Thrombosis Update 18 (2025) 100196

Contents lists available at ScienceDirect

Thrombosis Update

journal homepage: www.sciencedirect.com/journal/thrombosis-update

Involving patients and the public in cancer associated thrombosis research: A strategy for success

Michelle Edwards [a], Kathy Seddon [a], Elin Baddeley [a], Anne Gulbech Ording [b], Mark Pearson [c], Isabelle Mahe [d], Simon Mooijaart [e], Frederikus A. Klok [e], Simon I.R. Noble [a,*], on behalf of the SERENITY consortium

[a] Division of Population Medicine, Marie Curie Palliative Care Research Centre, Cardiff University, Cardiff, Wales, United Kingdom
[b] Danish Center for Health Services Research, Department of Clinical Medicine, Aalborg University, Aalborg University Hospital, Denmark
[c] Wolfson Palliative Care Research Centre, Hull York Medical School, University of Hull, Hull, United Kingdom
[d] Université Paris Cité, Hôpital Louis Mourier, APHP, Service de Médecine Interne, Inserm UMR_S1140, Department of Innovative Therapies in Hemostasis Paris, France
[e] Department of Medicine - Thrombosis and Hemostasis, Leiden University Medical Center, Leiden, the Netherlands

ARTICLE INFO

Handling Editor: Dr Lucy Norris

Keywords:
Public involvement
Research partners
Public engagement
PIRIT tool
Cancer associated thrombosis
Patient centred care
SERENITY

ABSTRACT

The role of public involvement (PI) in biomedical research has never been greater, with accumulating evidence demonstrating its ability to improve the quality of research and the likelihood of translating findings into clinical practice. As the demand for meaningful PI in research continues to grow, research teams are required to provide more than a tokenistic acknowledgement of the role of public contributors to the success of a project.

This paper presents an overview of PI as a whole and specifically reflects on how it has added value, to an international cancer associated thrombosis research program. It introduces tools designed to guide teams unfamiliar with PI, introducing the Public Involvement in Research Impact Toolkit (PIRIT) which provides a structure for planning and reporting on PI activities from the study inception through conduct, to its impact.

1. Background

Public Involvement (PI) has been gaining international recognition as an essential component of conducting high quality biomedical research [1]. However, the extent to which researchers integrate PI into their work remains variable, with some reducing it to a mere "box ticking exercise", where public contributions risk being tokenistic [2,3]. Within the field of cancer associated thrombosis (CAT) research, a greater understanding of the lived experience of patients and carers has enriched our understanding of the condition and how we should treat it [4–10]. Such lived experiences are vital to inform the design, delivery and implementation of CAT research, especially when public contributors are engaged as genuine partners in the process.

This paper outlines the key components of functional PI, drawing on key policy documents that shape the PI programme in the United Kingdom (UK). It also explores the various opportunities for integrating PI in CAT research culminating in an overview of a pan European project currently running across fourteen academic institutions within eight countries.

2. Defining PI

Poor engagement with PI is usually driven by an incomplete understanding of what PI involves and how it can measurably improve research outcomes. Without a clear definition of PI, it is impossible to accurately evaluate its activities and contributions to a project. In addition, terms such as "Public Involvement" and "Public Engagement" are often confused, leading to sub-optimal practice. For clarity, this paper follows the definition of PI provided by the UK Health Research Authority:

> "research carried out 'with' or 'by' members of the public, rather than 'to', 'about' or 'for' them. It means that patients or other people with relevant experience contribute to how research is designed,

* Corresponding author. Marie Curie Palliative Care Research Centre 3rd Floor, Neuadd Meirionydd, Cardiff University, Heath Park Campus, CF14 4YS, Wales, United Kingdom.
E-mail address: NobleSI1@cardiff.ac.uk (S.I.R. Noble).

https://doi.org/10.1016/j.tru.2024.100196
Received 4 October 2024; Accepted 11 December 2024
Available online 13 December 2024

conducted and disseminated. It does not refer to research participants taking part in a research study." [11].

This is distinct from Public Engagement (PE) which the UK National Co-ordinating Centre for Public Engagement defines as:

"the myriad of ways in which the activity and benefits of higher education and research can be shared with the public. Engagement is by definition a two-way process, involving interaction and listening, with the goal of generating mutual benefit." [12].

Some even use PE as an overarching term for many activities in research, including PI. New definitions continue to emerge in the hope of addressing this confusion. Recently, terms such as Patient and Public Involvement and Engagement (PPIE) and Public Involvement and Engagement (PIE) have been coined although their impact and distinction is yet to be clarified.

3. Drivers for PI in research

The overarching reason to embrace PI is simple: it leads to better research. The UK Health Research Authority suggest those engaged in PI produce better and more effective research because.

- studies are designed to be of greater relevance to participants
- studies are more likely to be acceptable to participants
- study information is clearer and easier to understand
- participants have a better experience with the research
- study results are communicated more effectively to participants at the end of the study [11].

The planning and implementation of PI is a high priority to policy makers [13], funders [14,15], researchers and more recently by academic journals [16,17], and patient organisations. Grant funding organisations require researchers to develop strategies to ensure meaningful involvement of patients and the public in their research. In the UK, frameworks, guidelines, and training resources are available for researchers and the public, including resources to support the planning and reporting of PI [18,19].

4. Conducting research with public involvement

PI contributors should be actively involved in a research project from the inception to the dissemination of findings and also in developing a pathway to impact. PI can enhance various aspects of research, including prioritising research agendas and the commissioning of research, the way research is conducted, and the communication and translation of research findings into policy and practice [20]. They also make an important contribution to the cultural relevance of studies at research design phase by providing a broader understanding and also enhancing the cultural relevance of findings during data interpretation and reporting [21].

The likelihood of successfully integrating PI into research increases by following the four principles outlined by the UK Health Research Authority [11]. These are described below.

4.1. Principle 1: involve the right people

Ideally researchers should involve people with lived experience of the condition being studied. Sometimes this may not be possible, e.g. when the condition that is studied has a poor prognosis or affects the ability to communicate, and it may be more appropriate to involve carers or significant others who have relevant experience with the condition. Representation from patient groups is useful, especially when the public contributor can represent the perspectives of the wider patient body. Finally, it is essential that the contributor reflect the demographics most affected by the studied condition, considering factors such as gender, age, ethnicity, lifestyle choices or socioeconomic deprivation.

4.2. Principle 2: involve enough people

It is important to ensure adequate PI representation from those whom the research is of relevance to. A single contributor is unlikely to fully capture the views of the whole population. In our research centre, we involve at least two PI contributors for each study, ensuring that they come from diverse backgrounds and have various experiences. This approach ensures a comprehensive understanding of the needs and perspectives of the target populations.

4.3. Principle 3: involve those people enough

PI contributors should be involved in as many aspects and stages of the research project as possible. Ideally, they should be involved from the planning stage, before funding has been awarded. It will enhance the planning of the study and ensure its relevance to the patient population. They may also identify potential recruitment challenges, helping to mitigate such issues before they arise.

4.4. Principle 4: describe how it helps

Researchers are expected to inform funders and regulatory authorities on how PI has contributed to the study. This includes providing details on.

- The relevant experience the contributors brought to the project
- The specific activities they engaged in
- The benefits their involvement provided to the study
- The plans for sharing study findings with stakeholders

5. Reporting on PI

Reporting on the contribution of PI to a research project is most effective when conducted through a structured format which can outline where PI was successful and where its contribution was limited or could have been enhanced. A systematic review of frameworks designed to support, evaluate or report on PI in health-related research identified 65 published frameworks from 10 countries [22]. These comprise priority setting frameworks (prioritising topics for future research), study-focused frameworks (including PPI at all stages of the research process), report-focused frameworks (checklists for critically appraising a published study for the quality and comprehensiveness of PPI), and partnership-focused frameworks (partnerships between researchers, lay people or lay organisations). Most of these have been rarely used beyond the research groups that developed them, suggesting models for PI implementation are not always transferable between settings [22].

The UK Public Involvement Standards Development Partnership developed standards against which researchers could benchmark their activity (Fig. 1) [23]. However retrospective benchmarking PI activity against these has been largely subjective and with a growing opinion that PI involvement should be evaluated in real time to enable it to be proactively managed [24]. Recently, the Marie Curie Research Group and Wales Cancer Research Centre in Cardiff University have developed The Public Involvement in Research Impact Toolkit (PIRIT) for this purpose, which is available free online at https://www.cardiff.ac.uk/marie-curie-research-centre/patient-and-public-involvement/public-involvement-in-research-impact-toolkit-pirit [25]. PIRIT includes a Planning Tool and a Tracking tool to support researchers collaborating with public contributors, it uses the UK national standards and aims to.

- Proactively integrate PI into the research project
- Track the activity of PI public contributors and evaluate their influence on the research

- INCLUSIVE OPPORTUNITIES:
  - Offer public involvement opportunities that are accessible and that reach people and groups according to research needs.
- WORKING TOGETHER:
  - Work together in a way that values all contributions, and that builds and sustains mutually respectful and productive relationships.
- SUPPORT & LEARNING:
  - Offer and promote support and learning opportunities that build confidence and skills for public involvement in research.
- COMMUNICATIONS:
  - Use plain language for well-timed and relevant communications, as part of involvement plans and activities
- IMPACT:
  - Seek improvement by identifying and sharing the difference that public involvement makes to research
- GOVERNANCE:
  - Involve the public in research management, regulation, leadership and decision making

Fig. 1. United Kingdom Public Involvement Standards for research [23].

- Produce a report which benchmarks activities against the UK Standards for Public Involvement.

The PIRIT Planning Tool comprises a checklist of potential PI activities that may be available through the research pathway enabling teams to objectively assess whether and how they meet the relevant standards. The PIRIT Tracking Tool provides a spreadsheet to record when and how the public contributed to the research. Furthermore, it allows teams to document their intended activities, the impact of the PI involvement, the significance of this involvement, and how it relates to the standards.

6. PI in thrombosis research

Patient involvement and engagement is particularly pertinent in thrombosis research, due to the balance of competing risks and impacts to quality of life, and the different priorities and values expressed by healthcare professionals and patients [26]. Such issues highlight the complexity of the condition and need to understand the patient experience in order to meaningfully shape thrombosis research [27]. This was emphasised in a recent scoping review of qualitative studies in thrombosis research, which recommends PI in all stages of thrombosis research, to ensure it aligns with patients' needs. It also emphasises the significant value of patients' knowledge and experience of navigating the physical, psychological and emotional aspects of thrombosis [28]. The benefits of meaningful patient involvement in thrombosis research is well documented, with recommendations for future directions, including sharing experiences of patient involvement/engagement methods, and reporting on the impact of these efforts on patient outcomes [27]. Ironically, a recent stakeholder research priority setting exercise in venous thromboembolism did not initially involve patient partners [29,30]. However, this was quickly realised and addressed, leading to increased support for increasing patient involvement and engagement in thrombosis research, and the shaping of future research priorities [30–32].

Specific to CAT research, the UK standards were used to evaluate PI during the Hospice Inpatient Deep vein thrombosis Detection study (HIDDen). This multicentre, prospective, longitudinal, observational study aimed to explore the prevalence, symptom burden and natural history of VTE in patients with advanced cancer [24,33]. This study was conducted by one of the study public contributors, who had also been involved in the development of UK Standards. The evaluation concluded that all six standards were met, with the greatest opportunities in 'working together' and 'support and learning'. Meeting the 'governance' standard was less complete; while there was evidence of participation in decision making process, there was less involvement in management, regulation, and leadership. Following the publication of this paper, PI continued to shape the subsequent research project. With the support of the lead PI contributor, a round table discussion was organized with representation from all relevant UK professional and patient organisations. Through this forum, the data were presented and discussed, with particular emphasis on how the research would influence practice and identify any ongoing unanswered questions. The representatives from patient organisations provided valuable insights into which questions were important to them and this formed the basis of the follow up study HIDDen2 [34].

7. PI in the context of multinational research

The numerous benefits that international collaboration and recruitment in large clinical trials are widely recognised and supported by regulatory and governance frameworks. However, such studies bring additional challenges to the delivery of meaningful PI. When considering the four principles of effective PI, principle 1: "involve the right people", is particularly pertinent. Previous research has revealed that the experience, preferences and values of patients with CAT vary across different countries and healthcare systems [5–9,35]. Therefore, effective PI requires public contributors from as many participating countries as possible. This requirement adds potential challenges for countries where PI within research is in its infancy and lacks access to public contributors. Local investigators may not fully appreciate the value of PI, which can further restrict involvement. For the remainder of this paper, we will share our experience and reflections on implementing PI into a multinational mixed methods study: SERENITY.

The SERENITY study is a Horizon Europe and Innovate UK funded pan-European, mixed methods project to develop a Shared Decision

Making Support Tool (SDMST) to support decisions about the management of antithrombotic therapy (ATT) in cancer patients nearing the end of life [36]. The challenges of anticoagulation in the cancer setting are well recognised, particularly in those with progressive advanced disease [37,38]. Both the thrombotic and bleeding risks increase as the cancer progresses; pulmonary emboli are seen in 50 % of cancer patients at post mortem, with at least 28 % of hospice patients exhibiting radiological evidence of femoropopliteal DVT [33,39]. However, many of these cases were largely asymptomatic, leading to the current thinking that thromboembolism may be part of the agonal process [40]. Conversely, bleeding at the end of life is often distressing for patients carers and even healthcare professionals [4,41,42], including for bleeding which is classed as minor according to ISTH definitions [43]. The majority of advanced cancer patients receiving ATT continue this treatment until death, despite a clinically relevant bleeding rate of up to 11 % [44,45]. Discontinuing ATT can reduce bleeding events at the end of life while symptoms associated with recurrent venous or arterial thromboembolism can be managed with end of life medicines [46]. While stopping ATT as end of life approaches seems intuitively appropriate, the decision is more complex than merely comparing bleeding and thrombosis rates. Decisions should be made collaboratively with the patient within the context of their own experience of thrombosis and ATT, as well as their the their individual values, preferences, and goals of care [47–49].

SERENITY is a five-year programme of research conducted by an interdisciplinary consortium from 14 research institutions across 8 countries in the UK and Europe. Comprising of eight work packages (see Table 1 and Fig. 2) the research programme aims to develop, evaluate and implement a multi-national SDMST.

8. Patient and public involvement in the SERENITY study

To ensure meaningful PI across all work packages and represent all countries involved in the project, the SERENITY consortium established a PI task group to oversee activities throughout the project. With the range of methodologies used across all work packages, a strategic plan has been applied to enable collaborations between a team of PPI experts, work-package leads and research teams.

The PI team based at Cardiff University consists of a Professor of Supportive Medicine (SN), a PI lead researcher and WP lead for PI (ME), a lead public contributor (KS) and a research associate (EB). The lead public contributor has extensive experience in PI and has supported five studies specific to CAT. She was involved in developing the UK standards for PI as well and more recently the development of PIRIT. The main aim of the PI team is to support the SERENITY study research teams to engage with patient and public contributors to help ensure that the research is appropriately conducted, is of high quality, and to optimise impact by ensuring that the development and implementation of the SDMST in local health services is suitable for the needs of local populations [50]. In accordance with guidance from our main national research bodies – the National Institute for Health and Care Research (NIHR) and Health and Care Research Wales (HCRW) – we have prioritized inclusivity in our recruitment of public contributors [19,51]. Consequently we have enlisted a public contributor focused on quality, diversity and inclusion to help recruit from minority and hard to reach populations. The involvement of public contributors from different countries is crucial and a significant responsibility of the lead public contributor and the WP lead has been to support, reassure and guide teams who are new to the concept of PI.

9. Successful recruitment of public contributors

The approach described below illustrates how the PI team in Cardiff have engaged with contributors in SERENITY and this model of practice has been applied to each WP. Most public contributors in SERENITY will be people with personal experience of cancer and thrombosis or experience of caring for someone with these conditions. However a degree of flexibility is necessary to facilitate recruitment for each WP and may require the support of research funders, PI networks, patient organisations and local patient groups. Within Cardiff, organisations including Health and Care Research Wales, the Wales Cancer Research Centre and Marie Curie Voices have supported the recruitment of public contributors. Being mindful of Principle 1: “Involve the right people” and Principle 2: “Involve enough people”, we have also engaged with members of PI groups (e.g. primary care and epidemiology PI groups) within our research networks to discuss specific aspects of the study. We have also engaged with a patient involvement group at a Regional Cancer Centre and with Thrombosis UK a national thrombosis charity.

A similar model of engagement with groups from other European countries will ensure a diverse contribution across the WPs. Each WP is responsible to recruit public contributors through their established networks. The PI team will work with the research teams to advise on recruitment and ensure research participants are not overburdened. The

Table 1
SERENITY work packages (ATT: antithrombotic therapy, VTE: venous thromboembolism, ATE: arterial thromboembolism, SDMST: shared decision making support tool, WP: work package, RCT: randomised control trial.

Work package	Brief Description	Participating countries (lead country)
1a Realist Review	A realist synthesis of literature pertaining to clinical practice and factors influencing deprescribing of ATT.	Led by UK
1b Flash mob study	A survey of clinical practice completed by a large number of clinicians over a one week period and a discreet choice experiment to explore evidence of current practice	Led by Germany. All countries participated.
2 Epidemiology Study	Epidemiological study analysing patient database to explore adherence and persistence with ATT in terminally ill cancer patients and investigate risks of major and clinically relevant bleeding, VTE, and arterial ATE by ATT exposure.	The Netherlands, UK, Denmark (led by The Netherlands)
3 Qualitative study	Interviews with clinicians to understand their experiences of deprescribing antithrombotic medication and identify facilitators and barriers. Interviews with patients to understand their experiences of taking ATT and their perceptions about being involved in shared decisions about stopping or continuing ATT towards the end of life.	Denmark, UK, France, Spain (led by Denmark)
4 Delphi Consensus Study	Delphi process using data from WP1-3 to gain consensus on contents of SDMST and clinical outcomes for the RCT.	UK and EU countries (led by France)
5 Development and Testing of the SDMST	A team of web developers and shared decision making experts will design and develop the tool and user- test it with patients (and carers).	The Netherlands, UK (led by The Netherlands)
6 Randomised Control Trial	Cluster RCT comparing usual care with use of the SDMST in patients with advanced cancer receiving ATT.	Netherlands, Italy, France, UK. Led by Netherlands
7 Dissemination	Dissemination strategy to ensure results of each WP are made available to stakeholders including healthcare professionals, patients, carers policy makers and researchers. Creating pathway to impact wherever possible.	Led by Poland. All countries participating.

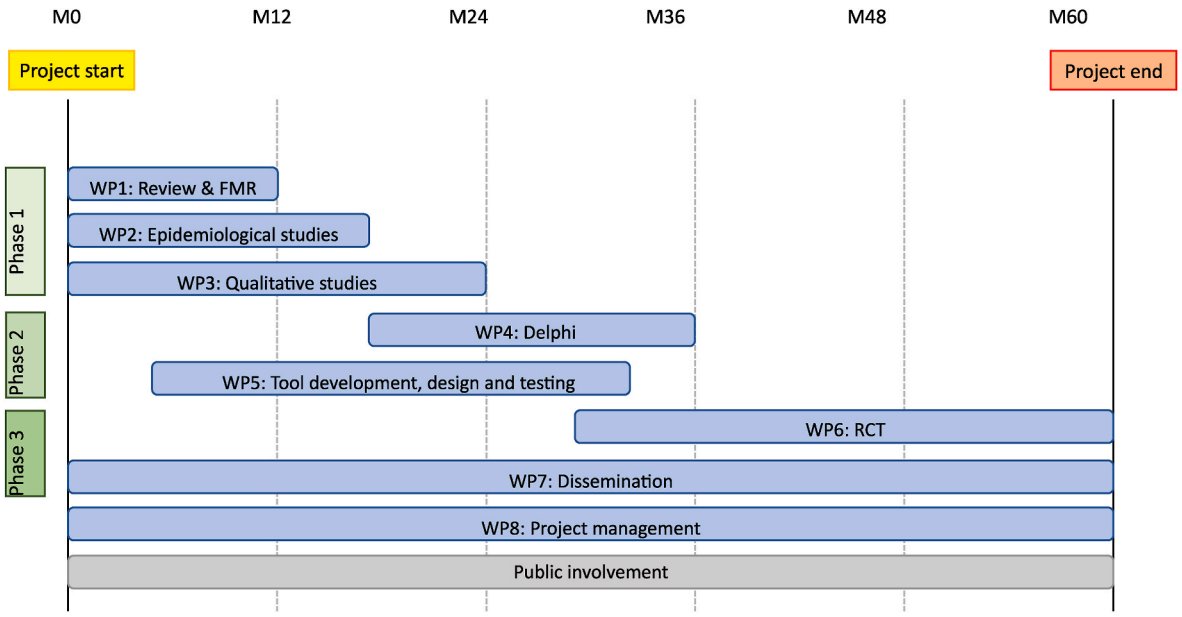

Fig. 2. Schematic of SERENITY research program outlining work packages. (M: month, WP: work package, FMR: flash mob research, RCT: randomised control trial).

complexity of the design of SEREINTY necessitates the involvement different sub-groups of public contributors with experience of involvement in specific research methods (e.g. developing Delphi surveys, engaging with epidemiological data) as well as those with lived experience of cancer or taking ATT.

10. Implementing the serenity PI strategy

The PI strategy is summarised in Fig. 3 and comprises two overarching categories: strategic-level (planning and evaluating PI in the study as a whole), and work package-level (with more detailed planning and evaluation of PI activities within each of the work packages). Although it is beyond the scope of this paper to discuss each component in depth, fundamental aspects of the strategy are discussed below.

- **Aligning strategy with research programme**

The PI activities, and those lead by the PI team, are accountable to the SERENITY Study Steering Group which consists of the two Chief investigators and work-package leads. The work package lead for PI and lead public contributor are key members of the consortium. PI is a recurring agenda item on monthly steering group meetings and quarterly meetings of the wider consortium. During the study steering group meetings, they report on the progress of PI and collaborate with work package leads to ensure PI is integrated throughout the study.

- **Exploratory work: understanding the team**

At the start of the study, a survey was distributed to all work package

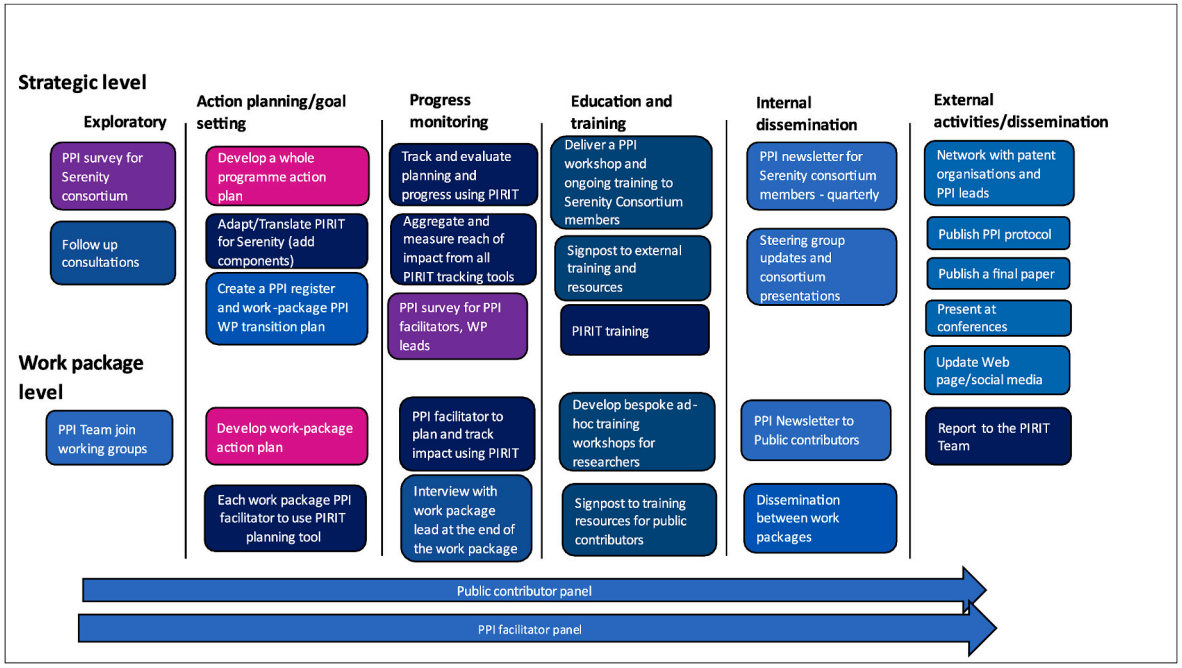

Fig. 3. Serenity public involvement strategy.

research teams exploring their experience of PI and to identify the resources available for PI recruitment, funding, training and support. This survey has helped distinguish those experienced with PI and those needing more focussed support and training. This process has been enhanced through ongoing dialogue with work package leads and local public contributors. This collaboration has allowed the PI team to understand the aims and objectives of each research activitiy, methodologies used, and explore the capacity of the research teams to incorporate PI contributors effectively.

- **Consistent documentation and reporting**

The PIRIT planning tool is being used to collate information and evaluate PI planning and execution. A register of PI contributors is also being collated from all work package teams to document details of the activities of their involvement in various activities. Wherever public contributors have capacity and interest, joining other work packages is encouraged particularly where their input can facilitate a smooth transition.

- ***PI training***

Training has been made available for all consortium members and public contributors. This initiative began with an initial online workshop, followed by tailored training designed to meet the needs and activities of each individual. This approach has ensured that all members have a clear understanding of public involvement with a shared vision of its application in the study, what impact it has on the design and delivery of the research, and how that can reflect on future care, delivery and patient experience outcomes.

- **Evaluating impact and Dissemination of the PI strategy**

In the UK, the PIRIT tool is becoming the cornerstone of PI planning and evaluation and this also applies for the SERENITY study. To assess the impact of PI activities on each work package and research group, a designated PI contact will complete the PIRIT tracking tool in collaboration with public contributors and with the researchers involved in their work package.

We will identify and describe the successes and challenges encountered in planning, implementing and tracking the impact of PI. From this analysis, we will make recommendations for future European PI policymakers, funders, researchers, public involvement and engagement organisations and the general public.

11. Lessons learned

For PI within a study to be meaningful, deliverable and impactful, it must be considered an integral part of the research project and supported adequately to facilitate its success. Too often, teams have politely acquiesced to the presence of a "patient representative" without providing the necessary financial or structural support to ensure their input is of value.

Based on our experience in this field, it is imperative that funding for PI activities are properly accounted for in grant proposals. This includes costs for the public contributors time, travel arrangements and where necessary, costs of providing care for dependents during their PI activities. Time should also be allocated for the PI lead to coordinate contributor activity, provide training to research staff, oversee PI activity and ensure these are recorded appropriately. Cost estimates should cover the entire duration of the grant, extending into the dissemination period.

12. Conclusion

Research teams have realised the high value of PI in cancer associated thrombosis research and have developed strategies for implementing and evaluating PI, guided by national standards and tools. Public involvement in large multi-national and multi-component studies necessitates scaling up of efforts to enhance research collaboration and to facilitate culturally relevant, inclusive and acceptable research to diverse populations.

The success of the PI strategy in the SERENITY Study depends on the PI team being embedded in the whole research programme and the building of a strategy to flexibly and responsively plan, facilitate and evaluate the impact of PI. The lived-experience and cultural insights provided by patient and public contributors from several countries are crucial for informing the research conduct, the interpretation and dissemination of findings in this Pan-European study. This process is iterative, and reflection on areas of failure are as informative as celebrations of success. An openness to learning and improving is essential, yet such scrutiny should be guided by the objectivity that a tool such as PIRIT provides, ensuring a systematic approach to planning and evaluation of this essential component of meaningful, impactful research.

Acknowledgements and funding

The study is part of the research project SERENITY – "Towards Cancer Patient Empowerment for Optimal Use of Antithrombotic Therapy at the End of Life" (https://serenity-research.eu/). This project has received funding from the European Union's Horizon Europe research and innovation action under grant agreement No 101057292. Additionally, United Kingdom Research and Innovation (UKRI) has provided funding under the United Kingdom government's Horizon Europe funding guarantee [grant agreement No 10039823 for Cardiff University and 10038000 for Hull York Medical School].

Views and opinions expressed are however those of the authors only and do not necessarily reflect those of the European Union or The European Health and Digital Executive Agency. Neither the European Union nor the granting authority.

CRediT authorship contribution statement

Michelle Edwards: Conceptualization, Project administration, Writing – original draft. **Kathy Seddon:** Conceptualization, Project administration, Writing – review & editing. **Elin Baddeley:** Data curation, Project administration, Writing – review & editing. **Anne Gulbech Ording:** Conceptualization, Writing – review & editing. **Mark Pearson:** Conceptualization, Writing – review & editing. **Isabelle Mahe:** Writing – review & editing. **Simon Mooijaart:** Writing – review & editing. **Frederikus A. Klok:** Conceptualization, Funding acquisition, Writing – review & editing. **Simon I.R. Noble:** Conceptualization, Project administration, Writing – original draft, Funding acquisition.

Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

References

[1] J. Brett, S. Staniszewska, C. Mockford, S. Herron-Marx, J. Hughes, C. Tysall, et al., Mapping the impact of patient and public involvement on health and social care research: a systematic review, Health Expect. 17 (5) (2014) 637–650.

[2] L.M. Andrews, H. Allen, Z.A. Sheppard, G. Baylis, T.W. Wainwright, More than just ticking a box…how patient and public involvement improved the research design

and funding application for a project to evaluate a cycling intervention for hip osteoarthritis, Research Involvement and Engagement 1 (1) (2015) 13.
[3] D. Supple, A. Roberts, V. Hudson, S. Masefield, N. Fitch, M. Rahmen, et al., From tokenism to meaningful engagement: best practices in patient involvement in an EU project. Research Involvement and Engagement 1 (1) (2015) 5.
[4] S. Seaman, A. Nelson, S. Noble, Cancer-associated thrombosis, low-molecular-weight heparin, and the patient experience: a qualitative study, Patient Prefer. Adherence 8 (2014) 453–461.
[5] S. Noble, H. Prout, A. Nelson, Patients' Experiences of LIving with CANcer-associated thrombosis: the PELICAN study, Patient Prefer. Adherence 9 (2015) 337–345.
[6] C. Font, A. Nelson, T. Garcia-Fernandez, H. Prout, P. Gee, S. Noble, Patients' experience of living with cancer-associated thrombosis in Spain (PELICANOS), Support. Care Cancer 26 (2018) 3233–3239.
[7] N.B. Benelhaj, A. Hutchinson, A.M. Maraveyas, J.D. Seymour, M.W. Ilyas, M. J. Johnson, Cancer patients' experiences of living with venous thromboembolism: a systematic review and qualitative thematic synthesis, Palliat. Med. 32 (5) (2018) 1010–1020.
[8] S. Noble, A. Nelson, J. Scott, A. Berger, K. Schmidt, P. Swarkar, A. Lee, Patient experience of living with cancer-associated thrombosis in Canada (PELICANADA), Res Pract Thromb Haemost 4 (1) (2019) 154–160.
[9] T. Woulfe, K. Mann, D. Pollack, P. Swarnkar, A. Nelson, S. Noble, "Wolverine, I think it's called: blood thinners but in tablets." Patients experience of living with cancer associated thrombosis in New Zealand (PELICANZ), Thromb. Res. 189 (2020) 35–38.
[10] S. Noble, N. Pease, J. Sui, J. Davies, S. Lewis, U. Malik, et al., Impact of a dedicated cancer-associated thrombosis service on clinical outcomes: a mixed-methods evaluation of a clinical improvement exercise, BMJ Open 6 (11) (2016) e013321.
[11] HRA, Public involvement. https://www.hra.nhs.uk/planning-and-improving-research/best-practice/public-involvement, 2022. Health Research Authority (UK).
[12] National Coordinating centre for public engagement, Introducing public engagement [Available from: https://www.publicengagement.ac.uk/about-engagement/what-public-engagement, 2023.
[13] A. Horobin, Going the extra mile – creating a co-operative model for supporting patient and public involvement in research, Research Involvement and Engagement 2 (1) (2016) 9.
[14] S. Denegri, T. Coldham, S. Eglin, R. Frost, L. Kerridge, R. Matthews. Going the ExtraMile: Improving the Nation's Health and Wellbeing through Public Involvement in Research, NIHR, London, 2015. https://www.nihr.ac.uk/going-the-extra-mile.
[15] K. Walshe, M. McKee, P. Groenewegen, J. Hansen, J. Figueras, S. Boccia, et al., Reshaping the agenda of the European Commission for the health systems and policy research in Europe within Horizon 2020, Epidemiology, Biostatistics and Public Health 10 (2) (2013). https://doi.org/10.2427/8951.
[16] A. Price, M. Clarke, S. Staniszewska, L. Chu, D. Tembo, M. Kirkpatrick, et al., Patient and public involvement in research: a journey to co-production, Patient Educ. Counsel. 105 (4) (2022) 1041–1047.
[17] P. Wicks, T. Richards, S. Denegri, F. Godlee, Patients' roles and rights in research, BMJ 362 (2018) k3193.
[18] National Institute of Health Research. PPI (Patient and Public Involvement) Resources for Applicants to NIHR Research Programmes 2019 [Available from: PPI (Patient and Public Involvement) Resources for Applicants to NIHR Research Programmes. https://www.nihr.ac.uk/.
[19] Health and Care Research Wales. Involving the public in your research [Available from: https://healthandcareresearchwales.org/researchers-support-and-guidance-researchers-develop-research-idea/involving-public-your-research.
[20] S. Staniszewska, N. Jones, M. Newburn, S. Marshall, User involvement in the development of a research bid: barriers, enablers and impacts1, Health Expect. 10 (2) (2007) 173–183.
[21] J. Brett, S. Staniszewska, C. Mockford, S. Herron-Marx, J. Hughes, C. Tysall, et al., Mapping the impact of patient and public involvement on health and social care research: a systematic review, Health Expect. 17 (5) (2014) 637–650.
[22] T. Greenhalgh, L. Hinton, T. Finlay, A. Macfarlane, N. Fahy, B. Clyde, et al., Frameworks for supporting patient and public involvement in research: systematic review and co-design pilot, Health Expect. 22 (4) (2019) 785–801.
[23] Partnership UPISD, UK Standards for Public Involvement: Better Public Involvement for Better Health and Social Care Research, NIHR, 2019.
[24] K. Seddon, J. Elliott, M. Johnson, C. White, M. Watson, A. Nelson, et al., Using the United Kingdom standards for public involvement to evaluate the impact of public involvement in a multinational clinical study, Res Involv Engagem. 7 (1) (2021) 22.
[25] Centre. MCRCatWCR. Public Involvement in Research Impact Toolkit (PIRIT) https://www.cardiff.ac.uk/marie-curie-research-centre/patient-and-public-involvement/public-involvement-in-research-impact-toolkit-pirit2023 .[.
[26] A.M. Gwozdz, C.M.M. de Jong, L.S. Fialho, T. Likitabhorn, F. Sossi, P.B. Jaber, et al., Development of an international standard set of outcome measures for patients with venous thromboembolism: an International Consortium for Health Outcomes Measurement consensus recommendation, Lancet Haematol 9 (9) (2022) e698–e706.
[27] L. Duffett, Patient engagement: what partnering with patient in research is all about, Thromb. Res. 150 (2017) 113–120.
[28] L. Genge, A. Krala, T. Tritschler, G. Le Gal, N. Langlois, S. Dubois, et al., Evaluation of patients' experience and related qualitative outcomes in venous thromboembolism: a scoping review, J. Thromb. Haemostasis 20 (10) (2022) 2323–2341.
[29] M. Cushman, G.D. Barnes, M.A. Creager, J.A. Diaz, P.K. Henke, K.R. Machlus, et al., Venous thromboembolism research priorities: a scientific statement from the American heart association and the international society on thrombosis and haemostasis, Res Pract Thromb Haemost 4 (5) (2020) 714–721.
[30] A.A. Hojen, M. Sogaard, K. Seddon, S. Noble, Patient public involvement and engagement in thrombosis research: not just for the intrepid, Res Pract Thromb Haemost 5 (1) (2021) 245–246.
[31] S. Noble, Patient engagement in research: are we really worse than orthopaedics? Thromb. Res. 150 (2017) 111–112.
[32] G.D. Barnes, M. Cushman, Response: patient and caregiver engagement in venous thromboembolism research, Res Pract Thromb Haemost 5 (1) (2021) 247.
[33] C. White, S. Noble, F. Swan, M. Watson, V. Allgar, E. Napier, et al., 'Hospice inpatient deep vein thrombosis detection (HIDDen) in advanced non-malignant diseases': a longitudinal pilot study, BMJ Support. Palliat. Care 12 (e6) (2022) e767–e770.
[34] T. Kitson, E. Osborne, S. Noble, N. Pease, R. Alikhan, C. Bryant, et al., HIDDEN2: study protocol for the hospital deep vein thrombosis detection study in patients with cancer receiving palliative care, BMJ Open 13 (9) (2023) e073049.
[35] I. Mahe, J. Chidiac, M. Pinson, M. Pinson, P. Swarnkar, A. Nelson, et al., Patients experience of living with cancer associated thrombosis in France (Le PELICAN), Thromb. Res. 194 (2020) 66–71.
[36] J. Goedegebuur, D. Abbel, S. Accassat, W.P. Achterberg, A. Akbari, V.M. Arfuch, et al., Towards optimal use of antithrombotic therapy of people with cancer at the end of life: a research protocol for the development and implementation of the SERENITY shared decision support tool, Thromb. Res. 228 (2023) 54–60.
[37] S. Noble, The challenges of managing cancer related venous thromboembolism in the palliative care setting, Postgrad. Med. 83 (985) (2007) 671–674.
[38] S.I. Noble, K. Hood, I.G. Finlay, The use of long-term low-molecular weight heparin for the treatment of venous thromboembolism in palliative care patients with advanced cancer: a case series of sixty two patients, Palliat. Med. 21 (6) (2007) 473–476.
[39] J.L. Ambrus, C.M. Ambrus, I.B. Mink, J.W. Pickren, Causes of death in cancer patients, J. Med. 6 (1) (1975) 61–64.
[40] P.M. Sandset, A.E.A. Dahm, Is venous thromboembolism a problem in patients with cancer in palliative care? Lancet Haematol 6 (2) (2019) e61–e62.
[41] S. Noble, A. Matzdorff, A. Maraveyas, M.V. Holm, G. Pisa, Assessing patients' anticoagulation preferences for the treatment of cancer-associated thrombosis using conjoint methodology, Haematologica 100 (11) (2015) 1486–1492.
[42] A.J. Lloyd, S. Dewilde, S. Noble, E. Reimer, A.Y.Y. Lee, What impact does venous thromboembolism and bleeding have on cancer patients' quality of life? Value Health 21 (4) (2018) 449–455.
[43] M. Feehan, M. Walsh, H. Van Duker, J. Godin, M.A. Munger, R. Fleming, et al., Prevalence and correlates of bleeding and emotional harms in a national US sample of patients with venous thromboembolism: a cross-sectional structural equation model, Thromb. Res. 172 (2018) 181–187.
[44] S. Noble, S. Banerjee, N.J. Pease, Management of venous thromboembolism in far-advanced cancer: current practice, BMJ Support. Palliat. Care 12 (e6) (2019) e834–e837.
[45] B. Tardy, S. Picard, F. Guirimand, C. Chapelle, M. Danel Delerue, T. Celarier, et al., Bleeding risk of terminally ill patients hospitalized in palliative care units: the RHESO study, J. Thromb. Haemostasis 15 (3) (2017) 420–428.
[46] H. Cook, K.A. Walker, M. Felton Lowry, Deprescribing interventions by palliative care clinical pharmacists surrounding goals of care discussions, J. Palliat. Med. 25 (12) (2022) 1818–1823.
[47] S. Noble, Venous thromboembolism in palliative care patients: what do we know? Thromb. Res. 191 (Suppl 1) (2020) S128–S132.
[48] N. Chin-Yee, P. Tanuseputro, M. Carrier, S. Noble, Thromboembolic disease in palliative and end-of-life care: a narrative review, Thromb. Res. 175 (2019) 84–89.
[49] S.R. Allende-Pérez, G. Cesarman-Maus, A. Peña-Nieves, A. Arcos, P. Baz-Gutiérrez, J. Robles, et al., Venous thromboembolism in patients with cancer receiving specialist palliative care, Clinical and Applied Thrombosis/Hemostasis. 28 (2022) 10760296221081121.
[50] S. Staniszewska, J. Brett, C. Mockford, R. Barber, The GRIPP checklist: strengthening the quality of patient and public involvement reporting in research, Int. J. Technol. Assess. Health Care 27 (4) (2011) 391–399.
[51] National Institute of Health Research, UK Standards for Public Involvement: Better Public Involvement for Better Health and Social Care Research, 2018. London.