

Table S1: Baseline characteristics of participants in patient journey mapping

Informant	Age	Gender	Living status	Employment status	Co-morbidities or prior VTE
Informant 1	47	Male	Not alone	Employed	Diabetes
Informant 2	45	Female	Not alone	Employed	DVT
Informant 3	58	Male	Alone	Disability pensioner	Prior DVT associated with substance use disorder
Informant 4	74	Female	Not alone	Retired	IBD
Informant 5	59	Male	Not alone	Employed	Osteoarthritis
Informant 6	55	Male	Alone	Unemployed	None
Informant 7	55	Male	Not alone	On sick leave	Diabetes, peripheral artery disease
Informant 8	75	Male	Not alone	Retired	Hypertension
Informant 9	78	Female	Alone	Retired	Hip fracture
Informant 10	76	Female	Alone	Retired	COPD

Abbreviations: DVT, deep vein thrombosis; VTE, venous thromboembolism; IBD, inflammatory bowel disease; PAD, peripheral artery disease; COPD, chronic obstructive pulmonary disease.

Table S2: Themes identified in data analysis

Research question	Themes
Which opportunities for patient engagement were offered and how?	Inclusive opportunities Recruitment and combination of patient representatives Ways to be involved Patient representatives' motivation to contribute Barriers to contribute
What described the process of working together both formally and informally?	Working together Relationship and group dynamics Tensions in working together
What was the support offered to the patient representatives and what was their learning opportunities?	Support and learning Prior experience with PPI Preparation of patient representatives Aligning expectation
Were the patient representatives' voices heard, valued, and respected in the research project?	Governance Valuing the voices of patient representatives Extern support and organization of the project
How was communication perceived by patient representatives involved?	Communication Layman language vs. clinical language Personal experience vs. professional experience Online meetings vs. physical meetings
What significance was attributed to patient engagement by patients, HCP and researchers?	Impact Improved research Value of patient engagement