important for the evaluation and the contributions of each partner to be recognised and for all of the partners to commit to getting involved in providing the information required for the evaluation.

All throughout the pilot project, the FNIHB-QC performed various functions that were essential to the implementation of the service. However, some of their actions taken with a silo-based approach and in a less than optimal concerted fashion with the other partners, such as for the development and provision of training or for the signing of the collective prescriptions, render more difficult the project appropriation process among the communities and the other partners of the project. In addition, this interferes with one of the project's objectives related to local autonomy development and capacity-building among the communities. When continuing the project, additional efforts will have to be



made to ensure that the actions taken by the regional players are carried out in a concerted fashion.

9.5 THE EVOLUTION OF THE DR REMOTE SCREENING PROJECT

The communities of the pilot project, Eagle Village, Timiskaming, Winneway and Wolf Lake, are now in their third year of screening. Only the community of Winneway was unable to continue the project according to the established calendar due to the lack of a trained nurse to provide the DR screening in the community. It will be necessary to resolve this issue during the upcoming months in order to enable the community to continue the project. Updated training for the technicians as well as training for the new nurse(s) will be offered in the community.

To date, besides the communities involved in the pilot project, there are six First Nations communities in Quebec that provide the DR remote screening service. The communities that joined the project during the second phase of implementation are carrying out their second wave of screening this year. Newly implemented communities are also offering the service to their populations this year for the first time. As of October 2012, 432 tests had been performed among the ten communities in which the project was implemented.

For the communities in which the screening service was implemented after the pilot project, it seems to be easier to ensure that the follow-up delays are respected by the ophthalmologists. This fact may be simply due to the availability of the ophthalmologists. In fact, these communities are located in socio-sanitary regions that are different from those of the pilot project communities. However, the problem related to patient follow-up once they have been referred to an ophthalmologist following screening received in a community has yet to be resolved. No modes of communication have yet to be established in order to ensure that the health centre nurses are informed of whether or not the patient must receive follow-up and screening from an ophthalmologist or even in the community they reside in. The attempt will be made while the project is in progress to implement solutions in order to address this grey area.

Based on the experiences associated with the pilot project and the preliminary results obtained by this evaluation, modifications were made to the way in which the project is implemented in the communities. For example, the presentation of the project to the regional health professionals (physicians, pharmacists and ophthalmologists) is carried out by the nurse who is responsible for the project at FNIHB-QC, while the presentation of the project to the communities is carried out by the E-Health Agent of the FNQLHSSC. Therefore, they each do their share of the presentations. It was therefore possible to save money related to travelling and this way of doing things also allowed for reducing the amount of time devoted to this activity.

Another initiative that was carried out aiming to reduce travel time and cost is the training of the nurses and technicians over the course of the same week and within the actual health centres. The training sessions also coincide with the first screenings provided to



the patients. This way of proceeding avoids the need for the trainers to travel twice and for the nurses to leave their health centres in order to attend training in Montreal. The fact that the first screenings occur shortly after the training of the workers can also be perceived as being beneficial for the workers who can therefore quickly apply what they have learned.

The difficulties related to collaboration between the various partners of the project are still present. They sometimes have the effect of slowing down the activities related to implementation and make it necessary to review the ways of doing things in order to enable the project to be implemented in a greater number of interested communities.

“Word of mouth” between the communities has given the project certain notoriety. It was observed during the presentations provided to the new communities that the health directors and nurses were already informed about the project and demonstrating a willingness to participate even before knowing all of the details and implications.

Consequently, the evaluation of the pilot project had a springboard effect for the deployment of the services among the other First Nations communities of Quebec. In fact, this evaluation was a strategic process allowing for a comprehensive understanding of the various stakes related to the implementation of a pilot project supported by telehealth. The evaluation therefore allowed for making adjustments from a strategic, operational, technological and organisational perspective.

9.6 CONCLUSION

The evaluation of the implementation of the DR remote screening pilot project allowed for obtaining various information that will help to improve the implementation of the project, but also the implementation of other services provided by the community health centres through telehealth. Furthermore, the evaluation unveiled certain factors that can facilitate or even hinder the implementation of the service, such as the stability of the human resources in place and the establishment of protocols between the health facilities.

Many benefits were also documented through the interviews and the analysed questionnaires. The users of the service thus appreciate the proximity of the service to their place of residence and the decreased travelling, the acquisition of new knowledge, increased awareness regarding diabetes and its consequences as well as the quality and flexibility of the service provided in their local health centres. From the point of view of the workers, many benefits were also identified and are mainly related to the local capacity-building and autonomy of the health centres.

Various reflections can be made regarding the continuation and sustainability of the project. First of all, as was mentioned in the chapter discussing the economic analysis of the project, the costs associated with image analysis represent a significant portion of the budget allocated to provide the service. It would therefore be interesting to study the



possibility of transferring the image analysis and diagnosis emission centre to the public health system and having the associated costs covered by the *Régie de l'assurance maladie du Québec* (RAMQ). In the same vein, in order to increase the cost-effectiveness of the screening service, it would be interesting to study the possibility of also making the screening test accessible by the non-Aboriginal population residing in proximity to the communities offering the service. Another reflection to be considered, also with the objective of rendering the project more efficient, is the possibility of including more communities sharing the same equipment. In fact, by improving the camera transportation planning, it is foreseeable to have a greater number of communities sharing a same camera without hindering the project's effectiveness.

This exploratory study, which was particularly interested in the perceptions of the workers and the realities experienced in the field, is a process that should be continued. In fact, certain elements could not be studied in an in-depth fashion in the context of this study given the scope of the project to be evaluated and the limited time and resources. It would therefore be interesting to explore, secondly, the connection between this project and other players gravitating around the First Nations communities such as the general practitioners, the *Centres de santé et de services sociaux* (CSSS) and the ASSS. Furthermore, this second component of the evaluation could allow for making observations regarding the differences and similarities in the implementation of the service among communities stemming from other regions of Quebec and which are faced with different organisations and strategic and socio-political contexts.

The collaboration of the community workers in different steps of the evaluation can contribute to increasing their awareness as to the evaluation process of a project while developing an evaluation culture within the actual communities. This evaluation culture, in addition to supporting informed decision-making within the health centres, can enable the communities to set up various information collection systems allowing them to readjust their interventions on an ongoing basis.

Therefore, a participatory evaluation dealing with all of the elements of the project allowed for a comprehensive, developmental and strategic vision in addition to opening the way for the creation and utilisation of mechanisms and tools that are adapted to the implementation context thereby ensuring the sustainability of the new service. The observation has also been made that the evaluation process and community support, throughout the entire pilot project, were just as important and rich in information as the results derived from the actual data collection process.

As acknowledged in the literature, the early screening of diabetes and its complications remains a key element leading to a reduction in the harmful consequences that diabetes can have on the health of those who are affected. The evaluation of the DR remote screening pilot project demonstrated the importance of banking on the development of these types of services for the First Nations population. We hope that the results of this evaluation will be able to assist the First Nations decision-makers, in collaboration with



the various levels of government and organisations, in guiding the actions that will have a positive impact on the health of the members of the communities.



BIBLIOGRAPHY

- AANDC – Aboriginal Affairs and Northern Development Canada (2000). *Band Classification Manual*.
- AANDC - Aboriginal Affairs and Northern Development Canada (2008). *Indian Registry, December 31, 2007*.
- Acton KJ, Burrows NR, Moore K, Querec L, Geiss LS, Engelgau MM (2002). *Trends in diabetes prevalence among American Indian and Alaska native children, adolescents, and young adults*. Am J Public Health, 92 : 1485-1490.
- AETMIS - Agence d'évaluation des technologies et des modes d'intervention en santé (2008). *Dépistage de la rétinopathie diabétique au Québec*. 130 pages.
- AMOQ - Association des médecins ophtalmologistes du Québec (2010). *La rétinopathie diabétique*. <http://www.amoq.org/InfoSurMaladies/InfoSurMala-diab.htm>
- Assembly of First Nations of Quebec and Labrador (2005). *First Nations of Quebec and Labrador Research Protocol*. 79 pages
- Brassard P, Robinson E, Lavallee C (1993). *Prevalence of diabetes mellitus among the James Bay Cree of northern Quebec*. CMAJ, 149 : 303-307.
- Brousselle, A., Champagne, F., Contandriopoulos, A-P., Hartz, Z. (2011). *L'Évaluation: Concepts et méthodes*, 2e édition. Presses de l'Université de Montréal. 332 pages.
- Burke V, Zhao Y, Lee AH, Hunter E, Spargo RM, Gracey M, Smith RM, Beilin LJ, Puddey IB (2007). *Predictors of type 2 diabetes and diabetes-related hospitalization in an Australian Aboriginal cohort*. Diabetes and impaired glucose tolerance in Aboriginal Australians: prevalence and risk. Diabetes Research and Clinical Practice, 78: 360-368.
- Canadian Diabetes Association (2008). *2008 Clinical Practice Guidelines of the Canadian Diabetes Association for the prevention and treatment of diabetes in Canada*. Can J Diabetes, 32 suppl. 1: 225 pages.
- Champagne F, Brousselle A, Hartz A, Contandriopoulos A-P, Denis J-L (2009). *L'analyse de l'implantation*. In L'évaluation : concepts et méthodes. Presses de l'Université de Montréal : Montreal. 300 pages.
- Chew EY (2003). *Epidemiology of diabetic retinopathy*. Hosp Med, 64 : 396-399.
- Daniel M, Gamble D (1995). *Diabetes and Canada's Aboriginal peoples: the need for primary prevention*. Int J Nurs Stud, 32 : 243-259.
- Diamond JP, McKinnon M, Barry C, Geary D, McAllister IL, House P, Constable IJ (1998). *Non-mydratic fundus photography: a viable alternative to fundoscopy for identification of diabetic retinopathy in an Aboriginal population in rural Western Australia?* Aust N Z J Ophthalmol, 26 : 109-115.



- Fagot-Campagna A, Pettitt DJ, Engelgau MM, Burrows NR, Geiss LS, Valdez R, Beckles GL, Saaddine J, Gregg EW, Williamson DF, Narayan KM (2000). *Type 2 diabetes among North American children and adolescents: an epidemiologic review and a public health perspective*. J Pediatr, 136 : 664-672.
- FNQLHSSC – First Nations of Quebec and Labrador Health and Social Services Commission (2006). 2002 First Nations of Quebec Regional Longitudinal Health Survey, 213 pages.
- FNQLHSSC (2007a). *2007-2017 First Nations of Quebec Health and Social Services Blueprint: Closing the Gaps... Accelerating Change*. 105 pages.
- FNQLHSSC (2007b). *2007-2010 Telehealth Strategic Plan*. 44 pages.
- FNQLHSSC (2008). *Portrait of accidental and intentional physical injuries occurring in First Nations communities in Quebec, from 2004 to today*. 184 pages.
- FNQLHSSC (2011). *Scan on diabetes among the First Nations communities of Quebec*. 107 pages.
- Froissart S. (2010). *Vision, orientations et stratégies de développement de la télésanté au Québec*. Rapport de la table ministérielle en télémédecine.
- Gagnon MP, Duplantie J, Fortin JP, Landry R (2006). *Implementing telehealth to support medical practice in rural/remote regions: what are the conditions for success?* Implement Sci, 1 : 18.
- Gauthier B (2003). *Recherche sociale : De la problématique à la collecte de données*. Presses de l'Université du Québec : Sainte-Foy, Québec. 619 pages.
- Grimaldi A, & coll (2004). *Diabète de type 2*. Paris.
- Guba E, Lincoln Y (1989). *Fourth generation evaluation*. Sage Publications. 296 pages.
- Hammond CJ, Shackleton J, Flanagan DW, Herrtage J, Wade J (1996). *Comparison between an ophthalmic optician and an ophthalmologist in screening for diabetic retinopathy*. Eye (Lond), 10 (Pt 1) : 107-112.
- Harris SB, Gittelsohn J, Hanley A, Barnie A, Wolever TM, Gao J, Logan A, Zinman B (1997). *The prevalence of NIDDM and associated risk factors in native Canadians*. Diabetes Care, 20 : 185-187.
- Health Canada (2000). *Diabetes among the Aboriginal populations in Canada: The Facts. Aboriginal Diabetes Initiative*, 41 pages.
- Health Canada (2002). *Diabetes in Canada*, second edition, 63 pages.
- Health Canada (2005). *Statistical profile of the health of the First Nations in Canada*.
- Hutchinson A, McIntosh A, Peters J, O'Keeffe C, Khunti K, Baker R, Booth A (2000). *Effectiveness of screening and monitoring tests for diabetic retinopathy--a systematic review*. Diabet Med, 17 : 495-506.



- Jones S & Edwards RT (2010). *Diabetic retinopathy screening: a systematic review of the economic evidence*. Diabet Med, 27 : 249–256.
- Kamholz KL, Cole CH, Gray JE, Zupancic JA (2009). *Cost-effectiveness of early treatment for retinopathy of prematurity*. Pediatrics, 123 : 262-269.
- Karagiannis A, Newland H (1996). *Mobile retinal photography. A means of screening for diabetic retinopathy in aboriginal communities*. Aust N Z J Ophthalmol, 24 : 333-337.
- Kaur H, Maberley D, Chang A, Hay D (2004). *The current status of diabetes care, diabetic retinopathy screening and eye-care in British Columbia's First Nations Communities*. Int J Circumpolar Health, 63 : 277-285.
- Klein R, Klein BE, Moss SE (1984). *Visual impairment in diabetes*. Ophthalmology, 91 : 1-9.
- Kohner EM, Aldington SJ, Stratton IM, Manley SE, Holman RR, Matthews DR, Turner RC (1998). *United Kingdom Prospective Diabetes Study, 30: diabetic retinopathy at diagnosis of non-insulin-dependent diabetes mellitus and associated risk factors*. Arch Ophthalmol, 116 : 297-303.
- Kyvik KO, Nystrom L, Gorus F, Songini M, Oestman J, Castell C, Green A, Guyrus E, Ionescu-Tirgoviste C, McKinney PA, Michalkova D, Ostrauskas R, Raymond NT (2004). *The epidemiology of Type 1 diabetes mellitus is not the same in young adults as in children*. Diabetologia, 47 : 377-384.
- Lee ET, Begum M, Wang W, Blackett PR, Blevins KS, Stoddart M, Tolbert B, Alaupovic P (2004). *Type 2 diabetes and impaired fasting glucose in American Indians aged 5-40 years: the Cherokee diabetes study*. Ann Epidemiol, 14 : 696-704.
- Lloyd CE, Klein R, Maser RE, Kuller LH, Becker DJ, Orchard TJ (1995). *The progression of retinopathy over 2 years: the Pittsburgh Epidemiology of Diabetes Complications (EDC) Study*. J Diabetes Complications, 9 : 140-148.
- Maberley D, Walker H, Koushik A, Cruess A (2003). *Screening for diabetic retinopathy in James Bay, Ontario: a cost-effectiveness analysis*. CMAJ, 168 : 160-164.
- Maberley D, Morris A, Hay D, Chang A, Hall L, Mandava N (2004). *A comparison of digital retinal image quality among photographers with different levels of training using a non-mydratic fundus camera*. Ophthalmic Epidemiol, 11 : 191-197.
- Martin JD, Yidegiligne HM (1998). *The cost-effectiveness of a retinal photography screening program for preventing diabetic retinopathy in the First Nations diabetic population in British Columbia, Canada*. Int J Circumpolar Health, 57 Suppl 1 : 379-382.
- McConnell EA, Newland HS, Manning J, Paech M (1993). *Technology assessment applied: a comparison of ophthalmic diagnostic techniques to detect diabetic retinopathy among Aboriginal people in central Australia*. Contemp Nurse, 2 : 23-28.



- McDermott R, Rowley KG, Lee AJ, Knight S, O'Dea K (2000). *Increase in prevalence of obesity and diabetes and decrease in plasma cholesterol in a central Australian aboriginal community*. Med J Aust, 172 : 480-484.
- Milburn MP (2004). *Indigenous Nutrition*. American Indian Quarterly, 28: 411-34.
- Miles MB, Huberman AM (1994). *Qualitative Data Analysis: An Expanded Sourcebook*. Sage: Thousand Oaks, CA. 338 pages.
- Mohamed Q, Gillies MC, Wong TY (2007). *Management of diabetic retinopathy: a systematic review*. JAMA, 298 : 902-916.
- Monnier, É (1992). *Évaluations de l'action des pouvoirs publics* (2e édition). Économica. 245 pages.
- MSSS - Ministère de la Santé et des Services sociaux du Québec (2007). *Prestation et financement des services de santé et des services sociaux destinés aux Autochtones (Premières Nations et Inuits)*. 28 pages.
- MSSS (2010). *Centres de santé et de services sociaux - RLS*.
<http://www.msss.gouv.qc.ca/reseau/rls/>
- NHMRC (2000). *Nutrition in Aboriginal and Torres Strait Islander Peoples*. National Health and Medical Research Council, Australia, 266 pages.
- Ohinmaa A, Hailey D, Roine R (2001). *Elements for assessment of telemedicine applications*. Int J Technol Assess Health Care, 17 : 190-202.
- Oster RT, Virani S, Strong D, Shade S, Toth EL (2009). *Diabetes care and health status of First Nations individuals with type 2 diabetes in Alberta*. Can Fam Physician, 55: 386-393.
- Patton MQ (1997). *Utilization-Focused Evaluation*. Sage Publications, 431 pages.
- Patton MQ (2008). *Utilization-Focused Evaluation*. Sage Publications, 688 pages.
- Pollex RL, Hanley AJ, Zinman B, Harris SB, Hegele RA (2006). *Clinical and genetic associations with hypertriglyceridemic waist in a Canadian aboriginal population*. Int J Obes (Lond), 30 : 484-491.
- Rema M, Premkumar S, Anitha B, Deepa R, Pradeepa R, Mohan V (2005). *Prevalence of diabetic retinopathy in urban India: the Chennai Urban Rural Epidemiology Study (CURES) eye study I*. Invest Ophthalmol Vis Sci, 46 : 2328-2333.
- Rogers, E.M. (1983). *Diffusion of innovations*. Free Press: New York. 143 pages.
- Rossi PH & Freeman HE (1993). *Evaluation. A Systematic Approach*. 5Th Edition. Sage Publications, Inc : Newbury Park, California. 488 pages.
- Roy S.N. (2003). *L'étude de cas*. In Recherche sociale : De la problématique à la collecte de données. Presses de l'Université du Québec : Sainte-Foy, Québec. 619 pages.



- Saylor K (2005). *Risk reduction for type 2 diabetes in aboriginal children in Canada*, 49-52.
- Secrétariat aux affaires autochtones (2009). *Amérindiens et Inuits – Portrait des nations autochtones du Québec*. 62 pages.
- Silva PS, Cavallerano JD, Aiello LM (2009). *Ocular telehealth initiatives in diabetic retinopathy*. Curr Diab Rep, 9 : 265-271.
- Sinclair SH (2006). *Diabetic retinopathy: the unmet needs for screening and a review of potential solutions*. Expert Rev Med Devices, 3 : 301-313.
- Singer DE, Nathan DM, Fogel HA, Schachat AP (1992). *Screening for diabetic retinopathy*. Ann Intern Med, 116 : 660-671.
- Soto-Pedre E (2009). *Epidemiology of diabetic retinopathy in a Chinese population*. J Diabetes Complications, 23 : 138-139.
- Stake, RE (2006). *Multiple Case Study Analysis*. Guilford Press, 342 pages.
- Statistics Canada (2008). *Aboriginal Peoples in Canada: Inuit, Métis and First Nations, 2006 Census*. 59 pages.
- St-Cyr Tribble D, Saintonge L (1999). *Réalité, subjectivité et crédibilité en recherche qualitative: quelques questionnements*. Recherche qualitative, 20: 113-125.
- Swanson M (2005). *Retinopathy screening in individuals with type 2 diabetes: who, how, how often, and at what cost--an epidemiologic review*. Optometry, 76 : 636-646.
- Szathmary EJE (1994). *Non-Insuline Dependent Diabetes Mellitus Among Aboriginal North Americans*. Annual Review of Anthropology, 23 : 457-482.
- Tennant MT, Rudnisky CJ, Hinz BJ, MacDonald IM, Greve MD (2000). *Teleophthalmology via stereoscopic digital imaging: a pilot project*. Diabetes Technol Ther, 2 : 583-587.
- Whited JD (2006). *Accuracy and reliability of teleophthalmology for diagnosing diabetic retinopathy and macular edema: a review of the literature*. Diabetes Technol Ther, 8 : 102-111.
- Williams R, Airey M, Baxter H, Forrester J, Kennedy-Martin T, Girach A (2004). *Epidemiology of diabetic retinopathy and macular oedema: a systematic review*. Eye (Lond), 18 : 963-983.
- Young TK, Reading J, Elias B, O'Neil JD (2000). *Type 2 diabetes mellitus in Canada's First Nations: status of an epidemic in progress*. CMAJ, 163 : 561-566.
- Yu CH, Zinman B (2007). *Type 2 diabetes and impaired glucose tolerance in aboriginal populations: a global perspective*. Diabetes Res Clin Pract, 78 : 159-170.
- Zghal-Mokni I, Jeddi A, Boujemaa C, Ben Hadj AW, Gaigi S, Ayed S (2001). *Epidemiology and development of macular edema in the diabetic*. Tunis Med, 79 : 668-671.



