

Experience of a healthcare transnational network on paediatric transplantation in the implementation of indicators and quality standards for continuous improvement

ID Abstract: 145



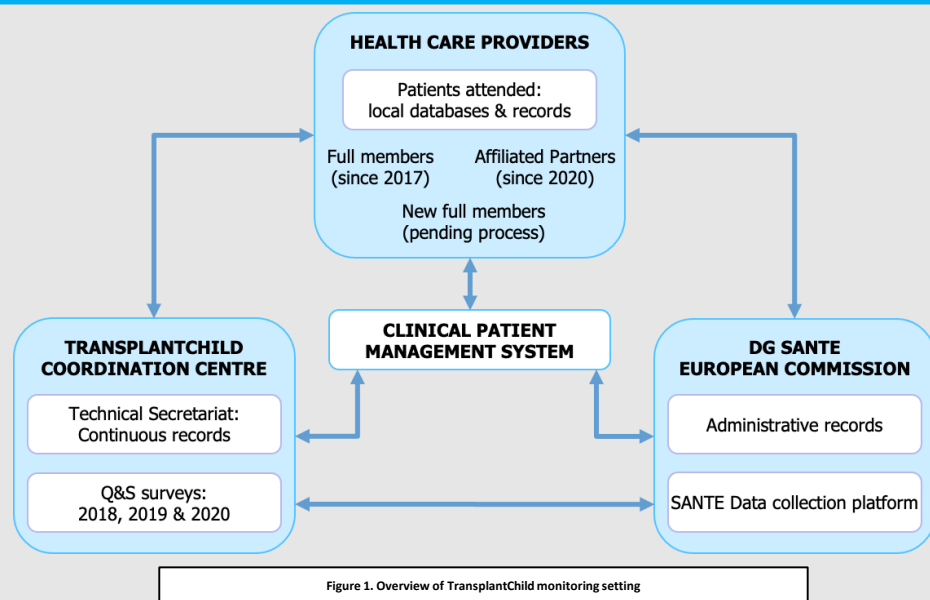
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Background

Since February 2017 European Reference Networks (ERN) harness the collective expertise of Healthcare Providers (HCP) from across the European Union, aiming to offer a high level of expertise, produce good practice guidelines and implement outcome measures and quality control following in all these a multi-disciplinary approach.

Objectives

Describe the experience of an ERN in ensuring quality and safety (Q&S) at transnational level through its governance processes, periodic monitoring activities and compliance of HCP members with specific quality standards and those established by the European Commission (EC).



Methods

Data are collected through periodic Q&S surveys launched to HCP members. In this setting (figure 1), EC is responsible for ensuring operational criteria for all networks and HCPs while each one of these are responsible for its own periodic self-assessment, and the definition and use of specific indicators according to the ERN topic. Periodic survey fulfillment by HCP covers the Common Core set of ERN Indicators established by the EC, and also specific indicators and quality standards. Results from the monitoring exercises are presented and validated in ERN regular governance meetings and network open-access webinars.

Results

MS	HCP	Follow up patients reported by	Area of expertise (reported caseload during last year/organ)							Overall
			LI	KD	Int	MO	LU	HE	HSC	
1. BE	Cliniques Universitaires Saint Luc -Bruselas	Xavier Stephenne	350							350
2. FR	Hôpital Necker - Enfants malades	Christophe Chardot	250	140	24		8	95	600	1117
3. FR	Hôpital Bichat - Paris	Sophie Branchereau	550							550
4. GE	Hannover Medical School	Ulrich Baumann Anette Melk	250	90						250
5. IT	ISMETT, University of Pittsburgh Medical Center Italy	Francesco Cirillo	86			2				88
6. IT	Ospedale Pediatrico Bambino Gesù	Manila Candusso	450			19				469
7. IT	Hospital Papa Giovanni XXIII	Lorenzo D'Antiga								
8. LI	Vilnius University Hospital Santariskiu Klinikos	Jelena Rascon	10	11		1		1	46	69
9. IT	Azienda Ospedaliera di Padoova	Elisa Benetti	75	150						225
10. NL	Wilhelmina Children's Hospital	Caroline Lindemans							336	336
11. PO	Children's Memorial Health Warsaw	Piotr Kaliciński	337	215		2				554
12. PT	Centro Hospitalar do Porto	Conceição Mota		32						32
13. PT	Hospital Santa Maria. Centro Hospitalar Lisboa Norte	Rosario Stone		53						53
14. PT	Centro Hospitalar e Universitário de Coimbra, EPE	Maria Francelina Lopes	8							8
15. SE	Children's Hospital, Skåne University Hospital	Lisa Sartz								
16. SE	Karolinska University Hospital	Lars Wennberg	105	72		8				185
17. SP	La Paz University Hospital	Paloma Jara	277	140	45		2	50	235	749

Figure 2. Summary results from Q&S survey 2020 Activity full members

In 2017, mandatory and recommended quality standards were approved considering a minimum expertise per type of transplantation together with a minimum activity over most recent years. Overall reported HCP activity consisted of 5035 patients attended in follow-up clinics in 2020 (all transplantation types) (figure 2). Network members also provided data about pre-transplantation patient evaluation, waiting list's patient care, and transplantation procedures performed. Data provided on patient and graft survival was lower than 50% and therefore was not valid for analysis.

Conclusion

Q&S surveys have proven critical for the consolidation and further growth of the network. Its periodic release facilitates benchmarking & monitoring indicators both at European, network & local levels. Data collected is being used to review not only mandatory and recommended standards for continuous improvement within TransplantChild but also periodic indicators reporting to EC & stakeholders will help to improve in the European setting the level of complex and long-term care provided that is currently needed after transplant and demanded by patients and families.