Beyond a Seat at the Table: The Added Value of Family Stakeholders to Improve Care, Research, and Education in Neonatology

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Objectives To analyze activities involving veteran resource parents and patients in a family partnership program; their perspectives were also explored.

Study design The multiple roles assumed by family stakeholders in neonatal initiatives were reviewed. Quality control questionnaires were distributed to resource parents and patients and providers who worked with them. Mixed methods were used to analyze results.

Results Thirty resource parents and patients were involved in a total of 653 activities related to clinical care (n = 413), teaching (n = 31), and research (n = 209); 7 initiatives were described to illustrate the positive impact of family stakeholders on clinical care, teaching, and/or research. Resource parents and patients had different degrees and intensity of involvement: all were involved in low-risk initiatives and 9 in more complex activities. In the questionnaire, family stakeholders all described positive impacts associated with their participation and benefits to themselves, such as meaning making. Three resource parents reported traumatic memories that occurred during medical simulations. The majority of providers report that resource parents and patients improved their projects, but some also report this new collaboration is complex.

Conclusions Although stakeholder participation increasingly is recommended, practical knowledge and the impact of their participation is scarce. Having several resource parents and patients bring their contributions may be more valuable than a few "expert stakeholders." Recruiting and orienting resource parents and patients toward different types of activities should take into account the complexity and risks of the tasks. Family stakeholders are appreciated and have a positive impact on projects in which they are involved. *(J Pediatr 2019;207:123-9).*

Parental presence in the neonatal intensive care unit (NICU) has increased.[1] Today, parents are encouraged to be physically present, are integrated in their infants' care, and their perspectives are reported.[2-8] In the research domain, family stakeholder participation also is increasing. Several agencies, such as the National Institutes of Health Research (United Kingdom) and Patient-Centered Outcomes Research Institute, require that patients have a "seat at the table."[9,10] Veteran patients/parents also are integrated in many other activities, such as peer-to-peer support or quality control initiatives.[11,12] Many different terms are used to describe parent stakeholders, such as veteran parents or resource parents and patients.[1,11,13] Although stakeholder participation is encouraged, these experiences are rarely published, making knowledge transfer difficult.[14] Most NICUs working with resource parents and patients collaborate with a single or a few individuals. For example, in the Canadian Neonatal Network,[15] comprising the 17 academic NICUs in Canada, there are 11 resource parents outside of our center who generally are the only resource parents in their center. Since 2011, multiple resource parents and patients have been integrated in our center. The goals of this investigation were to examine the multiple roles assumed by these family stakeholders and describe the impact of their integration in different initiatives.

Methods

The Partenariat Famille team was created in 2011 to recruit, integrate, and coordinate resource parents and patients in Sainte-Justine University Health Center, a mother–child tertiary care, university-affiliated hospital that delivers ~4000 babies each year. The NICU is a 70-bed unit with up to 33 ventilated patients and admits, on average, 1100 neonates a year.

For the purpose of this report, resource parents and patients will be used to describe stakeholders who had a previous NICU experience, both parents and

NICU	Neonatal intensive care unit
PTSD	Post-traumatic stress disorder

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ex-patients. Resource parents and patients were recruited among former parents, or patients who had reached adulthood, either because they came forward to participate or were suggested as potential family stakeholders by providers. They were all offered compensation to participate. All initiatives in which they are involved are considered quality improvement projects where results are critically examined and further interventions to improve are planned and implemented. For complicated initiatives, resource parents and patients receive specific training. For example, to evaluate research results, they may be required to sign a confidentiality agreement; to have access to the NICU, resource parents need to follow the same training as that given to volunteers. In contrast, for many simple initiatives, such as reviewing information given to parents, resource parents are not required to have any specific training.

Description of the Roles Assumed by Resource Parents and Patients

All the records pertaining to activities performed by resource parents and patients since 2011 were reviewed and systematically analyzed including the role assumed by stakeholders as well as the identity of providers involved. The term initiative is used to describe specific types of projects in which resource parents and patients were involved. The initiatives were categorized as either research, clinical, or teaching initiatives; they were classified further as whether they required stakeholders to be physically present in the hospital and/or to have direct contact with new parents, students, or researchers.

Because the majority of resource parents and patients were integrated in more than 1 initiative on more than 1 occasion, we also have described the total number of activities in which they participated. For example, a resource parent who has cotaught a palliative care course 3 times would be analyzed as having participated in 1 teaching initiative requiring student contact, and in a total of 3 activities.

Questionnaires

From January to April 2017, a quality control questionnaire was distributed to all resource parents and patients. We analyzed the answers to open-ended questions regarding their positive and negative experiences and the perceived impact of their implications.

All providers involved in projects implicating resource parents and patients also were asked to complete a questionnaire. Answers to open-ended questions were analyzed describing the advantages and difficulties related to their participation and description of the impact of family stakeholders on their projects.

Qualitative data from the open-ended questions were analyzed using thematic content analysis with NVivo12 (QSR International, Melbourne, Australia).[16,17] Themes and subthemes were rigorously defined for each question. Two trained independent investigators (1 neonatologist and 1 resource parent) independently coded all the data. A specialist in mixed methods supervised each step of their work and assessed coding reliability. Discrepancies were resolved through consensus. Quantitative data were analyzed with descriptive statistics only. This project was approved by the Research Ethics Committee of the CHU Sainte-Justine Research Center as a quality improvement project.

Results

Since 2011, 30 resource parents and patients have teamed up with 27 providers and participated in a total of 653 activities in 47 types of initiatives: 28 resource parents and 2 resource patients (**Table I**; available at www.jpeds.com). Their children were born between 1999 and 2017, between 23 and 38 weeks of gestational age. The 2 resource patients are 25-year-old adults born extremely preterm who do not have children. Eight of the resource parents have been recruited since 2017 (after the quality control questionnaires. Demographic variables of resource parents and patients who answered the questionnaire were similar to those of the total number of resource parents and patients now integrated in our program) (**Table I**).

Description of Initiatives

Clinical Care and Administration. Thirty resource parents and patients were involved in 413 activities in 23 types of initiatives (**Table II**): 303 activities took place outside the hospital setting and 221 did not involve any contact between resource parents and patients and new parents (**Table II**).

Examples. In 2017, the unit moved to a 70-bed single-room NICU. Before the move, we ran multi-disciplinary mock codes to ensure that the design of the unit and the manner in which teams would work and communicate was optimal. Eight resource parents participated in these 2 days of interdisciplinary simulation. They played the role of the "NICU parent" in different scenarios. The resource parents pointed out 6 items not mentioned by providers that needed improvement. For example, in the new unit, rooms have many large windows. Resource mothers pointed out they were expressing their milk in front of teams of high school boys playing football or to providers in the corridor. Frosted glass in windows was strategically placed. During a mock code, a resource father doing kangaroo care with his baby (manikin) felt insecure in his position "stuck behind the incubator and the closet." Indeed, further mock codes with resource parents demonstrated that urgent access to the manikin in skin-to-skin care was difficult. The configuration of the room was optimized with resource parent input, and since the move, there have been no incidents in which babies could not be reached urgently.

The hospital administration produced a brochure, without parental input, informing parents about visitations, sleeping arrangements, showers, cell phone use, etc, which was called "Règles de vie" ("Rules of life"). Before using it in neonatology, it was reviewed by 5 resource parents, who all found it infantilizing, consisting largely of a list of items parents could not do. Resource parents optimized the document, now called "Caring Together." Fifteen NICU parents have given feedback regarding the document; all found it useful but reported that they also would appreciate receiving the

Table II. Clinical care and administrative activities in which resource parents/patients were integrated (total of 413 activities)

No. activities	Description of initiatives	No. resource parents and patients involved
In hospital setting/Interaction with families (145 activities)		
44	Bedside support in the unit: during or outside of clinical rounds (no. days)	1
20	Social and cultural activities (eg, scrapbooking)	1
37	Welcome visit for new parents: NICU, personnel, routine, etc	6
15	Structured support groups: "Being a Parent in Neonatology"	6
10	Structured parent information sessions (filling forms, planning discharge)	1
10	Parent navigator sessions: hospital resources, living arrangements, etc	1
5	Testimonies/narratives (for teams or new parents)	3
6	Matched buddies (bereaved resource parent) for bereaved parents/family initiatives	3
In hospital setting/No interaction with families (158 activities)		
40	Optimization of living arrangements for new parents (no. interventions)	1
22	Coordination of resource parent program (no. tasks)	5
21	Participation in clinical interdisciplinary meetings	5
20	Recruitment/training/support for "new resource parents and patients"	6
16	Hospital design/redesign initiatives: design and visits before moving to single-room unit, evaluation of new equipment/procedures, simulations (playing the parent role in a quality control team)	8
16	Integration in clinical care committees: humanization of care, "transition to single rooms," family integrated care, "morning rounds," pain, etc	9
9	Quality control projects (design, results, impact measures, etc)	3
14	Clinical "ethics" meetings to discuss complex situations	5
Outside the hospital setting/Interaction with families (47 activities)		
12	Matched buddies for new bereaved parents (Internet or phone)	3
10	Matched buddies for new parents: communication via Internet or phone	1
25	Contribution to dedicated Web sites and parent discussion groups/testimonies on social media (video, narrative, life stories, etc)	4
Outside the hospital settings/No interaction with families (63 activities)		
21	Fundraising for the PAF team (annual race and other individual initiatives) and/or PAF representation for the hospital foundation	10
7	Production, coproduction, and/or evaluation–optimization of information given to parents and families	18
28	Interventions in the media (written and oral)	7
7	Protocol development and audits (skin-to-skin, visitation policy, breastfeeding, family integrated care, pain, etc)	2

PAF, Partenariat Famille.

information orally, by meeting a clinician or ideally a parent. In a previous quality control investigation, 82% of the 92 participating parents also reported that they would have appreciated meeting "old NICU parents" during the hospitalization. These results led to the following pilot project in which 2 resource parents meet new NICU parents weekly as a group. Parents are welcomed, given the information in the "Caring Together" document, and exchange together about family centered topics. Six resource parents have moderated these pilot meetings where 55 new NICU parents have participated. Our quality control survey held during the week after each parent meeting (66% participation rate) indicates that 79% of participants found the meeting with resource parents useful and 83% wished to participate in more meetings of the kind to exchange with resource parents.

Education. Six resource parents were involved in 31 activities in 7 types of initiatives related to medical education (**Table III**; available at www.jpeds.com).

Examples. Since 2013, medical students have a 2-hour course about pediatric palliative care, now given by clinicians and a resource mother whose child has a life-limiting illness. The mother tells her story and speaks about the impact—both negative and positive—her daughter's life has on her family. She also gives practical recommendations to students. This course has been given 5 times and the 176 students who answered the evaluation all gave a mark of 4/5 or higher.

During "communication" scenarios in medical simulation, the evaluation scale generally is developed by nonparent experts and the evaluation also is performed by clinicians. In our program, 7 resource parents have participated in developing a score sheet to evaluate communication with parents during an unsuccessful resuscitation (mock codes).

Research. Eleven resource parents and patients were involved in 209 activities in 17 types of research initiatives (**Table III**).

Examples. Many resource parents and patients are collaborators in investigations and participate in protocol development, reviewing consent forms, analysis of results, and presentations at conferences. This gives rise to innovative and rewarding investigations: research about parents also has become research with parents and patients.[1,18-22] Some resource parents and patients also provide a complementary parent/patient voice collaborating in writing opinion pieces with researchers and/or clinicians.[20,23]

Individual Participation of Resource Parents and Patients. Family stakeholders have various degrees of participation: from a minimum of 1 activity in 1 initiative to a maximum of 81 activities in 11 different initiatives. Twelve resource parents and patients were involved only in clinical care, 3 only in research, and 1 only in education, and the others were involved in 2 or 3 of these categories. Ten stakeholders have only been involved in initiatives with parent/student contact. None has been involved in all categories of initiatives (clinical, research, and teaching) with patient and/or provider contact.

Impacts of Resource Parent and Patient Participation

Resource Parents and Patients' Perspective. In 2017, all 22 resource parents and patients who had collaborated in at least 1 activity participated (100% participation; **Table I**). All (100%) described positive experiences and invoked 4 major themes to describe them.

1) Improving care/Making a difference (n = 19)
"I saw I could bring something to the NICU";
"I Want to improve things, make a difference."

2) Giving back/Helping other parents (n = 17)
"I hope my experience benefits other parents";
"Participate in a good cause, help as much as we can. We received so much."

3) Meaning making (n = 16)
"I want to do this in memory of my son";
"This brought something positive with regards to our daughter's illness. This was not the case before our resource parent experience (only negative aspects of the illness)."

4) Bringing the parental perspective (n = 15)
"Parents see protocols through different eyes."

Parents' comments about their experience often covered several of these themes together:

"This has changed my life. Participating in this project gave a voice to families who are not able to write in medical articles. It made me give a meaning to my experience. It is a legacy to my child's life. [. . .] She made it possible, and she made life better for other families";
"Being able to make a difference [. . .] sometimes it is easy to make things better. With simple solutions nobody sees."

Five resource parents and patients also reported limitations: 2 mentioned their difficulty to find time to participate. Three parents reported more significant impacts: reliving a traumatic experience during a simulation scenario. A father reported:

"I thought I was ready, I mean, I saw my son when he was reintubated and sick. But this brought it all back, years later. I knew it was a manikin, but the alarms, the beeps, the RTs, the alcohol smell. It brought it all back and I started to cry. The doctors were very understanding."

Providers' Perspective. Nineteen providers answered the questionnaire (70% participation): 10 neonatologists, 3 nurses, 2 fellows, 2 consultants, 1 neonatal nurse practitioner, and 1 lactation consultant.

The majority (90%) described advantages related to their collaborations with resource parents and patients, invoking 3 large themes:

1) The resource parents and patients' complementary role (n = 10):
"They bring a different and necessary point of view";
"They give us authentic feedback. Their collaboration is essential because they are front-line actors."

2) Resource parent's stories as essential to improve caring and communication (n = 9),
"The father brought the families' point of view and helped us understand the family perspective";
"For trainees, having a testimony with respect to communication is pure gold for students."

3) Improving research projects (n = 3)
"Feeling that our research questions and methods are endorsed and relevant to parents is important to us";
"They improve our projects because they provide new ideas, a fresh look."

Some clinicians also reported that interactions within committees were improved when resource parents and patients were present (n = 4):

"More respect among the members of the team in the presence resource parents and patients."
"Allows for a more patient-oriented multidisciplinary discussion."

Nine providers described some limitations. Most of the comments were related to the availability of resource parents and patients and the time/schedule management challenges (n = 5). The other difficulties were related to discomfort related to this new type of collaboration and the need for tools to facilitate this kind of work (n = 5).

Discussion

Over the last decade, there has been an increasing emphasis on the importance of family stakeholder involvement. This study reviewed a program of family stakeholder involvement, described their activities, and explored potential impacts of their participation.

Resource parents and patients can assume many different roles, and their integration brings unique perspectives and

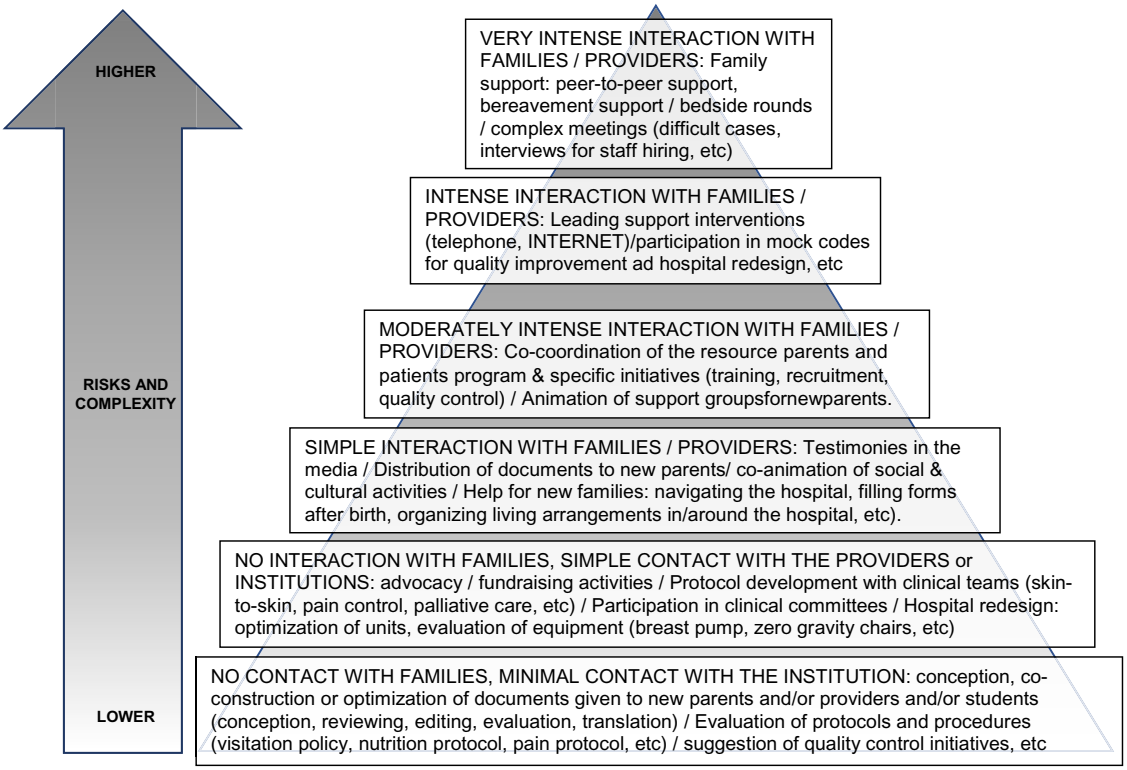

Figure 1. Pyramid of complexity and risks: clinical and administrative initiatives in which resource parents/patients can be integrated.

can enhance practice in many activities. Activities involving them require various levels of engagement and skillsets and have differing levels of difficulty and risks.[12,24,25] After being recruited, family stakeholders start with simpler, lower risk activities. Then, some get involved in activities of increasing complexity (**Figure 1**). For example, all information given to "new" NICU parents is reviewed by resource parents. This represents an activity that is common and can be achieved by any "ex-NICU" parent with minimal risk to the resource parents, to the new parents, and the clinical team. At the top of the "pyramid" are activities that involve some risk to stakeholders and new parents and are performed by more experienced stakeholders (**Figure 1**). Although some resource parents and patients wish to come back to the hospital and appreciate being in contact with new parents, others only participate in activities outside of the NICU, either because they do not want to come back to the unit, or they cannot for practical reasons. Many centers have 1 or 2 resource parents that are involved in many initiatives. These individuals often are prone to burnout or they may become very specialized in one specific activity, such as being on the research ethics committee. These systems are fragile and can be limited as they rest on the shoulder of few "expert stakeholders." We have found that having many resource parents and patients with different interests and profiles enriched and strengthened our program. In our model, any "ex-NICU parent/patient" can have a seat at the table.

Family stakeholders and providers reported positive impacts that helped improve clinical care, teaching, and research, but 3 resource parents also reported traumatic experiences associated with flashbacks. Symptoms of post-traumatic stress disorder (PTSD) are not uncommon for parents after an NICU experience.[26-28] We worked on strategies to decrease traumatic experiences in resource parents and involved our unit psychologist and the perspectives of experienced resource parents. The literature regarding adverse events experienced by family stakeholders is scarce. Studies primarily focus on the positive aspect of these new partnerships and rarely examine patient/parent perspectives. We invited the 3 resource parents who reported flashbacks to suggest strategies for improvement. They identified elements that could trigger flashbacks such as visiting the NICU, hearing alarms, or seeing a resuscitation (mock codes), which reflects findings in the literature.[27-29] Because these "NICU" triggers are not present in the resource parents' everyday life, the strategy was not to mitigate the impact of triggers, but rather to avoid exposure to activities with potential triggers for more fragile parents. Symptoms of post-traumatic stress disorder (PTSD) also decrease over time in NICU parents.[27,28] We decided to add a level of security in our recruitment strategies by only inviting resource parents and patients to participate in "risky" activities (**Figure 1**) at least 3 years after their NICU experience and at least 2 years after participation in simple activities. We also describe potential flashbacks

to participating resource parents before they collaborate in initiatives with potential traumatic triggers (**Figure 1**). Despite their flashbacks, all 3 resource parents who reported them continued to be involved in our group. Since implementing those safety steps, there were no traumatic events reported by resource parents. We are also considering whether the completion of a "PTSD questionnaire" (Impact of Event Scale–Revised) is feasible and desirable before resource parents engage in complex activities.[27]

Although providers who worked with resource parents and patients generally consider family stakeholder integration positive, some also report being uncomfortable at times and/or finding this new integration complex. This may be due to the novelty of many of the roles being assumed by resource parents and patients. For example, most neonatologists never had a formal evaluation by a parent while in training. We expect that with time, providers will find such involvement routine and beneficial. We should keep in mind that significant gaps of knowledge still remain regarding recruitment and training of family stakeholders, as well as training of providers who collaborate with them.

The main limitation of this study is that it is from a single center. It is a quality control team project; although it examined each initiative in a quality improvement fashion, it was not designed to systematically measure impacts on neonates, such as a pre-post study for each initiative described. In contrast, we describe multiple initiatives and activities with a large group of resource parents and patients, as opposed to one or very few resource parents involved in specific projects.

Participation of resource parents and patients is still uncommon. **Figure 2** (available at www.jpeds.com) presents several practice points that may be helpful for those who wish to embark in such collaborations. Because of the lack of evidence, these should be regarded as basic practical ones that need to be evaluated. Although partnering with family stakeholders is recommended in many areas of medicine, practical descriptions relative to the specific activities they can do are scarce. Furthermore, because of many factors, some providers or researchers, less familiar or comfortable, may be more inclined to only involve a few family stakeholders at the end of a project, where their voice is less likely to be heard or to add value.[30] In our model, family stakeholders have more than a "seat at the table." We believe that every parent and patient can provide something valuable and improve care, teaching, and/or research.[30] ■

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Data Statement

Data sharing statement available at www.jpeds.com.

References

1. Bourque CJ, Dahan S, Mantha G, Robson K, Reichherzer M, Janvier A. Improving neonatal care with the help of veteran resource parents and patients: an overview of current practices. Semin Fetal Neonatal Med 2018;23:44-51.
2. Umberger E, Canvasser J, Hall SL. Enhancing NICU parent engagement and empowerment. Semin Pediatr Surg 2018;27:19-24.
3. O'Brien K, Robson K, Bracht M, Cruz M, Lui K, Alvaro R, et al. Effectiveness of Family Integrated Care in neonatal intensive care units on infant and parent outcomes: a multicentre, multinational, cluster-randomised controlled trial. Lancet Child Adolesc Health 2018;2:245-54.
4. French KB. Care of extremely small premature infants in the Neonatal Intensive Care Unit: a parent's perspective. Clin Perinatol 2017;44:275-82.
5. Gaucher N, Payot A. Focusing on relationships, not information, respects autonomy during antenatal consultations. Acta Paediatr 2017;106:14-20.
6. Janvier A, Lantos J. Ethics and etiquette in neonatal intensive care. JAMA Pediatr 2014;168:857-8.
7. Arnolds M, Xu L, Hughes P, McCoy J, Meadow W. Worth a try? Describing the experiences of families during the course of care in the neonatal intensive care unit when the prognosis is poor. J Pediatr 2018;196:116-22, e3.
8. Ballantyne M, Bernardo S, Sozer A, Orava T, McPherson AC, Church P, et al. A whole new world: a qualitative investigation of parents' experiences in transitioning their preterm child with cerebral palsy to developmental/rehabilitation services. Dev Neurorehabil 2018;1-11.
9. Forsythe L, Heckert A, Margolis MK, Schrandt S, Frank L. Methods and impact of engagement in research, from theory to practice and back again: early findings from the Patient-Centered Outcomes Research Institute. Qual Life Res 2017;27:1-15.
10. Selby JV, Beal AC, Frank L. The Patient-Centered Outcomes Research Institute (PCORI) national priorities for research and initial research agenda. JAMA 2012;307:1583-4.
11. Hall SL, Ryan DJ, Beatty J, Grubbs L. Recommendations for peer-to-peer support for NICU parents. J Perinatol 2015;35(suppl 1):S9-13.
12. Celenza JF, Zayack D, Buus-Frank ME, Horbar JD. Family involvement in quality improvement: from bedside advocate to system advisor. Clin Perinatol 2017;44:553-66.
13. Robson K, MacMillan-York E, Dunn MS. Celebration in the face of trauma: supporting NICU families through compassionate facility design. Newborn Infant Nurs Rev 2016;16:225-9.
14. Haines KJ, Kelly P, Fitzgerald P, Skinner EH, Iwashyna TJ. The untapped potential of patient and family engagement in the organization of critical care. Crit Care Med 2017;45:899-906.
15. Barrera M, Atenafu EG, Schulte F, Bartels U, Sung L, Janzen L, et al. Determinants of social competence in pediatric brain tumor survivors who participated in an intervention study. Support Care Cancer 2017;25:2891-8.
16. Bazeley P, Jackson K. Qualitative data analysis with NVivo. Thousand Oaks (CA): Sage Publications Limited; 2013.
17. Hsieh HF, Shannon SE. Three approaches to qualitative content analysis. Qual Health Res 2005;15:1277-88.
18. Janvier A, Farlow B, Wilfond BS. The experience of families with children with trisomy 13 and 18 in social networks. Pediatrics 2012;130:293-8.

19. Guon J, Wilfond BS, Farlow B, Brazg T, Janvier A. Our children are not a diagnosis: the experience of parents who continue their pregnancy after a prenatal diagnosis of trisomy 13 or 18. Am J Med Genet A 2014;164A:308-18.
20. Janvier A, Farlow B, Baardsnes J, Pearce R, Barrington KJ. Measuring and communicating meaningful outcomes in neonatology: a family perspective. Semin Perinatol 2016;40:571-7.
21. Janvier A, Barrington K, Farlow B. Communication with parents concerning withholding or withdrawing of life-sustaining interventions in neonatology. Semin Perinatol 2014;38:38-46.
22. Chu LF, Utengen A, Kadry B, Kucharski SE, Campos H, Crockett J, et al. "Nothing about us without us"—patient partnership in medical conferences. BMJ 2016;354:i3883.
23. Janvier A, Farlow B. Arrogance-based medicine: guidelines regarding genetic testing in children. Am J Bioeth 2014;14:15-6.
24. Sofolahan-Oladeinde Y, Newhouse RP, Lavallee DC, Huang JC, Mullins CD. Early assessment of the 10-step patient engagement framework for patient-centred outcomes research studies: the first three steps. Fam Pract 2017;34:272-7.
25. Martin G. An introduction to the patient-centered outcomes research institute. Neonatal Netw 2016;35:409.
26. Kim W, Lee E, Kim K, Namkoong K, Park E, Rha D. Progress of PTSD symptoms following birth: a prospective study in mothers of high-risk infants. J Perinatol 2015;35:575.
27. Ahlund S, Clarke P, Hill J, Thalange NK. Post-traumatic stress symptoms in mothers of very low birth weight infants 2-3 years post-partum. Arch Womens Ment Health 2009;12:261-4.
28. Elklit A, Hartvig T, Christiansen M. Psychological sequelae in parents of extreme low and very low birth weight infants. J Clin Psychol Med Settings 2007;14:238-47.
29. Yehuda R, Hoge CW, McFarlane AC, Vermetten E, Lanius RA, Nievergelt CM, et al. Post-traumatic stress disorder. Nat Rev Dis Primers 2015;1:15057.
30. Allen SV, Sparling K, Montori VM. Patient and family engaged care—going beyond tactical buzzwords. BMJ 2017;356:j1155.

Partnering with resource parents and patients: practice points and recommendations
1. **Creating a resource parents and patients team**: in addition to a parent, the team should consist of, at minimum, a physician and nurse, one of whom has an administrative role. -It is important to have the involvement and support of the administration: they should understand the role of resource parents and patients.
2. **Communicating with others who work with resource parents and patients**: experienced teams can make some practical **recommendations** as to what works and what doesn't; they have often learned from their successes and failures.
3. **Starting small and slowly complexifying**: starting small with simple projects and goals that are easily reached ensures that the team gains experience while having a rewarding experience. Simple tasks are those at the bottom of the "pyramid" of complexity" (Figure 1): review of written information given to NICU parents and /or current protocols; resource parents and patients involvement in clinical care committees; review of education materials; review of consent forms in clinical research.
4. **Defining roles and responsibilities**: Resource parents and patients should know what role(s) they are expected to play as team members on this project, with whom they work, who they can contact for questions (and how), and how long their participation will last. They should know if and how much and when they will be compensated/remunerated. Clinicians, administrators, or/and researchers working with them should also know what the resource parents and patients role and their roles are in the team.
5. **Quality control**: Obtaining feedback about resource parents and patients and provider satisfaction in the team is important.This way, teams can learn from their mistakes and build on their strengths. After each project, resource parents and patients should receive practical information about how they have helped their team.
5. **Advancing the field**: teams who work with resource parents and patients should report and share their experience, the documents they use for recruiting and training new parents, as well as the impacts of these new collaborations.
6. **Creating a community**: coordinating efforts with others who also involve resource parents and patients, whether in the same institution but in different disciplines, or between neonatal teams or hospitals. Creating a "Resource parents and patients Bank" or registry of resource parents and patients may lead to increased collaborations between parents and providers/researchers.

Figure 2. Practice points and recommendations.

Table I. Demographic information about participating resource parents/patients

Demographics	Total number of resource parents and patients (n = 30)	Resource parents and patients who filled the quality control questionnaire (n = 22)
General demographics		
Mothers	21 (70%)	16 (73%)
Age (average, y)	38	38.5
University education	22 (73%)	16 (73%)
Married or living with common-law partner	20 (67%)	15 (68%)
Number of years participation as a resource parent	3.5	4
Participation >2 y	15 (50%)	15 (68%)
Born in Canada	26 (87%)	20 (91%)
French as first language	22 (73%)	15 (68%)
Bilingual (French and English written and spoken)	16 (54%)	11 (50%)
NICU experience		
Had child or children not hospitalized in NICU	16 (53%)	13 (59 %)
More than 1 NICU child admitted	8 (27%)	7 (32%)
Length of hospitalization of NICU child >3 mo	19 (63%)	14 (64%)
Prematurity as main diagnosis of NICU admission	24 (80%)	19 (86%)
Bereaved NICU parents	8 (27%)	8 (36%)

Table III. Initiatives related to medical education in which resource parents and patients were involved

No. activities	Description of initiatives related to medical education (total n = 31 activities)	No. resource parents and patients involved
In hospital or university setting/direct interactions with students/trainees (17 activities)		
9	Testimonials/narratives integrated in courses	3
5	Co-teaching with providers/educators (workshops, case-based learning)	2
2	Parental presence during simulations (including discussion with trainees)	1
1	Co-evaluation of trainees (simulation scenarios, case-based learning)	1
In or outside of hospital or university setting—No interactions with students/trainees (14 activities)		
9	Narrative (written story used for teaching in a specific course)	3
3	Co-construction of material used for medical education	2
2	Review/optimization of materials used for medical education	2

No. activities	Description of research initiatives (total n = 209 activities)	No. resource parents and patients involved
In hospital/research center setting/Direct interaction with researchers/participants (49 activities)		
15	Collaboration with research teams to develop protocols	4
9	Member of Parent Advisory Board	6
4	Collaboration in data acquisition: focus groups, questionnaires, etc	2
11	Collaboration in data analysis or interpretation of results	9
4	Member of Data Safety and Monitoring Committee	2
4	Knowledge transfer: return of study results	2
2	Collaboration in recruitment of families for a research project	1
Outside hospital/research center setting/Direct interaction with researchers/participants (43 activities)		
21	Presentation at conferences, panel (testimonial or parental perspective about a clinical topic)	6
9	Co-teaching at conferences (workshops)	3
7	Co-presentation of study results at conferences	4
6	Presentation of study results or parental perspective (alone)	3
Outside hospital settings/No contact with participants—none or minimal contact with researchers (117 activities)		
11	Collaboration in data coding, analysis, or interpretation of results	9
8	Co-develop, review, or optimize studies and research protocols	5
33	Creation of information and consent forms for studies	7
25	Co-writing and co-editing abstracts	5
31	Co-writing and co-editing articles	5
9	Parent sole authors of articles (parental perspective, narratives)	6