**Appendix 1. Interview guide time 1**

For the INESSS Lyme team and the patient partners

1. What are your expectations about your expected contribution to the project? /what are your expectations about patient contribution to the project?
2. What would you like to learn from this experience of partnership with patients? /What would you like to learn from this experience of partnership with the INESSS?
3. What does a successful patient partnership project mean to you?
4. What does a failed patient-partnership project mean to you?
5. What are the objectives of the patient partnership in your project?
6. How will each member of the project management team, including patients, work to achieve the objectives?
7. Is there a mandate for your project team members, including patient partners, that explains how the patient partnership will be carried out? If so, please describe this mandate
8. Have the partners discussed together and formalized how each member of the partnership will contribute to the project (e.g., financial resources, equipment, expertise, experiential knowledge)? If yes, please describe your roles and responsibilities.

**Appendix 2 - Interview guide time 2**

For the patient partners

* Was your role well defined and did you feel well prepared to participate in the work? If not, what suggestions would you make to improve this preparation?
* How did the documents that were sent to you to enable you to participate in the work meet your expectations and needs (were the documents clear, appropriate level of language, definition of appropriate acronyms, etc.)?
* Do you have any suggestions for making these documents even more useful or appropriate for your participation?
* Was your presence essential at every Advisory committee meeting?
* In what way were you able to influence the recommendations, can you give us some examples?
* How have you been involved in the literature review?
* How are you been involved with the work done with the patients’ associations?

For the INESSS Lyme team and the INESSS methodology team.

* What were the issues identified at the onset to involve Lyme disease patients in the mandate?
* What were the different patient engagement options that were considered? How did they come about and were discussed? Which ones were chosen and why?
* What was the patient selection process?
* Did the patients selected meet the need? Why?
* How was the training you had with the patient partners helpful or not to the mandate?
* How were you involved in conducting the patient experience literature review?
* How did you work with the patient partners? How did you adapt or not adapt your work methods?
* During the advisory committee, how were patients able to share their point of view and influence the recommendations? Can you give us some examples?
* What was the contribution of patient associations to the achievement of the mandate?
* What was the contribution of the literature review to the achievement of the mandate?
* What was the contribution of the patients’ interviews to the achievement of the mandate?
* What did you learn during this process?

For the healthcare professionnals

- How can technical issues such as Lyme disease benefit from the experience of patients who have lived with the disease?

- What are the most significant contributions made by the two patient partners (e.g., in the context of the committee, what are the most significant contributions made by the two patient partners and can you give us some examples)?

- Were some of the themes discussed during the committee not suitable for the participation of the patient partners? If yes, why?

- In what way was the profile of the patient partners adapted to the mandates?

- In relation to the participation of the two patient partners on the advisory committee, what were the most appreciated ways of carrying out the mandate? And the least appreciated?

**Appendix 3 - Survey for the Advisory committee members (except Patient partners)**

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| --- | --- |
| In the past (e.g., in an evaluation project, a process of continuous improvement of care and services, or on a working committee). | Yes/no/I don’t know |
| I've had training in patient partnerships in the past.  | Yes/no/I don’t know |
| I felt ready to work in partnership with patients on this project. | Strongly agree/agree/neither agree nor disagree/disagree/strongly disagree |
| Patient partners brought a perspective to the project that no one else could bring. | Strongly agree/agree/neither agree nor disagree/disagree/strongly disagree |
| The contributions of patient partners over the course of the project were valued by the team and committee members. | Highly Valued/Average Valued/ Not Valued |
| To what extent has the contribution of patient partners influenced the course of the project? | A lot/a little/moderate/not at all |
| Does working in partnership with patients motivate you to change your practices? | often/in some circumstances/almost never/never |