



Canadian Nutrition Society
Société canadienne de nutrition



CPPENA

Canadian Patient Parenteral &
Enteral Nutrition Alliance

ACPAEP

Alliance canadienne des patients sous
alimentation entérale ou parentérale

Patient and Caregiver Needs Assessment Results

Résultats d'évaluation des besoins du patient et du
fournisseur de soins



Demographics

- Majority of respondents are patients and women

	English Survey (n = 121)	French Survey (n = 18)
Respondents (%)		
Patients	68	89
Health professionals	19	6
Caregiver/family member	11	6
Other	2	0
Gender (%)		
Men	24	28
Women	75	72
Fluid/non-binary/two-spirited	1	0
Age (years)		
18-30	8	0
31-40	5	11
41-50	18	6
51-60	20	33
61-70	26	17
71+	21	28



Q3: The most important ways that CCPENA can support patients and caregivers?

Key findings:

- Opportunities for connection and networking
- Information sessions, resources and educational materials
- Patient support groups

Please note:

No responses from French survey.

#	RESPONSES
1	informations sessions/ conferences. patients being able to share experiences/ideas and learn from each other
2	provide connection for adult patients on home tube feeding.
3	support, encouragement, suggestions/recommendations/tips
4	Exchange experiences, either between patients, between caregivers or both
5	Support groups. Information on healthy lifestyles.
6	Patient support groups
7	Develop resources/education materials to support clinical management
8	Homecare nurses to help with connection/disconnection, injection of medication for patients who can't be 100% autonomous with HPN at home.
9	Help them by providing support and be a resource that can help them answer practical questions related to TPN
10	networking, education
11	educational tools, any tips/product suggestions to aid in day to day management of living with central venous access/TPN
12	education
13	Opportunities for connection between patients and education



Q4: What resources, **tools** or education should we try to address?

Key findings:

- Canadian-specific content related to patients on HPN or with SBS
- Webinars, conferences, seminars, infographics, etc.
- Assessment tools for caregivers
- Apps
- Access to nutrition products/recipes
- Resource access for support groups

Please note:

No responses from French survey.

#	RESPONSES
1	resource access for support groups .
2	creating national care standards for home tube fed patients
3	Info on different diagnoses of why people may be on PN or EN, medication management, caregiver stressésupport In the form of handouts, monthly newsletters, website
4	Assesment tools to provide help to caregivers.
5	Patient education seminar and information sheet. Connect patients with mentors
6	Managing short bowel (especially meds, fluids)
7	-Canadian guidelines on certain subjects regarding HPN so the practice could be more homogenous across country/province: CRBSI protocols, connection/disconnections protocols, HPN needs for certain population (cirrhosis, patients on dialysis, etc) -Meetings few times a year between different HPN programs across provinces/country to discuss complex cases, transplant cases, etc.
8	An app to help with pn
9	Access to nutrition products-ie) ORS recipes or products +/- funding, oral supplements like copper/Zn-where to get it, education tidbits such as high output management, sessions on behavior change, like they do for weight loss or prep for bariatric surgery. However, it would behavior change for adopting a new diet such as in SBS. SBS patients do not get to "prepare" for the diet on a presurgery pathway like a bariatric sx pt for example, it is thrust upon them b/c of an event leading to surgery and now they must adopt lifestyle/diet changes. Mental Health topics for dealing with lifestyle change, feeling sheltered b/c they can't go out d/t diarrhea or high ostomy losses or weakness etc.
10	central venous access device best practice/making travel easier/
11	education about the treatment process, the nutrition needs, PN solutions they're taking, infection prevention
12	Webinars, conferences, shared educational tools/infographs, Canadian-specific content related to patients on HPN or with SBS. Opportunities for professionals to connect and share as well.



Q11: What resources do you use to currently manage your/patients HPN?

	English Survey (n = 121)	French Survey (n = 18)
Resources (%)		
HPN Program Staff	95	33
HPN Peer Support	9	33
The Oley Foundation	16	0
Teaching Manual	33	58

Other resources that are currently used include:

- Family support
- Homecare
- ACH nurses
- Personal interactions with national and global patients and professionals, conferences, seminars, reading, web
- Saskatchewan TPN program set up and staff
- Facebook group
- CHUM de Quebec
- A manual provided by the TPN department at the University of Montreal
- CLSC
- Clinical nurse at the gastroenterology department
- “I receive parenteral nutrition. No one helps me. I do everything myself.”



Q12: What additional resources would be useful to assist you in managing/better managing your/patients HPN?

Key findings:

- Others included website monthly newsletters, better bedside manner training, HPN staff member available to visit new patients at home to help them set up everything, guidance on using space efficiently, general information on procedures, peer support, resources for the weekly dressing
- Many also mentioned they have the support they require

	English Survey (n = 121)	French Survey (n = 18)
Additional resources (%)		
Recorded webinars	39	43
Online tutorials/How to videos	61	21
Infographics on specific topics	41	14
Resource guide	46	50
Links to funding support programs	26	36
Links to other organizations	33	21
Access to home care nursing support	27	50



Q13: What types of education sessions or meetings are of interest to you?

TOP 3:

- 1) Webinars
- 2) In-person meetings (2-3 hours in length)
- 3) Mini virtual conference (3-4 hours in length)

Q14: What topics would you like included in education initiatives?

Other topics not listed:

- Pregnancy on HPN
- Vegan options
- Communication
- Knowledge from experienced
- Unexpected issues
- Retirement homes for TPN patients

Top 10 of 28 topics	English Survey (n = 121)	French Survey (n = 18)
1	Travel	New products/technology
2	Central venous catheter	Central venous catheter
3	Dehydration	Long-term complications
4	Long-term complications	Emergency Preparedness
5	New products/technology	Research
6	Advocating for self/family	Funding support
7	Quality of life on HPN	Advocating for self/family
8	Diet	Quality of life on HPN
9	Psychosocial issues	Physical activity
10	Teduglutide for ASB Syndrome	Diarrhea



Q15: How often should education sessions or meetings be offered?

	English Survey (n = 121)	French Survey (n = 18)
Yearly	18	33
Quarterly (every 3 mo.)	37	33
Semi-annually (every 6 mo.)	37	33
Other	9*	0

*As needed or when
new issues arise

Q16: Do you have any barriers to attending virtual education sessions?

- The majority (>80%) stated “no” in both surveys
- Some barriers included conflicts with schedules, visual impairment and unable to access computer, health status, no internet or interest in computer technology, language (i.e. hosting a session in French).

Q17: Do you have any barriers to attending in-person events?

- At least 1/3 of respondents experienced barriers
- Barriers included time, distance, expense, health status, impact on family, Covid-19, travel



Q18: Would you find it useful to be able to participate in some form of networking, peer group activity?

- The majority stated “yes” (59% in English survey vs 87% in French survey)

Q19: What form of networking would be most effective to you?

	English Survey (n = 121)	French Survey (n = 18)
HPN Peer Support Network (%)	59	33
Networking events (available virtually) (%)	34	33
Online forum (%)	67	33
Other (%)	11	0

Other suggestions:

Events offered in French

Private intervention

All of the above