

Supplemental Methods

IBD data collection and definition of variables

Data collected included: demographics, sex, ethnicity, co-morbidities, IBD characteristics (year of diagnosis, IBD type, disease location, disease behaviour, disease activity) and previous and current medication. Body mass index (BMI) SDS were calculated for children >5 years old based on the World Health Organization (WHO) growth reference standards.(1)

Disease activity scores

Disease activity was assessed by the PUCAI in those with UC and IBD unclassified (IBD-U), and by the weighted paediatric Crohn's disease activity index (wPCDAI) in those with CD. Disease activity was categorized as remission, mild, moderate or severe according to pre-validated cut-offs.(2, 3) If disease activity scores were unavailable, the physician's global assessment (PGA) was used. Active disease was defined if the PGA was mild, moderate or severe. In case of an absent PGA a faecal calprotectin level of >250 was considered active disease.

Laboratory results

Faecal calprotectin levels and the following biochemical blood tests were obtained: erythrocyte sedimentation rate (ESR), C-reactive protein (CRP), haemoglobin, haematocrit, leukocytes, platelet count and albumin. Only faecal calprotectin levels obtained between 1 month prior to the VTE and 1 week after diagnosis of the VTE were included in this study. Blood results were included if obtained within 2 weeks prior to VTE diagnosis and 1 week after.

VTE data collection and definition of variables

Definition of VTE

A VTE was defined as a radiologically confirmed thromboembolism occurring in the veins of the upper limbs or superior vena cava (upper extremity DVT), lower limbs or inferior vena cava (lower extremity DVT), the dural venous sinuses (cerebral venous sinus thrombosis, CSVT), renal vein or right atrium or ventricle (intra-cardiac).

Definition of thrombophilia

Hereditary thrombophilia was defined as a proven protein S, protein C or anti-thrombin deficiency or factor V Leiden mutation. Acquired thrombophilia was defined as proven anti-phospholipid syndrome.

List of VTE risk factors

General VTE-related risk factors that were assessed included: presence of a CVC, hypertension, high dose oestrogen use, recent surgery, chronic heart disease, steroid therapy, malignancy, cigarette smoking, recent trauma, diabetes, pregnancy, sepsis, kidney disease, obesity, immobility, total parenteral nutrition, dehydration, hyperhomocysteinemia, sickle cell anaemia, hypovolemia and congenital disorders of glycosylation.

Definition of antithrombotic therapy complications

Type and duration of antithrombotic treatment and thromboembolic prophylaxis were obtained. Complications of antithrombotic treatment were defined according to a previously published paper by Mitchel et al.(4) Major bleeding was defined as any of the following: 1) fatal bleeding; 2) clinically overt bleeding associated with a decrease in haemoglobin of at least 20 g/L (i.e., 2 g/dL) in a 24-hour period;

3) bleeding that is retroperitoneal, pulmonary, intracranial, or otherwise involves the central nervous system; 4) bleeding that requires surgical intervention in an operating suite. Non-major bleeding was defined as a composite of 1) overt bleeding for which blood product is administered and not directly attributable to the patient's underlying medical condition and 2) bleeding that requires medical or surgical intervention to restore haemostasis, other than in an operating suite. Minor bleeding was defined as any overt or macroscopic evidence of bleeding that does not fulfil the criteria of major or non-major bleeding.

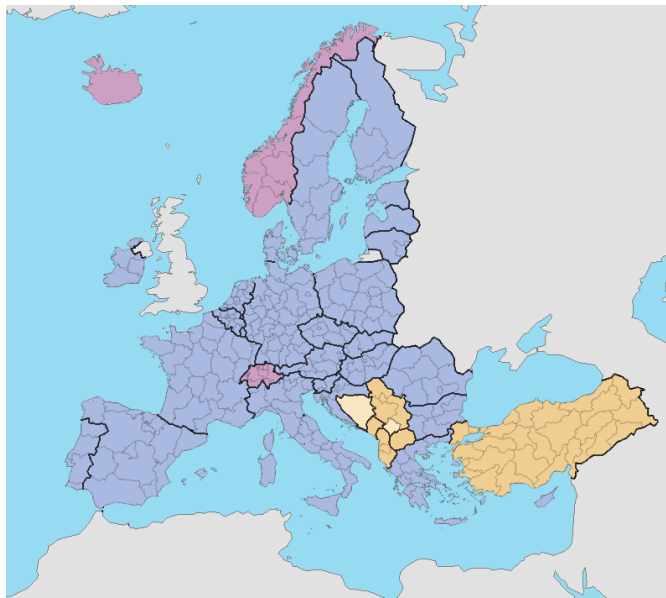
VTE outcome

Additional information on VTE recurrence, recovery status, persisting morbidity and mortality was collected.

Incidence data collection

Each year, active participants received an electronic survey. In this survey they stated how many patients they have under their care at that moment and whether this number of patients was based on an estimate or robust data (e.g. local database or patient notes). They provided additional information about their unit, location and other details regarding the paediatric population they are covering. They report at which age (upper limit) patients are usually transferred to adult care.

In addition, they report their geographical catchment area by selecting well-defined geographical areas, such as the Nomenclature of Territorial Units for Statistics (NUTS) classification from the Eurostat database, as demonstrated in Supplemental Figure 1.



Supplemental Figure 1.

Map of all Nomenclature of Territorial Units for Statistics (NUTS) regions in Europe.

As reporting centers may join the registry at different time points during the study period, the duration of patients at risk is different for each participating center. Subsequently, instead of counting the total number of patients at the start and end of the study, patient years were first calculated per center by multiplying the number of months a center was participating in the registry by the total number of PIBD

patients they have under their care. The sum of patient years for all active centers is used as denominator for the incidence calculation. Since centers might have more than one participating physician, when two responders were reporting from the same centre we selected the report of denominator data that was based on the robust data, or we averaged the estimates.

Search strategy on incidence of VTE in children

The search was conducted according to the search strategy below in Ovid Medline and Embase. Additional relevant publications were retrieved based on review of reference lists of included papers and through discussions with leaders in the field. We included studies if 1) the population included children and adolescents aged 0-20 years, 2) the article was written in English, 3) full text was available, and 4) incidence rates were reported or could be calculated based on the data provided in the manuscript. Studies focusing on a specific group of children (e.g. children with a malignancy) or neonates only were excluded. Studies merely reporting PE incidence data were excluded.

Embase: 1427 references retrieved

('venous thromboembolism'/mj/exp OR 'vein thrombosis'/mj/exp OR 'leg thrombosis'/mj OR (((venous OR vein OR lung OR pulmonary OR sinus OR cerebrosinial OR sinoven* OR portal* OR leg OR am OR legs OR arms OR extremit* OR limb*) NEAR/3 (thromboembol* OR thrombos* OR thrombus* OR thrombi OR embol*)):ti) AND ('juvenile'/exp OR 'pediatrics'/exp OR (pediatric* OR paediatric* OR child* OR infan* OR adolescen*):Ab,ti) AND ('incidence'/de OR 'epidemiological data'/de OR 'epidemiology'/de OR 'venous thromboembolism'/exp/dm_ep OR 'vein thrombosis'/exp/dm_ep OR (incidence* OR epidemiolog* OR (occurrence* NEAR/3 (rates OR rate))):Ab,ti) NOT ([animals]/lim NOT [humans]/lim) NOT [conference abstract]/lim AND ([english]/lim OR [dutch]/lim)

Medline ALL Ovid: 989 references retrieved

(*Venous Thromboembolism/ OR *Venous Thrombosis/ OR (((venous OR vein OR lung OR pulmonary OR sinus OR cerebrosinial OR sinoven* OR portal* OR leg OR am OR legs OR arms OR extremit* OR limb*) ADJ3 (thromboembol* OR thrombos* OR thrombus* OR thrombi OR embol*)):ti.) AND (exp infant/ OR exp child/ OR adolescent/ OR pediatrics/ OR (pediatric* OR paediatric* OR child* OR infan* OR adolescen*).ab,ti.) AND (Incidence/ OR Epidemiology/ OR *Venous Thromboembolism/ep OR *Venous Thrombosis/ep OR (incidence* OR epidemiolog* OR (occurrence* ADJ3 (rates OR rate))).ab,ti.) NOT (exp animals/ NOT humans/) AND (english.la. OR dutch.la.)

References

1. de Onis M, Onyango AW, Borghi E, Siyam A, Nishida C, Siekmann J. Development of a WHO growth reference for school-aged children and adolescents. Bull World Health Organ. 2007;85(9):660-7.
2. Turner D, Griffiths AM, Walters TD, Seah T, Markowitz J, Pfeifferkorn M, et al. Mathematical weighting of the pediatric Crohn's disease activity index (PCDAI) and comparison with its other short versions. Inflamm Bowel Dis. 2012;18(1):55-62.
3. Turner D, Otley AR, Mack D, Hyams J, de Bruijne J, Uusoue K, et al. Development, validation, and evaluation of a pediatric ulcerative colitis activity index: a prospective multicenter study. Gastroenterology. 2007;133(2):423-32.
4. Mitchell LG, Male C. Outcome measures in interventional trials for prevention or treatment of venous thrombosis in the pediatric population. Semin Thromb Hemost. 2011;37(7):840-7.

Supplemental Table 1. Adult and paediatric IBD guideline recommendations regarding VTE prophylaxis

Guideline and/or consensus statements	Recommendations
<p>Lichtenstein, American Journal of Gastroenterology, 2018 ACG Guideline for adult CD patients</p>	<p>No recommendations</p>
<p>Rubin, American Journal of Gastroenterology, 2019 ACG Guideline for adult UC patients</p>	<p>VTE prophylaxis with LMWH for hospitalized patients with acute severe colitis</p>
<p>Lamb, Gut, 2019 BSG Guideline for IBD patients</p>	<p>VTE prophylaxis with LMWH for hospitalized patients with acute severe colitis</p>
<p>Harbord, JCC, 2016 ECCO Guideline for extra-intestinal manifestations in adult IBD patients</p>	<p>VTE prophylaxis is recommended for all hospitalized IBD patients and should be considered following discharge from hospital and after recent surgery, and in outpatients with active disease</p>
<p>Van Rheenen, JCC, 2020 ESPGHAN/ECCO Guideline for pediatric CD patients (update)</p>	<p>No recommendations</p>
<p>Turner, JPGN, 2018 ESPGHAN/ECCO Guideline for pediatric UC patients (part 1) – ambulatory care</p>	<p>No recommendations</p>
<p>Turner, JPGN, 2018 ESPGHAN/ECCO Guideline for pediatric UC patients (part 2) – Acute Severe Colitis</p>	<p>VTE prophylaxis with LMWH for pediatric patients with acute severe colitis when 1 or more risk factors are present.</p> <p>Risk factors include: smoking, oral contraceptives, complete immobilization, CVCs (including PICC line), obesity, concurrent significant infection, known thrombotic disorder, previous VTE and family history of VTE.</p>
<p>Nguyen, Gastroenterology, 2014 CAG Consensus statements for VTE prevention in IBD patients</p>	<p>1) VTE prophylaxis with LMWH, low-dose UH or fondaparinux for all hospitalized adult IBD patients. 2) No VTE prophylaxis for children with IBD-related hospitalization without a previous VTE</p>

Supplemental Table 1. Overview of international adult and paediatric inflammatory bowel disease guidelines and the reported recommendations regarding thromboembolic prophylaxis. ACG, American College of Gastroenterology; BSG, British Society of Gastroenterology; CAG, Canadian Association of Gastroenterology; JCC,

Journal of Crohn's and Colitis; JPGN, Journal of Paediatric Gastroenterology and Nutrition; CD, Crohn's disease; CVC, central venous catheter; ECCO, European Crohn's and Colitis Organisation; ESPGHAN, European Society for Paediatric Gastroenterology Hepatology and Nutrition; IBD, inflammatory bowel disease; LMWH, low molecular weight heparin; PICC, peripherally inserted central catheter; UC, ulcerative colitis; UH, unfractionated heparin; VTE, venous thromboembolism.

Supplemental Table 2. List of rare and severe complications

List of rare but severe complications	
1	Death
2	Cancer
3	Severe neurological disease
4	Renal failure
5	Venous thromboembolism
6	Liver failure
7	Severe sepsis
8	Opportunistic infection
9	Bone marrow failure
10	Haemophagocytic lymphohistiocytosis
11	Other rare AND serious event related to IBD

Supplemental Table 2. List of complications that are monthly being registered in the PIBD-SETQuality Safety Registry.

Supplemental Table 3. Participating centers in Safety Registry

Country	Center
Albania, 1 center	University Hospital Center “Mother Teresa”, Tirana
Austria, 4 centers	Medical University of Graz, Graz Monash Children’s Hospital, Melbourne Department of Paediatrics, St John of God Hospital, Perth Queensland Children's Hospital, South Brisbane
Belgium, 3 centers	Ghent University Hospital, Ghent University Hospital Leuven, Leuven University Hospital Brussels, Brussels
Canada, 6 centers	Stollery Children's Hospital, Alberta Hospital for Sick Children (SickKids), Toronto British Columbia Children's Hospital, Vancouver Children's Hospital of Eastern Ontario, Ottawa IWK Health Centre, Halifax Alberta Children's Hospital, Alberta
Switzerland, 5 centers	University Children's Hospital Zürich, Zürich Clinique La Colline & Clinique des Grangettes, Geneva Kantonsspital Winterthur, Winterthur University Children's Hospital Basel, Basel University Children's Hospital Bern, Bern
Czech Republic, 1 center	Charles University Hospital, Prague
Germany, 7 centers	University Medical Centre Ulm, Ulm University Hospital of Giessen and Marburg, Marburg Klinikum Links der Weser, Bremen Universitätsklinikum Düsseldorf, Düsseldorf LMU Klinikum, Munich

	Darmstädter Kinderkliniken Prinzessin Margaret, Darmstadt GFO-Kliniken St Marien, Bonn
Spain, 3 centers	Hospital Germans Trias i Pujó, Barcelona Hospital Sant Joan de Déu, Barcelona Hospital Regional Universitario de Málaga, Málaga
Finland, 2 centers	Tampere University Hospital, Tampere Helsinki University Children's Hospital, Helsinki
France, 4 centers	Centre Hospitalier Universitaire d'Amiens Picardi, Amiens Centre Hospitalier Universitaire Descartes, Necker–Enfants Malades, Paris Centre Hospitalier Universitaire de Rouen Charles Nicolle, Rouen Centre Hospitalier Universitaire de Caen Normandie, Caen
Greece, 2 centers	Evangelismos Hospital, Athens "Aghia Sofia" General Children's Hospital, Athens
Croatia, 2 centers	University Hospital Centre Zagreb, Zagreb Children's Hospital Zagreb, Zagreb
Ireland, 2 centers	Children's Health Ireland (CHI) at Crumlin, Dublin St. Vincent's University Hospital, Dublin
Israel, 7 centers	Wolfson Medical Center, Holon Schneider Children's Medical Center of Israel, Petach Tikva Shaare Zedek Medical Center, Jerusalem Meir Medical Center, Kfar Saba Soroka University Medical Center, Beersheba Rambam Medical Center, Ruth Rappaport Children's Hospital, Haifa Sheba Medical Center, Tel Aviv
Italy, 10 centers	University of Naples Federico II, Naples Padua University Hospital, Padua Ospedale San Gerardo di Monza, Monza Sapienza University Hospital, Rome Giannina Gaslini Institute, Genoa Bambino Gesù Children's Hospital, Rome

	<p>Ospedale Maggiore "Carlo Alberto Pizzardi", Bologna</p> <p>Azienda Ospedaliera Universitaria Ospedali Riuniti di Foggia, Foggia</p> <p>Vittore Buzzi Children's Hospital, Milan</p> <p>University Hospital of Messina "G. Martino", Messina</p>
Japan, 1 center	National Center for Child Health and Development, Tokyo
Korea, 1 center	Kyungpook National University Children's Hospital, Daegu
Lithuania, 1 center	Vilnius University Children's Hospital, Vilnius
Luxembourg, 1 center	Les Hôpitaux Robert Schuman, Luxembourg
Malaysia, 2 centers	<p>University of Malaya Medical Centre, Kuala Lumpur</p> <p>Pantai Hospital Kuala Lumpur, Kuala Lumpur</p>
The Netherlands, 20 centers	<p>Amsterdam University Medical Center – center AMC, Amsterdam</p> <p>Gelre Ziekenhuis, Apeldoorn</p> <p>Ziekenhuis Gelderse Valleij, Ede</p> <p>Leiden University Medical Center, Leiden</p> <p>Jeroen Bosch Hospital, Den Bosch</p> <p>Medisch Centrum Alkmaar, Alkmaar</p> <p>St. Antonius Ziekenhuis, Nieuwegein</p> <p>Maastad Ziekenhuis, Rotterdam</p> <p>Rijnstate Ziekenhuis, Arnhem</p> <p>Isala Ziekenhuis, Zwolle</p> <p>Amphia Ziekenhuis, Breda</p> <p>Erasmus Medical Center - Sophia Children's Hospital, Rotterdam</p> <p>Catharina Ziekenhuis, Eindhoven</p> <p>Sint Franciscus Gasthuis & Vlietland, Rotterdam</p> <p>Amsterdam University Medical Center – center VUmc</p>

	<p>Medical Spectrum Twente, Enschede</p> <p>University Medical Center Utrecht - Wilhelmina Children's Hospital, Utrecht</p> <p>Maxima Medisch Centrum, Veldhoven</p> <p>Maastricht University Medical Center (MUMC), Maastricht</p> <p>University Medical Center Groningen (UMCG), Groningen</p>
Poland, 1 center	Children's Memorial Health Institute, Warsaw
Portugal, 1 center	Centro Hospitalar de São João, Porto
Romania, 1 center	Iuliu Hatieganu University of Medicine and Pharmacy, Cluj-Napoca
Serbia, 1 center	University Children's Hospital, Belgrade
Sweden, 2 centers	<p>Karolinska University Hospital, Stockholm</p> <p>Sachs Children and Youth Hospital, Stockholm</p>
Slovenia, 2 centers	<p>University Medical Centre Maribor, Maribor</p> <p>Ljubljana University Medical Centre, Ljubljana</p>
United Arab Emirates, 1 center	Al Jalila Children's Speciality Hospital, Dubai
United Kingdom, 27 centers	<p>Bedfordshire Hospitals, Bedford</p> <p>Royal Stoke University Hospital, Stoke-on-Trent</p> <p>Bristol Royal Hospital for Children, Bristol</p> <p>Brighton and Sussex University Hospitals, Brighton</p> <p>King's College Hospital, London</p> <p>Royal Hospital for Children Glasgow, Glasgow</p> <p>Great Ormond Street Hospital, London</p> <p>Addenbrooke's Hospital, Cambridge</p> <p>Royal London Hospital, London</p> <p>Royal Berkshire Hospital, Reading</p>

	<p>Royal Surrey County Hospital, Guildford</p> <p>Southampton Children's Hospital, Southampton</p> <p>Royal Devon and Exeter Hospital, Exeter</p> <p>Jenny Lind Children's Hospital, Norwich</p> <p>Morrison Hospital, Swansea</p> <p>Alder Hey Children's Hospital, Liverpool</p> <p>Royal Hospital for Sick Children, Edinburgh</p> <p>Gwent Healthcare, Newport, Wales</p> <p>Sheffield Children's Hospital, Sheffield</p> <p>Birmingham Women's and Children's Hospital, Birmingham</p> <p>Hull Royal Infirmary, Hull</p> <p>Leicester Children's Hospital, Leicester</p> <p>St George's University Hospital, London</p> <p>Nottingham Children's Hospital, Nottingham</p> <p>Royal Alexandra Children's Hospital, Brighton</p> <p>University College Hospital, London</p> <p>Maidstone and Tunbridge Wells Hospital, Maidstone</p>
United States, 8 centers	<p>University of Iowa Stead Family Children's Hospital, Iowa City (Iowa)</p> <p>GI Associates & Endoscopy Center, Jackson (Mississippi)</p> <p>Children's Hospital of Michigan, Detroit (Michigan)</p> <p>Novant Health Medical Center, Charlotte (North Carolina)</p> <p>Texas Children's Hospital, Houston (Texas)</p> <p>Seattle Children's Hospital, Seattle (Washington)</p> <p>Morristown Medical Center - Goryeb Children's Hospital, Morristown (New Jersey)</p> <p>C.S. Mott's Children's Hospital, Ann Arbor (Michigan)</p>

Supplemental Table 3. List of all 129 centers from 30 different countries participating in the PIBD-SETQuality Safety Registry and their paediatric IBD population, covering a total population of 24,802 patients.

Supplemental Table 4. Population-based cohort studies reporting incidence data of venous thromboembolism in children

Study	Country, Period	Study Design	Included types of VTEs	Total number of cases	Age	Reported or calculated incidence of VTE events in children /10.000/year	Study specific comments
Andrew et al.* Blood 1994	Canada, 1990-1992	Prospective registry in 15 tertiary care pediatric centers.	DVT, PE (no CSVT, PVT, RVT or other non-extremity VTE)	137 DVT + PE	1m-18y	0.07	This study reported an incidence of 5.3/10.000 hospital admissions.
Cheuck et al. Br J Surg 2004	Hong Kong, 2000-2001	Retrospective review Hong Kong CDARS using ICD-9-CM codes	DVT, PE	Unknown	5-14y	0.08 DVT 0.01 PE	This study did not report number of events, sample size or patient years.
Delluc et al.* Thromb Haemost 2016	France, 2013-2014	Prospective registry in Western France	Lower extremity DVT, PE (excluded other VTE types)	3 VTE	0-19y	0.32	Incidence calculated based on data provided in paper.
Heit et al. Mayo Clin Proc 2001	Minnesota (USA), 1980-1990	Retrospective review of medical records	DVT, PE	7 VTE	1-19y	0.1 male 0.4 female	This study only reported incidences for males/females separately. Did not report sample size.
Hong et al. PLoS ONE 2018	Korea, 2009-2013	Retrospective review of Korean HIRA databases	Lower extremity DVT, PE (excluded other VTE types)	Unknown	0-19y	0.035 (0-9y) 0.078 (10-19y)	This study reported incidence numbers for two age categories, but did not report number of events or sample size.
Kevane et al. BMJ open 2019	Ireland, 2016-2017	Retrospective review HIPE records (hospital discharges using ICD-10-CM codes)	VTE	4 VTE	0-17y	0.00	This study reported incidence and number of events. Not able to calculate sample size with provided data.
Lee et al.* Hong Kong Med J 2003	Hong Kong, 1995-2000	Retrospective review of hospital discharge records	DVT, PE, CSVT	8 VTE	1y-14y	0.074	Incidence calculated based on data provided in paper.

Molina et al.* Ann Acad Med Singapore 2009	Singapore, 2006	Retrospective review of ODS database based on hospital discharges	VTE	3 VTE	0-14y	0.101	Incidence calculated based on data provided in paper.
Park et al.* Korean Med Sci 2019	Korea, 2008-2016	Retrospective Korean Health Insurance Review and Assessment Service database	DVT, PE, CSVT, phlebitis and thrombophlebitis, RVT, PVT, thrombosis of vena cava	9,085 VTE	0-20y 0-1y 1y-5y 6y-10y 11y-15y 16y-20y	0.69 2.02 0.20 0.23 0.52 1.55	This study included patients aged 0-30y. Incidence was calculated for age group 0-20y based on data provided in paper.
Sabapathy et al.* J Pediatr 2016	Quebec (Canada), 1994-2004	Retrospective MED-ECHO & RAMQ database (hospital discharges using ICD-9-CM codes)	DVT, PE, CSVT, RVT	487 VTE 319 DVT 80 PE	1y-17y 1y-5y 6y-10y 11y-14y 15y-17y	0.29 0.04 0.03 0.06 0.16	Some patients had combination of VTEs.
Stein et al.* J Pediatr 2004	United States, 1979-2001	Retrospective NHDS database (hospital discharges using ICD-9-CM codes)	DVT, PE	64,000 DVT 13,000 PE	0-17y 0-1y 2y-14y 15y-17y	0.49 1.05 0.24 1.14	
Tuckuviene et al.* J Pediatr 2011	Denmark, 1994-2006	Retrospective; Danish National Patient Registry (ICD-10 code for VTE and/or arterial TE)	PE, DVT	331 VTE	0-18y 1-4y 5y-9y 10y-14y 15y-18y	0.21 0.38 0.020 0.019 0.050 0.85	A separate study was published by this author reporting the number of CSVT in the same study population.
Van Ommen et al.* J Pediatr 2001	The Netherlands, 1997-1999	Prospective registry of the Dutch Paediatric Surveillance Unit in primary, secondary and tertiary centers	VTE	99 VTE	0-18y 28d-1y 1y-4y 5y-9y 10y-14y 15y-18y	0.14 0.25 0.08 0.1 0.18 0.05	

Wändell et al.* J Thrombolysis 2019	Stockholm (Sweden), 2011-2018	Retrospective review using health data register (using ICD-10 codes)	VTE	233 VTE	0-18y	0.56	Incidence calculated based on data provided in paper.
CSVt only							
DeVeber et al. New Engl J Med 2001	Canada, 1992 - 1997	Registry based on ICD-9 coding	CSVt	160	0-18y	0.067	This study included neonates, but did not report raw data that could be separately analysed.
Grunt et al. Dev Med Child Neurol 2010	Switzerland, 2000-2008	Prospective registry	CSVt	65	0-16y	0.056	This study included neonates, but did not report raw data that could be separately analysed.
Kristofferson et al. Stroke 2020	Oslo (Norway), 2011 – 2017	Retrospective cross-sectional hospital population-based study	CSVt	9	0-18y	0.11	
Lee et al. Hong Kong Med J 2003	Hong Kong, 1995-2000	Retrospective review of hospital discharge records	CSVt	3	1-14y	0.03	
Sabapathy et al. J Pediatr 2016	Quebec (Canada), 1994-2004	Retrospective MED-ECHO & RAMQ database (hospital discharges using ICD-9-CM codes)	CSVt	32	1-17y	0.02	
Tuckuviene et al. Acta Paediatr Int J Paediatr 2011	Denmark, 1994-2006	Retrospective; Danish National Patient Registry (ICD-10 code for VTE and/or arterial TE)	CSVt	40	1-18y	0.03	

Supplemental Table 4. Overview of population-based cohort studies providing incidence data on venous thromboembolisms and cerebral sinus venous thrombosis in the general paediatric population. Studies that included children and young adults up to the age of 20 years old were included. DVT: deep venous thrombosis; PE: pulmonary embolism; VTE: venous thromboembolism; PVT: portal vein thrombosis; RVT: renal vein thrombosis; CSVT: cerebral sinus venous thrombosis. *These studies were included in the quantitative analysis (meta-analysis) of the VTE incidence in the general paediatric population.

Supplemental Table 5. IBD related characteristics at time of VTE diagnosis per patient

Case	VTE Type	IBD disease duration until VTE, m	Disease location	IBD in remission during VTE	PGA	Fcal (µg/g)	ESR (mm/hour)	CRP (mg/L)	Hb (mmol/L)	Platelet count (*10 ⁹ /L)	IBD treatment at time of VTE
ULCERATIVE COLITIS (n=11, 55%)											
13	Lower extremity DVT	33,5	E4	No	Severe	N/A	19	50	6.3	690	5-ASA, CS
14	IVC + lower extremity DVT	14,7	E4	Unknown	N/A	980	N/A	N/A	N/A	N/A	5-ASA
1	CSVT	0,2	E4	No	Moderate	5268	14	N/A	4.0	392	None
2	CSVT	0,1	E4	No	Severe	6000	N/A	187	5.5	667	None
6	CSVT	2,4	E4	No	Severe	1000	17	109	5.7	109	5-ASA, AZA, cyclosporine, IFX, MTX
10	CSVT	10,3	E4	No	Severe	N/A	N/A	N/A	N/A	N/A	Antibiotics, CS
18	Pulmonary embolus	48,1	E4	No	Severe	N/A	120	17	6.7	362	5-ASA
19	Pulmonary embolus + IVC	8,8	E4	No	Severe	N/A	N/A	12	N/A	253	5-ASA, ADA, CS
16	Lower extremity DVT	6,3	E4	No	Mild	5487	19	4	7.4	480	None
20	Lower extremity DVT	7,9	E4	No	Moderate	N/A	34	29	4.6	260	None
8	CSVT	0,3	E4	No	Moderate	2100	27	2	7.2	703	5-ASA, CS
IBD-unclassified (n=3, 15%)											
17	Upper extremity DVT	127,7	E4	Yes	None	194	57	27	6.0	548	5-ASA
4	CSVT	20,5	E4	No	Moderate	N/A	47	84	5.5	683	5-ASA, AZA, IFX
21	Other - right cardiac ventricle	20,5	E4	No	Severe	1174	19	23	5.0	292	6MP, CS, IFX
CROHN'S DISEASE (n=6, 30%)											
12	Lower extremity DVT	0,5	L3+L4	No	Moderate	2100	55	60	6.5	455	None
3	CSVT	11,7	L2	No	Mild	N/A	N/A	N/A	N/A	N/A	AZA, CS
5	CSVT	2,8	L3	Yes	None	6000	N/A	2	4.9	460	AZA, CS
7	CSVT	79,6	L3	No	Moderate	N/A	N/A	N/A	N/A	N/A	5-ASA, AZA, CS
9	CSVT + lower extremity DVT	0,2	L2	No	Severe	N/A	3	16	4.4	196	None
15	Lower extremity DVT	0,1	L3+L4	No	Moderate	N/A	82	2	6.8	470	CS

Supplemental Table 5. Individual IBD related characteristics at time of VTE diagnosis. VTE: venous thromboembolism; IBD: inflammatory bowel disease; PGA: physician's global assessment; Fcal: faecal calprotectin level; ESR: erythrocyte sedimentation rate; CRP: C-reactive protein; Hb: haemoglobin; DVT: deep venous thrombosis; SVC: superior vena cava; IVC: inferior vena cava; CSVT: cerebral sinus venous thrombosis; N/A: not available; 5-ASA: 5-aminosalicylate acid; CS: corticosteroid; AZA: azathioprine; ADA: adalimumab, 6MP: 6-mercaptopurine; IFX: infliximab; MTX: methotrexate.

Supplemental Table 6. VTE treatment and outcome

Case	VTE location	Anti-thrombotic therapy	Treatment duration, m	Anti-thrombotic therapy complication	>1 TE (recurrent /concurrent)	VTE recovery status	Consequences / disabilities
Intracranial, n=10							
1	<i>Multiple venous sinuses and left internal jugular vein</i>	LMWH, vit K-A	6	No	No	Fully recovered	Venous infarction with secondary haemorrhage Venous infarction with secondary haemorrhage, craniotomy, neurological impairment Venous infarction with secondary haemorrhage
2	<i>Superior sagittal sinus</i>	LMWH	6	No	No	Fully recovered	
3	<i>Multiple venous sinuses</i>	Enoxaparin, heparin	>6	No	Yes, recurrent	Partially recovered	
4	<i>Multiple venous sinuses and proximal internal jugular vein</i>	LMWH	3	No	No	Fully recovered	
5	<i>Multiple venous sinuses</i>	LMWH	6	No	No	Fully recovered	
6	<i>Multiple venous sinuses</i>	-	-	-	-	Fully recovered	
7	<i>Dural venous sinus, unspecified</i>	-	-	-	-	Death	
8	<i>Multiple venous sinuses</i>	Heparin, LMWH, vit K-A	6	Yes, non-major ^x	No	Fully recovered	
9	<i>Superior sagittal sinus and right femoral vein</i>	LMWH	3	No	Yes, concurrent	Fully recovered	
10	<i>Posterior sagittal sinus</i>	LMWH	-	No	No	Death	
Lower extremity, n=8[‡]							
11	<i>Proximal medial gastrocnemius veins</i>	LMWH	6	No	No	Fully recovered	Post thrombotic syndrome (persisting leg swelling). Lost to follow-up 2 months after VTE. Persisting mild right hemiparesis, gait asymmetry and mild cognitive impairments due to arterial TE.
12	<i>Common femoral vein to popliteal vein</i>	LMWH	3	No	No	Partially recovered	
13	<i>Lower IVC, common iliac, femoral, superficial femoral vein</i>	LMWH	6	Yes, minor [#]	No	Fully recovered	
14	<i>Femoral and popliteal vein*</i>	Heparin, LMWH	3 days, 1	No	Yes*, arterial, concurrent	Fully recovered*	
15	<i>Left posterior tibial vein</i>	LMWH, vitKA	3, 12	No	No	Fully recovered	

Upper extremity, n=1							
16	<i>Right basilic vein</i>	LMWH	3	No	No	Fully recovered	
Pulmonary, n=3							
17	<i>Subsegmental pulmonary embolus left lower lobe</i>	LMWH	3	No		Fully recovered	
18	<i>Proximal left pulmonary vein and IVC</i>	LMWH, vit K-A	3, ?	Yes, minor [#]	Yes, concurrent [¥]	Fully recovered	
19	<i>(Sub)segmental bilateral lower lobe, left posterior tibial, peroneal and popliteal veins</i>	Heparin, DOAC	1,5 day, >6	Yes, minor [°]	Yes, both [‡]	Fully recovered	
Other, n=1							
20	<i>Right cardiac chamber</i>	LMWH	3	No	No	Fully recovered	

Supplemental Table 6. VTE treatment and outcome. [‡]Three patients had a lower extremity DVT occurring together with another VTE type. ^{*}This patient was diagnosed with an arterial thrombosis in the middle cerebral artery branches at the time of VTE diagnosis. [¥] PE and concurrent thromboembolism in the IVC, diagnosed following an incidental finding on abdominal CT-scan. [°]Clinically overt gastrointestinal bleeding with a decrease in haemoglobin of at least 20 g/L in a 48-hour period, requiring modulation of antithrombotic therapy and transfusion of blood products. [#]Worsening of rectal bleeding, continuation of antithrombotic despite the complication. [°]Severe rectal bleeding requiring several blood transfusions in a patient with a concurrent *C. difficile* infection. [‡]DVT and concurrent PE (incidental finding on CPTA). Patient suffered from two episodes of recurrent DVT in left popliteal veins, both with complete resolution. VTE: venous thromboembolism; IBD: inflammatory bowel disease; IVC: inferior vena cava; CD: Crohn's disease; UC: ulcerative colitis; IBD-U; IBD-unclassified; LMWH: low molecular weight heparin; vit K-A: vitamin K antagonist; N/A: not available

Supplemental Table 7. The PIBD-VTE group

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Supplemental Table 7. Names and affiliations of all co-authors forming the PIBD-VTE group.