

## **NL SUPPORT's External Mid-term Evaluation Recommendations and Action Plan**

NL SUPPORT underwent its mid-term evaluation in the Fall of 2016. The evaluation was carried out by Malatest and Associates with the final report being presented in December 2016. The overall report was positive with the evaluation team concluding that:

“Overall, NL SUPPORT is relevant and addresses an ongoing need for Patient Oriented Research (POR), and is demonstrating above average performance given the stage of implementation, supporting the need for continued involvement and investment in NL SUPPORT. However, some improvements are required to further strengthen its design and delivery.”

The full report may be found at [http://www.nlsupport.ca/Home/NL-SUPPORT-Mid-Term-Assessment-\(1\)/NL-SUPPORT-Mid-Term-Assessment.aspx](http://www.nlsupport.ca/Home/NL-SUPPORT-Mid-Term-Assessment-(1)/NL-SUPPORT-Mid-Term-Assessment.aspx)

Eight specific areas were identified in which effectiveness could be improved:

- Communications overall require improvement, including the need for further clarification between TPMI and NL SUPPORT (mandates and organizational structure), general awareness and marketing for NL SUPPORT, bi-annual face-to-face meetings of the patient advisory council rather than teleconference which limits stakeholder engagement, the inclusion of a communication portal to formalize communication (access to documents, decision and planning in real-time rather than keeping track of email threads), and tailored consumable communications targeted to different stakeholders.
- On-boarding of stakeholders requires improvement, including the simplification of information and diagrams, and a reduction in the number of documents provided. Patients would like the information to be more accessible to them and more consumable (simple power point, common every-day language, pictures). They see the benefit in presenting the information in person on a regular basis.
- Patient engagement is still a work in progress with enhancements needed to support training and mentoring, as well as determining how best to recruit patients and sustain their interest over time without suffering “burn out.” Capacity development to learn about research and the role patients can play in it beyond providing initial insights is suggested. Capacity development for researchers on engaging with patients is similarly required to get more out of patient engagement and build value and understanding in patient’s contribution to multiple research processes.
- Stakeholder engagement (physician, healthcare provider, decision-maker, and funder) is also a work in progress with enhancements needed to incentivise engagement perhaps through small scale research funding competitions (e.g. a few thousand dollars to conduct client impact survey).
- Informal networking during the deployment phase has worked well but stakeholders would increasingly like to see the implementation of a formalized decision-making process specifying roles

and responsibilities (including time commitment), and conflict resolution processes for increased transparency.

- NL SUPPORT stakeholders would like to see increased investment in the popularization of research. Some stakeholders suggested that incentives be offered for best plain language presentation or poster at National SPOR conferences and jurisdictional events in NL. Similarly they would like to see research presentation events designed for general public consumption and discussion.
- There is a perceived lack of awareness of the SPOR networks as a resource pool to draw upon. This may improve as stakeholders participate in the SPOR Summit in Ottawa. The summit was appreciated by members of the patient advisory council for fostering patient engagement, disseminating SPOR materials (e.g., evaluation materials and templates), and developing ongoing collaboration structures for evaluation with other jurisdictional SUPPORT units.
- Disparities in access to POR exist between Newfoundland and Labrador Regional Health Authorities. Efforts to reduce these disparities by engaging in research in (and with) rural communities are recommended.

Outlined below is the NL SUPPORT Unit's action plan to address the above recommendations

Recommendation	Response (Agree or Disagree)	Management Action Plan	Responsibility	Timeline
<b>1. Communications overall require improvement:</b>				
1.1 Need for further clarification between TPMI and NL SUPPORT (mandates and organizational structure)	Agree	Review the current information on the relationship between TPMI and NL SUPPORT and revise to clarify areas of confusion. Revise the current organisational structure diagram	TPMI Executive	July 2017
1.2 General awareness raising and marketing for NL SUPPORT,	Agree	Continue to advertise the role of NL SUPPORT through traditional and social media sites Provide ongoing briefings to staff within MUN and partner organisations	Communications lead  NL SUPPORT Directors	Immediate  June 2017
1.3 Bi-annual face-to-face meetings of the patient advisory council rather than teleconference which limits stakeholder engagement,	Agree	Plan for the patient advisory council meetings to be held by video conference twice a year and face to face twice a year (May and October)	NL SUPPORT Director and Patient Engagement lead	Immediate effect
1.4 The inclusion of a communication portal to formalize communication (access to documents, decision and planning in real-time rather than keeping track of email threads),	Agree	Develop a user friendly communications portal on the NL SUPPORT website. Beta test with patient advisory council	Communications lead	Completion by October 2017
1.5 Tailored consumable communications targeted to different stakeholders.	Agree	Develop a strategy for communication targeted at the full range of stakeholders	Communications lead, knowledge translation lead and patient engagement lead	Completion by October 2017

<b>2. On-boarding of stakeholders requires improvement:</b>				
2.1 The simplification of information and diagrams, and a reduction in the number of documents provided.	Agree	See actions under 1.1 and 1.4 above	TPMI Executive and Communications lead	Completion by October 2017
2.2 Patients would like the information to be more accessible to them and more consumable (simple power point, common every-day language, pictures). They see the benefit in presenting the information in person in a regular basis.	Agree	See actions under 1.3 and 1.5 above	NL SUPPORT Directors Communications lead and patient engagement lead	Completion by October 2017
<b>3. Patient engagement is still a work in progress with enhancements needed to:</b>				
3.1 Support training and mentoring,	Agree	Continue the implementation of the training and capacity development strategy	Training and capacity development lead	Ongoing from 1 <sup>st</sup> Jan 2017
3.2 Determine how best to recruit patients and sustain their interest over time without suffering “burn out.”	Agree	Review and implement the findings of the recruitment study undertaken in summer 2016 to determine best approaches for recruiting and retaining patients. Determine best practices from other SUPPORT units	Patient engagement lead	Ongoing from 1 <sup>st</sup> Jan 2017
3.3 Capacity development to learn about research and the role patients can play in it beyond providing initial insights is suggested.	Agree	Involve patients in the POR training program planned for winter 2017. Work with patients to determine how they believe their role could be expanded. Identify successes/champions in patient	Patient engagement lead	Ongoing from 1 <sup>st</sup> Jan 2017

		engagement, share these stories and include more local / practical examples in our training sessions and communication efforts.		
3.4 Capacity development for researchers on engaging with patients is similarly required to get more out of patient engagement and build value and understanding in patient's contribution to multiple research processes.	Agree	Continue with the POR training program planned for winter 2017. Work with researchers to determine the barriers to effective patient engagement	Patient engagement lead	Ongoing from 1 <sup>st</sup> Jan 2017
<b>4. Stakeholder engagement (physician, healthcare provider, decision-maker, and funder) is also a work in progress with enhancements needed to:</b>				
4.1 Incentivise engagement perhaps through small scale research funding competitions (e.g. a few thousand dollars to conduct client impact survey).	Agree	Develop a clinician / health professional led small grants program to assist with facilitating research. Advertise across the province	NL SUPPORT Directors	Program to be launched in Jan 2017
<b>5. Informal networking during the deployment phase has worked well but stakeholders would increasingly like to see:</b>				
5.1 The implementation of a formalized decision-making process specifying roles and responsibilities (including time commitment), and conflict resolution processes for increased transparency.	Agree	Develop and share clear documentation regarding the decision making process Develop clear conflict resolution policies See actions under 1.1 above re organisational structure diagrams	TPMI Executive	Completion by October 2017

<b>6. NL SUPPORT stakeholders would like to see:</b>				
6.1 Increased investment in the popularization of research. Some stakeholders suggested that incentives be offered for best plain language presentation or poster at National SPOR conferences and jurisdictional events in NL.	Agree	Recommend to the National SPOR leads that a plain language poster competition be included in the 2018 SPOR SUMMIT. Ensure all local events include a best plain language poster award	NL SUPPORT Director	Jan 2017
6.2 Similarly they would like to see research presentation events designed for general public consumption and discussion.	Agree	In partnership with local community groups arrange a health day for fall 2017 at which local research projects will be showcased	NL SUPPORT Director, patient engagement lead and knowledge translation lead	Nov 2017
<b>7. There is a perceived lack of awareness of the SPOR networks as a resource pool to draw upon.</b>	Agree	Work with local and provincial networks to increase partnership working and awareness raising	NL SUPPORT Directors and network leads	Completion by Oct 2017
<b>8. Disparities in access to POR exist between Newfoundland and Labrador Regional Health Authorities. Efforts to reduce these disparities by engaging in research in (and with) rural communities are recommended.</b>	Agree	Develop an aboriginal communities specific grant for POR.  Provide targeted training on POR in rural areas, focussing initially on Western RHA and Labrador Grenfell RHA	NL SUPPORT Directors, Training and capacity development lead	Grant launch Jan 2017 Training Spring and Summer 2017