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Research Involvement
and Engagement

COMMENT **Open Access**

Co-developing preoperative therapy for Dupuytren's fasciectomy: lived experience and clinical expertise

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Abstract

Background Harnessing Lived Experience Expertise (LEE) and Clinical Expertise (CE) is essential for patient-centred research. Yet transparent reporting and critical reflection on their impact remain limited. This study details an iterative approach to integrating LEE and CE in the development of a preoperative therapy intervention for Dupuytren's fasciectomy, evaluating their influence on study design and implementation.

Objective To assess how LEE and CE shape intervention development, influence research decisions, and to identify associated challenges, successes, and best practice for integration into clinical research.

Methods A structured, multi-phase approach is implemented using the GRIPP2 short-form, a validated Patient and Public Involvement reporting framework. Activities include forming a steering committee, engaging patients and clinicians in intervention development, co-creating study materials, and refining trial protocols. Feedback is gathered through online meetings, surveys, and direct consultations. A LEE contributor co-authors this study, ensuring patient perspectives were embedded throughout.

Results Integrating LEE and CE leads to significant refinements in study design, including development of intervention content aligned LEE/CE priorities, clearer and more accessible patient-facing materials and outcome measures that reflect real-world patient concerns. Challenges include sustaining contributor engagement over time and balancing patient and clinician priorities.

Conclusion Embedding LEE and CE strengthens feasibility, and acceptability of intervention and research processes. Lessons learned emphasise the need for flexible, iterative engagement strategies and structured reporting to optimise involvement and enhance impact. Future work should explore how reporting frameworks support sustained contributor engagement and how LEE and CE shape accessibility, relevance and implementation of clinical research.

Patient and public contribution

This study details how people with lived experience of Dupuytren's disease, alongside clinicians, contribute to the design of a preoperative therapy intervention to improve Dupuytren's fasciectomy outcomes. They help shape

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study materials, refine the intervention, and prioritise outcome measures. A patient advocate co-authors this study, with reflections from both clinician and patient perspectives included.

Keywords Lived experience expertise, Clinical expertise, Public involvement, Collaboration and coproduction, Embedded consultation, Dupuytren's fasciectomy, Preoperative therapy

Introduction

As part of an ongoing PhD research collaboration between Dorset County Hospital NHS Foundation Trust and Bournemouth University, this study explores the role of Lived Experience Expertise (LEE) and Clinical Expertise (CE) in developing a preoperative therapy intervention for Dupuytren's fasciectomy, a surgery designed to remove the tight tissue in the palm so the fingers can straighten and move more freely. LEE refers to the knowledge gained through first-hand experience of a health condition [1]. While various terms are used to describe this concept, including Public Involvement (PI), Patient and Public Involvement (PPI), Patient and Public Involvement and Engagement (PPIE), and Community Engagement and Involvement (CEI), many of these terms do not explicitly reference patients or the value of lived experience. In parallel, we draw on the clinical expertise of surgeons, hand therapists, nurses and wound care specialists involved in the assessment, treatment, and rehabilitation of individuals with Dupuytren's disease (DD). Their contributions ensure appropriate consideration of clinical safety and feasibility, alongside practice-informed and scientific evidence [2]. We therefore use the terms LEE and CE to emphasise the value of individuals with personal and clinical experience of DD in shaping a more relevant intervention.

Research shows patients develop practical, experience-based knowledge, helping them translate medical information into meaningful life strategies [3, 4]. This knowledge is neither wholly separate from, nor identical to, clinical knowledge, positioning LEE and CE as mutually informative and essential for effective intervention development. This conceptual stance underpins the multifaceted, iterative design of the preoperative therapy intervention described in this study.

DD is a prevalent and progressive fibroproliferative condition affecting over two million people in the UK [5, 6]. Build-up of nodules and cords beneath the palmer skin can lead to fixed flexion contractures [7, 8]. The presurgical disease course often spans months to years, during which progressive contracture can affect hand function and limit activities of daily living. Patients become eligible for surgery only if a fixed flexion contracture significantly impacts function [9]. Dupuytren's fasciectomy, remains the most widely used and effective surgical treatment [10], with postoperative therapy playing a crucial role in optimising functional recovery [11].

A 2024 systematic review and subsequent survey, identify a clear lack of evidence for preoperative interventions in hand surgery [12, 13]. The survey highlighted Dupuytren's fasciectomy as a procedure that may particularly benefit from structured preoperative therapy, with clinicians noting that it is not routinely offered due to limited evidence and absent pathways, rather than lack of perceived value. Respondents also indicate a clinically feasible, structured intervention would be welcomed.

While postoperative therapy is well established within hand surgery generally, preoperative therapy remains underexplored, despite evidence of benefit in other musculoskeletal (MSK) specialisms [14]. Although DD differs pathologically, key therapeutic components used in postoperative hand rehabilitation share core principles with wider MSK practice. Preoperative interventions in other MSK contexts therefore remain informative, as mechanisms such as preparing tissues and enhancing surgical readiness are likely transferable.

Together, these findings demonstrate both a gap in evidence and clinical interest in developing a preoperative approach for Dupuytren's fasciectomy. The absence of any established pathway reinforces the need for co-designed intervention development that incorporates both LEE and CE to ensure relevance, acceptability, and feasibility. This is further supported by evidence of successful LEE/CE integration in other orthopaedic studies [15, 16].

To ensure transparent and systematic reporting of involvement activities, this study is underpinned by the Guidance for Reporting Involvement of Patients and the Public (GRIPP2) framework [17]. This is the first validated and internationally recognised tool for evaluating and documenting LEE/CE in health research and provides structured domains for planning, undertaking, and assessing involvement. Introducing GRIPP2 at the development stage ensures that LEE and CE activities are clearly defined, consistently recorded, and critically reflected upon throughout.

The need for structured LEE/CE involvement is particularly relevant when developing complex interventions, defined by the Medical Research Council (MRC) as interventions with multiple interacting components, variable implementation pathways, and context-dependent outcomes [18]. Preoperative therapy for Dupuytren's fasciectomy fits this definition, involving behavioural, educational, and therapeutic elements that require coordination within clinical settings. In line with the updated

MRC Framework for Developing and Evaluating Complex Interventions, this study represents the development phase of a new intervention that will undergo feasibility testing before progressing to a future randomised controlled trial (RCT). At this stage, the framework emphasises understanding how an intervention interacts with its context, articulating an initial programme theory, incorporating diverse stakeholder perspectives, identifying key uncertainties, and using iterative refinement to strengthen design [18]. The structured integration of LEE and CE in this study addresses these elements, embedding patient priorities, clinical feasibility, and real-world delivery considerations from the outset and producing an intervention ready for formal feasibility evaluation.

Study aim and objectives

The broader PhD research aims to design and evaluate a preoperative therapy intervention for Dupuytren's fasciectomy, using LEE and CE to ensure its relevance and acceptability. This study seeks to evaluate the use of LEE and CE within this research. The GRIPP2 short-form [17] is used to assess impact of LEE and CE on research decisions, intervention development, and refinement of study protocol. The findings provide insight into best practice and lessons learned, informing ongoing use of LEE and CE in this study and other research endeavours.

Aim

To document and evaluate LEE and CE's contribution to this research process, including their impact on intervention development and study design.

Objectives

- To describe the combined LEE and CE process in developing a preoperative therapy intervention.
- To assess the influence of LEE and CE on study design and trial protocol.
- To identify successes, challenges, and areas for refinement of LEE and CE integration.

Methods

This exploratory mixed methods study was undertaken as an exploration of LEE and CE impart on intervention development. In line with National Institute for Health and Care Research (NIHR) and Health Research Authority (HRA) guidance, the activities described in this paper are undertaken as LEE/CE endeavours and as such do not require NHS or university ethical approval. Formal ethical approval for the subsequent feasibility study has since been obtained (IRAS project ID: 349520).

To structure and report the involvement of LEE and CE in this study, the Methods and Results are organised in alignment with the GRIPP2 framework. This informed the three study phases and their associated activities (Fig. 1), enabling transparent reporting of LEE and CE integration and their effect on subsequent stage of intervention development (Tables 1, 2 and 3).

Phase 1: Establishing a LEE/CE strategy (Table 1)

Phase 1 focuses on establishing a clear and feasible strategy for integrating LEE and CE throughout the feasibility study. Due to Dupuytren's fasciectomy's lack of existing preoperative guidance, early, meaningful LEE/CE involvement is necessary to ensure genuine impact on study design and conduct. This requires moving beyond the tokenistic to a purposeful and achievable approach.

Phase 1 - activity 1: enrolment on the public involvement in research module

Why? To ensure the lead researcher has the skills and knowledge required to implement meaningful, non-tokenistic involvement.

What? The lead researcher's enrolment on a postgraduate Public Involvement education module covering best practice, ethics, and models of involvement. Learnings informed the decision to adopt an iterative and phased approach, using established operational definitions to develop an achievable and impactful LEE/CE strategy [19].

Phase 1 - activity 2: exploratory meeting with chair of the British dupuytren's society

Why? To secure early partnership with the main UK patient organisation and ensure the research reflected patient priorities.

What? An online meeting with the British Dupuytren's Society (BDS) chair, the lead researcher and the primary PhD supervisor, exploring interest in co-developing the research and identifying effective contribution strategies.

Phase 1 - activity 3: engaging potential members for the steering committee

Why? To establish a multidisciplinary committee capable of providing diverse perspectives from patients, clinicians, and the patient organisation.

What? Purposeful sampling to contact pre and postoperative Dupuytren's patients, hand therapists, dressings nurses, hand surgeons, and BDS representatives. Invitations, information pack (appendix 4) and follow-up calls outline expectations and confirm involvement.

Phase 1 - activity 4: first steering committee meeting

Why? To gather early LEE/CE insight into experiences of DD, information needs, and priorities for preoperative therapy, and to guide development of the LEE survey capable of capturing opinions from a wider group of people with lived experience.

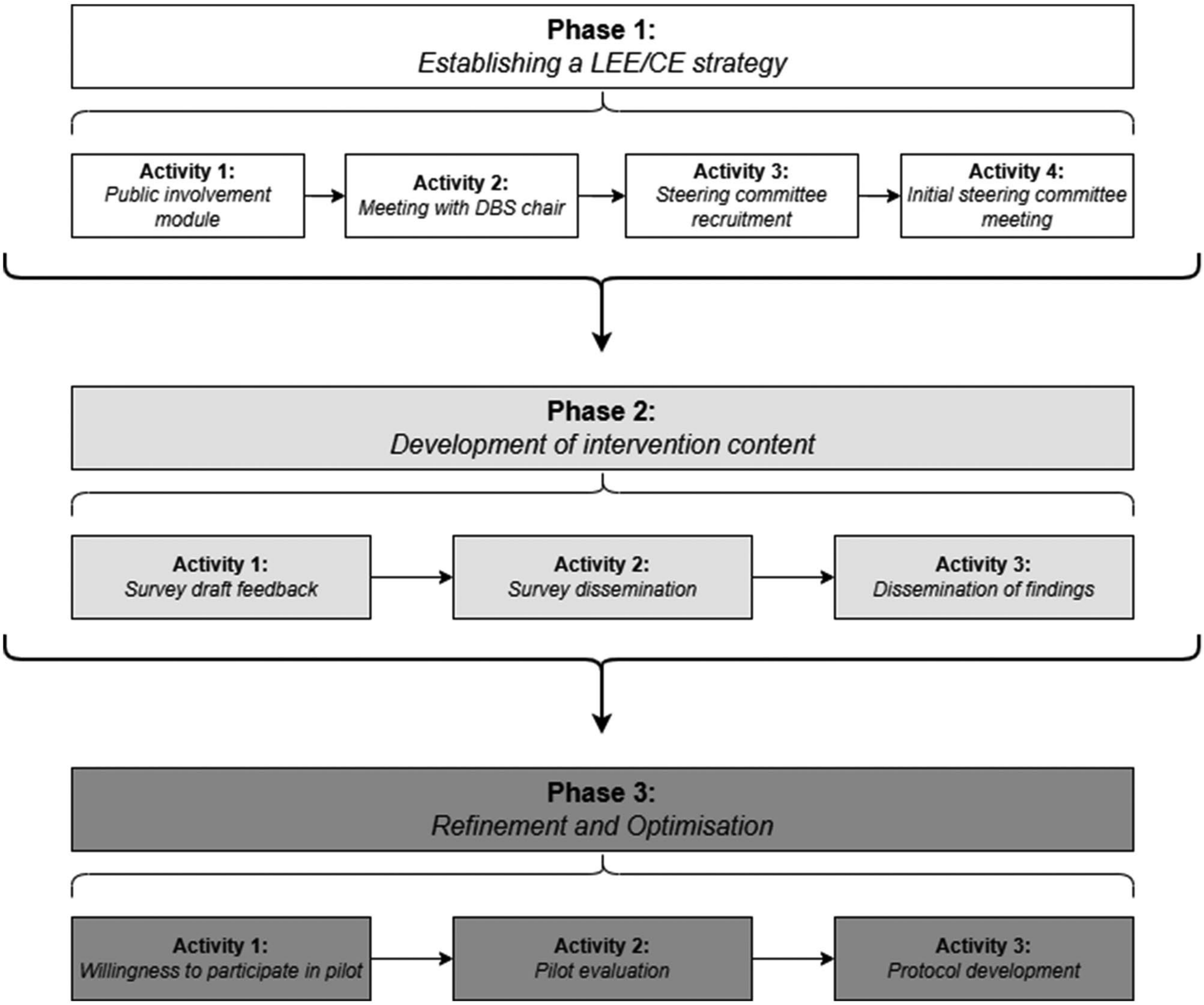

Fig. 1 Study phases and associated activities

What? A facilitated online meeting clarifying the committee's role, meeting objectives, and key definitions, alongside preliminary intervention concepts and an initial draft survey. Participants to share experiences and provide feedback on the proposed intervention and survey content.

Phase 2: development of intervention content (Table 2)

Phase 2 focuses on translating the LEE/CE output into concrete intervention content, the aim being to ensure the preoperative therapy intervention is relevant, feasible, and aligned with patient and clinician priorities through structured stakeholder involvement.

Phase 2 - activity 1: steering committee feedback on preliminary LEE survey

Why? To ensure the first draft of the LEE survey was clear, accessible and capable of capturing meaningful LEE insight.

What? Distribution of the draft survey to steering committee members, accompanied by instruction for review. Mechanisms for gathering review feedback include online, face-to-face, telephone or email to support inclusive participation, and follow-up calls to address any confusion and gather additional suggestions.

Phase 2 - activity 2: dissemination of survey via BDS

Why? To broaden LEE input and ensure that the perspectives of a wider group of people with lived experience informed the design of the subsequent research study.

What? Design a mixed methods survey using established survey principles to support clarity and ease of

Table 1 Evaluation - Phase 1 - Establishing a LEE/CE strategy

	Date	**Gripp2 reporting checklist**				
		1: Aim **Report the aim of the study**	**2: Methods** **Provide a clear description of the methods used for LEE/CE in the study**	**3: Results** **Outcomes—Report the results of LEE/CE in the study, including both positive and negative outcomes**	**4: Discussion** **Outcomes—Comment on the extent to which LEE/CE influenced the study overall. Describe positive and negative effects**	**5: Reflections** **Critical perspective—Comment critically on the study, reflecting on the things that went well and those that did not, so others can learn from this experience**
Phase 1 - Establishing a LEE/CE strategy						
1. Enrolment on the Public Involvement in Research module	04/23	*The primary objective of this module was to establish a structured and meaningful approach to LEE/CE by*: 1. Understanding best practices, ethics, and strategies for effective LEE/CE. 2. Identifying meaningful ways to integrate LEE/CE into research. 3. Evaluating LEE/CE models, their benefits, and challenges. 4. Developing a tailored LEE/CE strategy for relevance and impact. 5. Establishing criteria to assess and refine LEE/CE effectiveness.	*The module was co-facilitated by individuals with lived experience of various health conditions, providing valuable LEE/CE contributor insights.* *The learning process included*: Co-facilitated by individuals with lived experience, offering valuable insights. Covered LEE/CEE engagement strategies, definitions, and implementation. Explored co-production methods like focus groups and advisory committees. Introduced evaluation tools (e.g., GRIPP2, PIIAF) for measuring LEE/CE impact. Provided guidance on refining study design through expert discussions.	*The module guided the development of a structured, flexible LEE/CE strategy with key outcomes*: Blended LEE/CE Model – Combined embedded consultation, collaboration, and co-production. Engagement with BDS – Online meeting with the lead researcher, PhD supervisor, and BDS chair to explore involvement. Steering Committee Formation – Multidisciplinary team of patients, surgeons, therapists, dressings nurses, and the BDS chair. LEE/CE Evaluation Focus – Used GRIPP2 framework for systematic assessment and improvement.	*The module was pivotal in shaping a patient-centred research approach, leading to*: Blended LEE/CE Strategy – Ensured engagement across all study phases. Steering Committee – Secured diverse stakeholder input. Structured LEE/CE Evaluation – Enabled continuous monitoring and refinement. A structured consultation approach was to be adopted - balancing meaningful engagement with feasibility. Full user-led/co-production models were unfeasible due to time/resource constraints.	*The module provided critical insights but also highlighted areas for improvement*: *Positive Outcomes*: Flexible, pragmatic LEE/CE strategy keeping patient voices central. Reinforced structured evaluation for continuous improvement. *Challenges & Areas for Improvement*: Limited guidance on overcoming time and funding barriers. Resource-heavy examples were impractical for budget/time-limited studies.
2. Exploratory meeting with chair of the British Dupuytren's Society (BDS)	12/23	*The primary aim of this meeting was to*: Gauge BDS interest in co-designing the study. Assess feasibility of member involvement and co-production. Identify practical ways to integrate BDS input.	*Initial Contact*: Anna Sjoukje Schurer (BDS Chair) was approached for potential collaboration. *Meeting Setup*: A virtual meeting was held with the lead researcher (TBM), supervisor (CC), and BDS Chair (ASS). *Key Discussion Points*: - Patient Recruitment: BDS support in identifying and engaging participants. - Patient Perspective: BDS input on study design and relevance. - International Representation: Access to a diverse, global patient community. - Survey Distribution: BDS assistance in disseminating online surveys.	*Steering Committee Formation*: Agreed members include a hand therapist, dressings nurse, hand consultant, preoperative/postoperative patients, and a BDS representative. *Survey Development*: - Steering committee to refine key questions. - Dupuytren's Society to facilitate wider survey distribution. *Iterative Intervention Design*: - Patient input will shape the intervention based on lived experiences, focusing on: - Timing and format of preoperative information. - Preferred content, including education on postoperative expectations, exercises, scar massage preparation, and recovery milestones. *Additional Strategies*: - DBS chair to contribute to initial focus group for survey formulation. - Gather structured feedback post-meetings using GRIPP2 Short Form. - Share meeting agendas in advance to aid preparation. - Offer flexible communication options (pre/post-meeting feedback, chat function).	*Patient Perspectives Embedded in Study Design*: Discussions shaped the steering committee composition and informed survey development to capture broader patient input on intervention content. *Key Outcomes*: - Defining Preoperative Therapy Priorities: Emphasized post-surgical sensory changes, functional recovery expectations, and education re scar management. - Intervention Content Development: Agreed to distribute a survey via the Dupuytren's Society to ensure real-world patient input. - Expanding Patient Input: Leveraging the Dupuytren's Society's network broadened study reach and representation. - Structured Feedback Mechanisms: Introduced post-meeting feedback forms to maintain engagement and refine activities. - Balancing Stakeholder Input: Ensuring equitable engagement between patients and professionals may be challenging. *Overall Impact*: This LEE/CE activity significantly influenced the study, shaping a patient-centred intervention approach. The iterative approach fosters ongoing patient involvement, supported by feedback forms to optimise engagement throughout the study.	This LEE/CE activity shaped the study's direction, reinforcing patient-centred research. Insights gained will refine future LEE/CE strategies, improving engagement and impact. *Positive Outcomes* BDS Support & Credibility: Backing from the British Dupuytren's Society ensures the LEE/CE strategy remains relevant and strengthens patient representation. Expanded Patient Reach: Utilising the BDS network broadened study reach, securing diverse patient perspectives. *Challenges & Areas for Improvement* Lack of Meeting Agenda: A structured agenda could improve discussion efficiency and focus. Balancing Stakeholder Input: Structured formats are needed to ensure equal contribution from patients and professionals. strengthening engagement and impact in subsequent phases of the study.

Table 1 (continued)

	Date	Gripp2 reporting checklist				
		1: Aim **Report the aim of the study**	**2: Methods** **Provide a clear description of the methods used for LEE/CE in the study**	**3: Results** **Outcomes—Report the results of LEE/CE in the study, including both positive and negative outcomes**	**4: Discussion** **Outcomes—Comment on the extent to which LEE/CE influenced the study overall. Describe positive and negative effects**	**5: Reflections** **Critical perspective—Comment critically on the study, reflecting on the things that went well and those that did not, so others can learn from this experience**
3. Engaging potential members for the steering committee	01/24	*Steering Committee Formation* This activity aimed to establish a steering committee by engaging key stakeholders, including patients, healthcare professionals, and patient support group representatives. The aim of the steering committee was to ensure meaningful patient and public involvement from the outset, enhancing study relevance, accessibility, and impact.	*A targeted outreach approach was used to engage potential members.* - Stakeholder Identification: Pre- and postoperative Dupuytren's patients, hand therapists, dressing nurses, hand consultants, and BDS representatives were identified as key contributors. - Initial Contact: Invitations via post/email outlined the study, committee role, and level of involvement. - Follow-Up Engagement: Phone calls clarified expectations and addressed queries. - Information Sharing: Interested participants received a information pack explaining study objectives and involvement opportunities. - Meeting Invitation: Those interested were invited to an initial online meeting to discuss involvement and next steps, with flexible options provided. - Finalising Membership: A confirmed committee list was established, and a follow-up meeting was scheduled to initiate structured discussions.	*Activity Outcomes*: - Secured diverse stakeholder representation across the patient journey. - Strong participant enthusiasm reinforced the value of LEE/CE in shaping research outcomes. - Preoperative patient engagement was more challenging. - Coordinating availability across a multidisciplinary group requires planning. *Confirmed Steering Committee Members*: – 4 postoperative and 1 preoperative Dupuytren's patient – 2 hand therapists – 1 dressings nurse – 1 hand surgeon - Chair of the British Dupuytren's Society	Formation of Steering Committee ensured early integration of patient and professional perspectives. *Key Outcomes*: - Established a multidisciplinary committee to embed patient insights in study design. - Strong participant engagement reinforced the value of LEE/CE in enhancing research quality. - Difficulty recruiting preoperative patients, likely due to limited awareness of LEE/CE relevance at this stage of the patient journey.	This LEE/CE activity successfully established a collaborative framework for ongoing patient and stakeholder input. *Key Strength*: - Strong engagement and enthusiasm from postoperative patients and clinicians. *Key Challenges*: - Difficulty recruiting preoperative patients, indicating a need for greater awareness. - Scheduling challenges with busy professionals required flexible coordination.

Table 1 (continued)

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		1: Aim **Report the aim of the study**	**2: Methods** **Provide a clear description of the methods used for LEE/CE in the study**	**3: Results** **Outcomes—Report the results of LEE/CE in the study, including both positive and negative outcomes**	**4: Discussion** **Outcomes—Comment on the extent to which LEE/CE influenced the study overall. Describe positive and negative effects**	**5: Reflections** **Critical perspective—Comment critically on the study, reflecting on the things that went well and those that did not, so others can learn from this experience**
4. First steering committee meeting	02/24	*First Steering Committee Meeting – Key Objectives*: - Gathering Perspectives: Capturing insights from preoperative and postoperative patients and clinicians to identify gaps in pre- and postoperative therapy. - Understanding Patient Needs: Identifying beneficial preoperative interventions, key surgical outcomes, and preferred delivery methods. - Survey Development: Using committee input to design a patient survey, distributed via the Dupuytren's Society for broad engagement. - Patient-Centred Intervention Design: Ensuring the intervention is tailored to patient needs, enhancing both preoperative preparation and postoperative recovery. *LEE/CE Survey Refinement Objectives*: - Clarity & Accessibility: Ensuring survey wording is easily understood by all patients. - Fit for Purpose: Gathering meaningful data to shape intervention development. Direct feedback from the steering group helped refine the survey before wider distribution.	*Methods Used to Facilitate This Activity included*: - Meeting Scheduling: Availability preferences were gathered, and an online Teams meeting was held on 10/02/2024 for accessibility. - Pre-Meeting Preparation: Participants received an agenda, and key discussion points a week in advance to allow for thoughtful contributions. Draft survey questions (based on existing literature, clinical practice knowledge, and initial scoping discussions) were also distributed. - Structured Meeting Format: A brief presentation outlined the committee's purpose, meeting objectives, and key study terms. - Facilitated Discussion: Participants shared experiences and perspectives on preoperative therapy, guided by targeted questions. - Feedback Mechanism: Post-meeting feedback forms assessed session effectiveness and suggested improvements. - Compensation: Participants received a £25 One4All voucher in line with NIHR guidance.	The First Steering Committee Meeting highlighted priorities for the development of a preoperative intervention and informed the design of the upcoming survey. Key insight includes: - *Preoperative Education*: Clear, accessible information on the condition, treatment options, and recovery is essential for patient preparedness and satisfaction. - *Preoperative Support*: Patients valued peer support and Q&A opportunities to reduce anxiety and encourage therapy engagement. - *Multi-Format Information*: A mix of written, visual, and digital resources was recommended, with non-digital options for accessibility. - *Ongoing Engagement*: All participants were keen to remain involved as advisory group members. - *Outcome Measures*: Varying patient priorities made defining a single key outcome difficult, highlighting the need for flexible evaluation. - *Lack of Guidelines*: The absence of clear conservative management guidelines for Dupuytren's disease was identified as a research gap impacting preoperative therapy recommendations.	Insights gained from this activity have significantly influenced the study's direction. Key outcomes include: - *Multiple Outcome Measures*: No single measure can assess treatment effectiveness or surgical success due to varying patient priorities. The survey will prioritize the most relevant measures, likely emphasizing functional outcomes. - *Education & Expectation Setting*: Preoperative education and expectation-setting are crucial. The survey will identify which aspects should be prioritized to best support patient needs. - *Iterative Survey Development*: The committee will review and refine the survey draft before broader distribution, ensuring it addresses patient perspectives and research goals.	*Key Strengths*: - Online Delivery: Virtual meetings improved accessibility, efficiency, and allowed for recorded discussions. - Structured Agenda: Kept discussions focused and ensured key topics were covered. - Diverse Perspectives: Input from both patients and clinicians enriched discussions. *Key Challenges*: - Limited patient demographics: Participants were mostly middle-aged, educated men, with only one woman. Ost were also postoperative patients. - Scheduling Conflicts: Some invitees couldn't attend, limiting input. *Next Steps*: - Follow-ups: Individual meetings will capture absent participants' perspectives. - Feedback Review: Evaluating participant feedback to improve future meetings.

Table 2 Evaluation - Phase 2 - Development of intervention content

LEE/CE Activity	**Date**	**Gripp2 reporting checklist**				
		1: Aim **Report the aim of the study**	**2: Methods** **Provide a clear description of the methods used for LEE/CE in the study**	**3: Results** **Outcomes—Report the results of LEE/CE in the study, including both positive and negative outcomes**	**4: Discussion** **Outcomes—Comment on the extent to which LEE/CE influenced the study overall. Describe positive and negative effects**	**5: Reflections** **Critical perspective—Comment critically on the study, reflecting on the things that went well and those that did not, so others can learn from this experience**
Phase 2 - Development of Intervention Content						
1. Steering committee feedback on preliminary LEE survey	03/24	This LEE/CE activity aimed to gather steering committee feedback to refine the LEE survey before wider distribution. Key objectives included: - *Clarity & Accessibility*: Ensure wording and structure are easy to understand. - *Relevance & Comprehensiveness*: Capture key patient perspectives. - *Effectiveness*: Gather meaningful data to inform intervention development.	To ensured comprehensive input from committee members on the first LEE survey draft a flexible feedback approach was adopted. - *Survey Distribution*: Sent via email with clear review instructions. - *Feedback Options*: Members could respond via Teams, in-person, phone, or email. - *Follow-up*: When needed follow-ups allowed for clarifications, improvements, and feedback on structure and clarity.	Feedback led to several refinements in survey design, including: - *Clarity & Accessibility*: Reworded questions for better understanding, simplifying technical terms while maintaining accuracy. - *Relevance*: Removed redundant questions to improve focus. - *Length & Flow*: Streamlined sections to enhance completion rates while retaining key data. - *Differing Priorities*: Added a ranking system to gauge preference for functional outcomes vs. range of movement. - *Limited Patient Feedback*: Only two patients contributed; most input came from clinicians and the BDS chair.	Feedback from committee members helped ensure the survey was accessible, and relevant to both patients and clinicians. Key outcomes included: - *Improved Clarity & Flow*: Adjusted language and structure for better readability and response rates. - *Patient-Centred Priorities*: Added a ranking system to reflect patient-defined outcome importance. - *Limited Patient Input*: Only two patients provided feedback, highlighting the need for more flexible engagement options.	*What Worked Well*: - Providing a ranking system for various outcome measures allowed for patient and clinicians preferred outcome for assessment to be resented within the survey - Patient-Centred Refinements: Improved clarity, structure, and length made the survey more user-friendly. *Challenges & Areas for Improvement*: - Limited Patient Input: More efforts are needed to increase patient participation – possibly more time and reminders to provide feedback. - Balancing Simplicity & Detail: Future iterations should refine this balance, possibly with pilot testing prior to distribution. *Next Steps*: - Distribute the refined survey to more Dupuytren's patients via BDS. - Apply lessons learned to improve future LEE/CE engagement and inclusivity.
2. Dissemination of survey via Dupuytren's society	03/24	The primary aim of this activity was to ensure broad dissemination of the survey to Dupuytren's patients via the BDS to inform the design of the intervention. Key objective included: - *Maximise Reach*: Distribute the survey to a wide, representative patient sample across different disease stages and treatment experiences. - *Gather Insight*: Capture patient views on preoperative therapy, outcome measures, and intervention preferences. - *Boost Engagement*: Involve patients in shaping future interventions, enhancing the study's relevance and impact.	*Design & Development*: - Developed with steering committee input to ensure relevance and accessibility. - Followed established survey principles for clarity, neutrality, and ease of completion. - Included closed and open-ended questions to capture both qualitative and quantitative insights. *Distribution & Recruitment*: - BDS shared the survey via website, social media, and email newsletters. - Dupuytren's Research Group (US-based nonprofit) expanded reach by sharing it on their social media platforms. *Data Collection*: - Hosted on the JISC online survey system for secure, international participation. - Open for responses from March 11 to April 1, 2024.	*Survey findings include*: – 235 participant responses worldwide. – 93% of participant had undergone fasciectomy, 7% were awaiting surgery. - Preferred preoperative information format was face-to-face delivery, supplemented by visual and written leaflets, indicating a preference for multi-modal information. - Although preoperative Information delivery was considered important, there was no clear consensus on key content. - Participants expressed greater willingness to engage in splinting and massage over preoperative exercises. - Range of motion (ROM) was the most valued measure of surgical success.	Survey Insights Shaping Preoperative Intervention Design The survey results provided valuable patient perspectives, directly influencing the development of a patient-centred preoperative intervention. Key outcomes include: - *High Engagement*: Strong response rate highlights patient interest in improving preoperative care. - *Preferred Method of Information Delivery*: Face-to-face education, followed by visual and written materials, supporting a multi-modal approach for accessibility. - *Educational Needs*: While preoperative education was valued, no clear consensus emerged on key content, emphasizing the need for personalized or adaptable materials. - *Intervention Preferences*: Patients preferred passive interventions (splinting and massage) over active exercises, suggesting these should be prioritised while implementing strategies to support exercise adherence if necessary. - *Outcome Priorities*: ROM was the favoured over functional outcomes for measure surgical success.	*What Worked Well*: - High response rates provided valuable data, reinforcing the importance of patient involvement. - Collaboration with the BDS ensured broad participation and diverse patient input. - Clear patient priorities on methods of information delivery, engagement strategies, and outcome measures will directly shape the intervention. *Challenges & Areas for Improvement*: - While education was valued, no consensus emerged on key content, highlighting the need for further LEE/CE input. - Lower interest in active interventions suggests a need to explore barriers and motivational strategies. *Next Steps*: - Develop the intervention based on patient priorities. - Pilot test the intervention to assess feasibility and acceptability before full implementation.

Table 2 (continued)

LEE/CE Activity	Date	Gripp2 reporting checklist				
		1: Aim **Report the aim of the study**	**2: Methods** **Provide a clear description of the methods used for LEE/CE in the study**	**3: Results** **Outcomes—Report the results of LEE/CE in the study, including both positive and negative outcomes**	**4: Discussion** **Outcomes—Comment on the extent to which LEE/CE influenced the study overall. Describe positive and negative effects**	**5: Reflections** **Critical perspective—Comment critically on the study, reflecting on the things that went well and those that did not, so others can learn from this experience**
3. Dissemination of survey results		The aim with this activity was to communicate survey results to key stakeholders, including patients, clinicians, and researchers, highlighting the impact of patient contributions. Key objectives include: - Share findings with survey respondents and the broader patient community. - Show how patient input has influenced the study and shaped intervention development to encourage future engagement.	A visually engaging poster was created to summarise key findings using bullet points, graphics, and percentages for clarity and accessibility. Distribution methods included: - *Online Sharing*: The BDS and Dupuytren's Research Group posted the summary on their websites and social media, reaching both patients and professionals. - *Direct Communication*: Steering committee members received an email summary of the findings, along with appreciation for their contributions.	- *Positive Patient Engagement*: Patients appreciated seeing how their input directly shaped the study. - *Increased Awareness & Discussion*: The BDS and Dupuytren's Research Group's online sharing led to increased awareness among patients about potential for preoperative therapy for Dupuytren's Fasciectomy. - *Strengthened Stakeholder Relationships*: Clinicians and researchers acknowledged the value of LEE, encouraging stronger collaboration between patients, healthcare professionals, and researchers.	Dissemination of survey findings had several key outcomes, including: - *Validation from Patients & Stakeholders*: Positive feedback from LEE/CE contributors confirmed alignment with patient priorities, enhancing study credibility. - *Encouraged Ongoing Participation*: Demonstrating the impact of patient contributions motivated further engagement in research and future LEE/CE activities. - *Expanded Research Reach*: Dissemination via BDS and the Dupuytren's Research Group increased awareness of preoperative therapy interventions Dupuytren's fasciectomy. - *Demonstrated LEE/CE impact*: Sharing results kept contributors informed, reinforcing their role in shaping future research.	*What Worked Well*: - Visual Poster: Made complex findings clear and engaging. - Working with Patient Organisations: Dissemination through BDS and Dupuytren's Research Group ensured findings reached the right audience. - Direct Contributor Feedback: Strengthened collaboration and acknowledged steering committee input. *Challenges & Areas for Improvement*: - Limited Feedback: While findings were well received, no direct feedback was collected on how or if survey results influenced patient perspectives.

completion [20, 21]. Include closed and open-ended questions capturing both structured data and qualitative experiences. The BDS distributes the survey via website, social media channels, and email newsletters (appendix 2), with additional promotion via the US-based Dupuytren's Research Group. Survey runs from 11th March 2024 to 1st April 2024 on the JISC online survey platform.

Phase 2 - activity 3: dissemination of survey results

Why? To ensure transparency, maintain contributor engagement, and acknowledge the value of LEE contributions.

What? Creation of a visually engaging summary poster presenting key findings (appendix 3). The BDS and the Dupuytren's Research Group to share the poster on websites and social media channels. Steering committee members to receive emails update.

Phase 3: refinement and optimisation of intervention (Table 3)

Building on the strong preference for splinting expressed by patients in Phase 2, Phase 3 focuses on testing, evaluating, and optimising this patient proposed intervention to enhance feasibility, acceptability and alignment with patient and clinician needs. This primarily involves piloting the preoperative splinting intervention with patients nearing surgery, enabling real-time assessment of its practicality and tolerability, capturing lived experience specific to the surgical pathway. Additionally, review of trial protocol and patient-facing materials ensures clarity and alignment with patient expectations.

Phase 3 - activity 1: assessing willingness of patients to participate in preoperative splinting pilot

Why? To determine whether patients awaiting surgery are willing and able to take part in a preoperative splinting pilot, and to understand any practical barriers to participation.

What? Contact via letter up to six patients scheduled for Dupuytren's surgery within the upcoming eight weeks and follow up with a phone call to ascertain willingness to participate. The activity to be explicitly framed as a LEE activity, aimed at assessing acceptability and practicality, not a formal research study. Interested patients to receive an information pack and attend two preoperative appointments to trial the splinting intervention and gather feedback on comfort and feasibility.

Phase 3 - activity 2: pilot evaluation of preoperative splinting intervention

Why? To evaluate the feasibility, tolerance, and practicality of the intervention prior to incorporating it into a clinical trial.

Table 3 Evaluation - Phase 3 - Refinement and optimisation of intervention

LEE/CE Activity	**Date**	**Gripp2 reporting checklist**				
		1: Aim **Report the aim of the study**	**2: Methods** **Provide a clear description of the methods used for LEE/CE in the study**	**3: Results** **Outcomes—Report the results of LEE/CE in the study, including both positive and negative outcomes**	**4: Discussion** **Outcomes—Comment on the extent to which LEE/CE influenced the study overall. Describe positive and negative effects**	**5: Reflections** **Critical perspective—Comment critically on the study, reflecting on the things that went well and those that did not, so others can learn from this experience**
Phase 3 - Refinement and Optimisation of Intervention						
1. Assessing Willingness of Patients to Participate in Preoperative Splinting Trial	06/24	The aim of this activity was to evaluate patient interest in trialling a preoperative splinting intervention. *Key objective*: - Recruit 3–4 patients scheduled for upcoming Dupuytren's surgery to assess the feasibility of implementing preoperative splinting.-	Recruiting patients for this LEE activity required reaching beyond the steering group and engaging up-coming fasciectomy patients at Dorset County Hospital NHS Foundation Trust. The strategy involved: - *Patient Identification & Invitation*: Letters were sent to six patients scheduled for Dupuytren's surgery within eight weeks, inviting them to participate. - *Follow-Up Communication*: Each patient received a phone call to discuss the trial, address questions, and confirm willingness to participate. - *Participant Information*: Those who agreed were emailed detailed guidance on their involvement and expectations. - *Scheduling*: Each participant had two preoperative appointments to receive and trial the splinting intervention before surgery.	Out of the six patients contacted, three agreed to participate in the preoperative splinting intervention trial. The remaining three were interested but unable to commit due to prior commitments.	Response to this LEE activity demonstrated: - Patient interest in exploring preoperative splinting as a potential intervention. - Willingness of patients to participate suggests feasibility in recruiting for future studies, though the inability of the other three to commit highlights potential barriers related to scheduling and availability. - Scheduling conflicts prevented three interested patients from committing, highlighting the need for early recruitment to maximise participation.	*What Worked Well*: - Strong patient interest, even among those who declined, suggesting broader recruitment could succeed with more flexible scheduling. - Participants who agreed to take part were engaged and motivated, reinforcing feasibility for future trials. *Challenges & Areas for Improvement*: - Limited lead time restricted participation due to scheduling conflicts. Extending the recruitment period would allow for better planning and greater patient availability. *Next Steps*: - Conduct the splinting trial with the three recruited participants. - Gather patient feedback to refine the intervention and assess feasibility for future implementation.
2. Pilot Evaluation of Preoperative Splinting Intervention		The aim of this activity was to evaluate the feasibility, acceptability, and practicality of preoperative splinting for both patients and clinicians. *Key objectives included*: - Assess patient adherence and comfort when using the splint. - Identify challenges in fitting and time required for application. - Gather patient feedback on instructions, ease of use, and impact on daily activities.	Each participant attended two preoperative hospital visits. *First Appointment*: - Baseline joint measurements recorded. - Massage and stretching techniques performed on the affected joint. - Full-time circumferential cast applied to be worn until the second appointment. *Interim Follow-Up (1–2 Days Later)*: - Patients received a phone call to monitor comfort and adherence. *Second Appointment (3–7 Days Later)*: - Cast removed and joint re-measured to assess range of motion changes. - Patients provided feedback on comfort, adherence, and perceived benefits. *Data Collection*: - Objective Evaluation: Joint measurements taken before and after the intervention. - Patient Evaluation: Daily diary tracked pain levels, comfort, and functional limitations. - Therapist Evaluation: Assessment forms documented session duration and challenges in applying the cast.	The pilot trial of preoperative splinting showed: - Good patient adherence. - Minor comfort challenges and adjustments to daily activities were needed. - Initial discomfort and mild skin maceration occurred but improved over time. - All patients showed some improvement in ROM. - Reduction in joint circumference changes was observed. - Stretching tolerance and ease of splint application depended on contracture severity. - Patients found the protocol manageable.	The trial demonstrated good adherence levels, despite some minor challenges. All participants experienced improvements in active ROM, reinforcing the potential benefits of preoperative splinting. However, changes in joint circumference were inconsistent. A key finding was the variation in splint application ease and initial discomfort, which appeared to correlate with the severity of contracture. Additionally, one patient experienced mild skin maceration, emphasising the importance of ongoing skin integrity monitoring to prevent complications. Patient feedback was largely positive, with participants finding the protocol manageable. This supports the feasibility of implementing preoperative splinting as part of a structured intervention.	*What Worked Well*: - High Patient Adherence: Despite initial discomfort, all participants followed the protocol, supporting its feasibility. - Functional Gains: Patients reported improved function even while wearing the splint, highlighting its potential clinical benefit. - Protocol Simplicity: The intervention was well tolerated, with no major complications reported. *Challenges & Areas for Improvement*: - Skin Integrity Management: Mild maceration in one case highlights the need for better monitoring and patient education on skin care. - Stretching Tolerance: Patients with severe contractures found prolonged stretching difficult, suggesting a need for individualised adjustment schedules or extended casting duration. - Cast Maintenance: One participant struggled to keep the cast dry, highlighting the need for clearer care instructions. *Next Steps*: - Enhance Patient Instructions: Provide clearer guidance on splint maintenance, skin care, and activity adjustments as part of the patient information leaflet. - Develop a Standardised Protocol: Establish a structured protocol to support progression toward a larger clinical trial.

Table 3 (continued)

LEE/CE Activity	Date	Gripp2 reporting checklist				
		1: Aim Report the aim of the study	**2: Methods Provide a clear description of the methods used for LEE/CE in the study**	**3: Results Outcomes—Report the results of LEE/CE in the study, including both positive and negative outcomes**	**4: Discussion Outcomes—Comment on the extent to which LEE/CE influenced the study overall. Describe positive and negative effects**	**5: Reflections Critical perspective—Comment critically on the study, reflecting on the things that went well and those that did not, so others can learn from this experience**
3. Support the development of a trial protocol	10/24	The aim of this activity was to create a patient-centred feasibility trial protocol. By incorporating patient perspectives, the goal was to enhance clarity, and accessibility of study materials while maintaining scientific rigor. *Key Objectives included*: - Refine patient-facing documents to ensure clarity, readability, and accessibility. - Align trial design with patient priorities to optimise engagement and study impact.	To ensure meaningful LEE/CE integration in the trial protocol, a structured process was followed: - *Patient Consultation*: Steering committee members reviewed the study protocol and patient-facing documents for clarity and relevance. - *Feedback Collection*: Input was gathered via phone/video discussions, email, and tracked document comments. - *Iterative Refinement*: Suggestions were incorporated into revised materials, with follow-up discussions to ensure concerns were addressed.	LEE/CE involvement led to key refinements, including: - *Clearer Communication*: Patient information sheets were simplified, with medical jargon replaced or explained in lay terms. - *Improved Participant Information*: Additional details were included on what to expect before, during, and after participation. - *Greater Accessibility*: Large print documents were introduced to support diverse accessibility needs.	This LEE/CE activity played a vital role in refining the trial protocol, ensuring it was patient-centred and scientifically rigorous. By incorporating patient perspectives, the study design became more accessible, inclusive, and aligned with patient needs. Enhancements to patient-facing materials increased clarity, set clearer expectations, and reduced potential anxiety around participation. A gap in active involvement made re-engagement with steering committee members more challenging, emphasising the need for consistent communication to maintain long-term involvement.	*What Worked Well*: - An iterative review process allowed for meaningful patient input. - Simplified language and formatting made patient-facing documents more user-friendly. *Challenges*: - Some committee members were harder to reconnect with after a period of inactivity. Regular updates and ongoing communication are needed to maintain engagement and ensure continued LEE/CE input throughout the trial. *Next Steps*: - Implement revised patient materials into the trial protocol. - Enhance LEE/CE engagement by establishing consistent updates and check-ins to keep steering group members actively involved.

What? Participants to attend two preoperative appointments. The first to include therapist-led massage and stretching to improve soft tissue mobility [22], followed by a full circumferential cast to maintain prolonged stretch and support range of movement (ROM) gains [22–24]. Participants to be instructed to wear cast continuously until the second appointment. An interim phone call 1–2 days later to monitor comfort, adherence and concerns. At the second appointment, 3–7 days later, the cast to be removed, and ROM and skin integrity assessed. Patients to provide feedback on comfort, adherence, and perceived effects.
Evaluation to include:

- The time and ability to assess pre and post-intervention ROM measurements using a standard goniometer.
- Participants' daily diaries documenting pain levels, comfort, and any limitations in daily activities.
- Therapist assessment forms documenting patient interactions, recording session duration and challenges encountered during splint application.

Phase 3 - activity 3: development of a trial protocol

Why? To assess readability, clarity, and relevance of intervention material and alignment with patient and clinician expectation prior to ethics submission.

What? Steering committee members and pilot participants to review the draft protocol, information sheets, consent forms, and intervention instructions. Feedback to be gathered via phone/video discussion and email. Iterative revisions to be made with follow-up checks to confirm modifications and address concerns.

Results

Phase 1: establishing a LEE/CE strategy (Table 1)

Phase 1 - activity 1: enrolment on the public involvement in research module

Outcome: The preparatory module enabled the design of an involvement strategy grounded in established PPI definitions. The final approach combined two established operational definitions to guide the LEE/CE approach: *Embedded Consultation* and *Collaboration/Co-production*, balancing meaningful involvement with the practical constraints of postgraduate research. The aim was to pursue Collaboration and Co-production whenever possible, while maintaining meaningful Embedded Consultation that informed decisions and led to change. This multi-model approach has been used successfully in other postgraduate research [25].

Phase 1 - activity 2: exploratory meeting with chair of the British dupuytren's society

Outcome: Early engagement with the BDS highlighted the complementary value of both LEE and CE in delivering truly patient-centred research and confirmed strong patient interest in the research topic reinforcing the study's relevance to the Dupuytren's community. This informed two key decisions.

- Establishing a joint LEE/CE steering committee.
- Designing and disseminating a survey via BDS to increase patient reach.

Phase 1 - activity 3: engaging potential members for the steering committee

Outcome: A diverse steering committee was successfully assembled, comprising individuals with lived experience, clinical specialists, and patient-organisation representative. This ensured balanced expertise across the Dupuytren's care pathway.

Phase 1 - activity 4: first steering committee meeting

Outcome: Feedback from the meeting shaped both the intervention direction and survey content. Key insights included.

- LEE contributors prioritised clinical outcomes such as ROM.
- CE contributors emphasised functional recovery.
- All participants highlighted the importance of clear, accessible preoperative education, with LEE contributors requesting both digital and non-digital formats.

Differences between LEE and CE contributors highlighted the need for effective negotiation and informed the refinement of research priorities and survey design.

Phase 2: development of intervention content (Table 2)

Phase 2 - activity 1: steering committee feedback on preliminary LEE survey

Outcome: Steering committee feedback improved clarity, structure, and accessibility of survey questions (appendix 1). Language was simplified, redundant questions removed, and both functional and ROM outcomes included to reflect differing priorities. Although patient feedback was limited, follow-up conversations confirmed the final version aligned with their preferences. Survey refinement involved balancing clinical assumptions with patient priorities, ensuring joint input.

Phase 2 - activity 2: dissemination of survey via BDS

Outcome: 235 international responses to the survey was an exceptional result, reflecting substantial engagement from the Dupuytren's community (93% postoperative; 7% awaiting surgery). Key findings included.

- Strong willingness to undertake splinting and massage as apposed to exercise.
- Preference for face-to-face information delivery.
- Secondary preference for written/visual leaflets.
- Varied priorities for preoperative education content.
- ROM ranked as the most important outcome measure.

These insights directly informed intervention priorities and areas requiring refinement in Phase 3.

Phase 2 - activity 3: dissemination of survey results

Outcome: Dissemination of survey results to the steering committee and wider patient community reinforced the value of participant contributions. The summary poster was shared online and by email to support accessible dissemination. Committee members felt the survey accurately captured concerns and priorities, confirming intervention development was guided by meaningful patient and clinician insight.

Phase 3: refinement and optimisation of intervention (Table 3)

Phase 3 - activity 1: assessing willingness of patients to participate in preoperative splinting trial

Outcome: Three of six contacted patients agreed to trial the preoperative splinting intervention. Non-participation was due to scheduling conflicts rather than study burden, indicating acceptable feasibility for future recruitment.

Phase 3 - activity 2: pilot evaluation of preoperative splinting intervention

Outcome: The pilot demonstrated strong feasibility and acceptability, indicating.

- High adherence, with only minor discomfort or daily-activity limitations reported.
- Universal improvement in ROM, though swelling responses varied.
- Differences in stretch tolerance reflected baseline contracture severity.
- Patient diaries and clinician feedback indicated the intervention was practical, manageable, and perceived as beneficial.

These findings indicated successful intervention design.

Phase 3 - activity 3: development of a trial protocol

Outcome: Review by LEE/CE contributors led to substantial improvement in patient-facing materials, including.

- Simplified language.
- Clearer explanation of expectations across the treatment pathway.
- Availability of large-print versions.

These refinements enhanced clarity, supported informed decision-making, and increased likelihood of effective recruitment and retention.

Discussion

This study demonstrates the value of integrating LEE and CE in developing a preoperative therapy intervention for Dupuytren's fasciectomy. Evidence generated across Phases 1–3 shows involvement activities produce tangible improvements to intervention design and materials. This is consistent with existing literature, indicating that collaborative involvement between researchers, clinicians, and people with lived experience strengthens intervention design [26, 27]. The structured, phased LEE/CE approach, supported by transparent GRIPP2-reporting, aligns with evidence that multi-stage engagement enhances relevance, feasibility, and quality [17].

A key outcome is the development of an iterative involvement approach supporting engagement across multiple research stages. The steering committee provides a mechanism for integrating academic, clinical, and lived experience perspectives. Phase 1 steering committee discussions reveals differing preferences, patients prioritising ROM and clinicians emphasising functional recovery, necessitating the inclusion of both. This multidisciplinary collaboration ensures a balanced, practical approach to intervention development.

LEE/CE activities directly contribute to refining the research process and study materials, particularly during survey development. Steering committee feedback improves clarity and relevance of survey questions, consistent with wider literature showing co-designed tools better capture patient priorities and reduce response burden [28]. Dissemination through BDS enables wider participation demonstrating the value of close collaboration with patient organisations [29]. The high response rate demonstrates strong patient interest in preoperative therapy, emphasising the importance of incorporating their perspectives.

In contrast to wider physiotherapy literature, where patients typically favour active, exercise-based interventions [30, 31], survey respondents express a strong preference for passive modalities, particularly splinting and massage. This divergence may reflect the condition-specific context of DD, which many patients perceive as progressive and surgically managed, reducing expectations of active therapy. Importantly, this preference for splinting is reinforced during the next phase of LEE activity, in which patients awaiting surgery trialled a preoperative splinting intervention. Participants remain highly positive about the approach, demonstrating excellent adherence and reporting minimal disruption to daily function. As a result, the decision to centre the preoperative intervention around splinting is directly driven by LEE input. This provides a clear example of how lived experience shaped the direction, content, and practical design of the intervention, ensuring it aligns with patient priorities and real-world acceptability.

Another notable contrast is strong preference for face-to-face education, despite post-COVID research often reporting growing acceptance of remote rehabilitation delivery amongst patient populations [32]. This may be influenced by the participants' preference for passive interventions, many of which require in-person therapist application. It may also reflect the older age profile of this population, and a related reluctance, or difficulty engaging with digital technology. These findings highlight the value of incorporating condition-specific LEE/CE in research design. The pilot testing of preoperative splinting further reinforces these insights. Patient volunteers demonstrate willingness to engage, with their feedback informing refinement prior to trial implementation. Incorporating patient perspectives strengthens the clarity, accessibility, and acceptability of patient-facing materials.

Several enablers support the LEE/CE strategy, including early planning, use of multiple engagement formats and collaboration with BDS. However, challenges also emerge, most notably balancing inclusion of differing perspectives. This highlights the need for negotiation and consensus building between different contributors. Additionally, patient feedback is sometimes less extensive than that of clinicians and the BDS chair, consistent with literature noting confidence and perceived expertise can influence contributions [26]. Despite this, patients report their feedback has been well integrated, suggesting satisfaction with the study's direction. These observations emphasise the value of open communication, flexible involvement options and confidence building opportunities.

This study demonstrates how a phased, iterative LEE/CE approach, supported by the GRIPP2 framework, can be applied pragmatically within clinical research. The documented influence of LEE and CE on survey development, intervention refinement, and protocol design provides evidence of their equally valuable contributions. Given DD's lack of existing preoperative therapy guidance, implementation of complementary expertise was pivotal in developing an effective intervention acceptable to all. By providing a transparent account of the planning and implementation of LEE and CE, this study offers a model supporting future involvement strategies in hand therapy, surgical rehabilitation, and other fields seeking to embed meaningful, multi-perspective involvement.

Reflexivity and positionality

In the interest of transparency, we provide a joint reflexive account summarising the positionality of two main contributors who guided the involvement strategy: a clinical researcher, and a patient advocate. Positionality is recognised as an essential component of quality involvement reporting helping to illuminate how personal experiences, motivations, and assumptions influence decision-making within the research process [33].

As a clinical researcher, the lead author brings professional expertise in hand therapy but does not have lived experience of DD. This requires conscious attention to the limits of clinical knowledge and a deliberate commitment to embedding LEE throughout the project to ensure intervention development remains patient centred. From the perspective of the BDS chair as a patient representative, involvement carries different motivations, including ensuring the research address real patient needs, raising awareness of the condition, and enhancing the relevance of the emerging intervention.

These differing perspectives enrich the study offering complementary insight into feasibility, relevance and acceptability. A more detailed account of these two author's reflections, covering motivations, influence on decisions, perceived impact, and the challenges and benefits of the LEE/CE approach, is provided in Supplementary File 1.

Conclusion

This study demonstrates how integrating LEE and CE within a phased, iterative framework strengthens intervention development for Dupuytren's fasciectomy. Collaborative exchange between patients, clinicians, and researchers enable ongoing refinement, ensuring the intervention remains evidence-based, feasible, and genuinely reflective of real-world patient priorities. Key lessons for future research include the value of early and ongoing involvement, the need for structured yet adaptable involvement strategies, and the importance of clearly documenting how LEE and CE influence research decisions to avoid tokenism and maximise impact. These lessons will continue to inform subsequent stages of this doctoral research, ensuring continued responsiveness to LEE/CE feedback. Future work should explore how structured reporting frameworks such as GRIPP2 influence contributor engagement, strengthen intervention design, and support wider adoption of LEE and CE as core components of clinical research.

Supplementary Information

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Supplementary Material 1

Supplementary Material 2

Supplementary Material 3

Supplementary Material 4

Supplementary Material 5

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Author contributions

TBM: Conceptualisation, Methodology, Writing of Original Draft, Writing – Review & Editing, Project AdministrationAS: Writing of Original Draft, Writing – Review & EditingMH: Supervision, Writing – Review & EditingCC: Supervision, Writing – Review & EditingTC: Writing – Review & EditingEK: Writing – Review & EditingAll authors read and approved the final manuscript.

Data availability

Data is provided within the manuscript or supplementary information files. Any other data used during the current study are available from the corresponding author on reasonable request.

Declarations

Ethical approval

is not required for public and patient involvement and engagement activities.

Consent to participate, and consent to publish

Not applicable.

Competing interests

The authors declare no competing interests.

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