

Development and preliminary evaluation of an exercise-based telerehabilitation intervention for people with severe haemophilia

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BACKGROUND

- Chronic pain due to haemophilic arthropathy is reported by 30-71% of people with haemophilia (PWH). Exercise is shown to be effective for managing pain in other arthritides. It remains unclear if such an approach is safe, effective or acceptable to PWH.
- Study aim:** Evaluate the feasibility and acceptability of a telerehabilitation exercise intervention for PWH living with chronic pain using a mixed methods approach.

METHODS – Intervention development

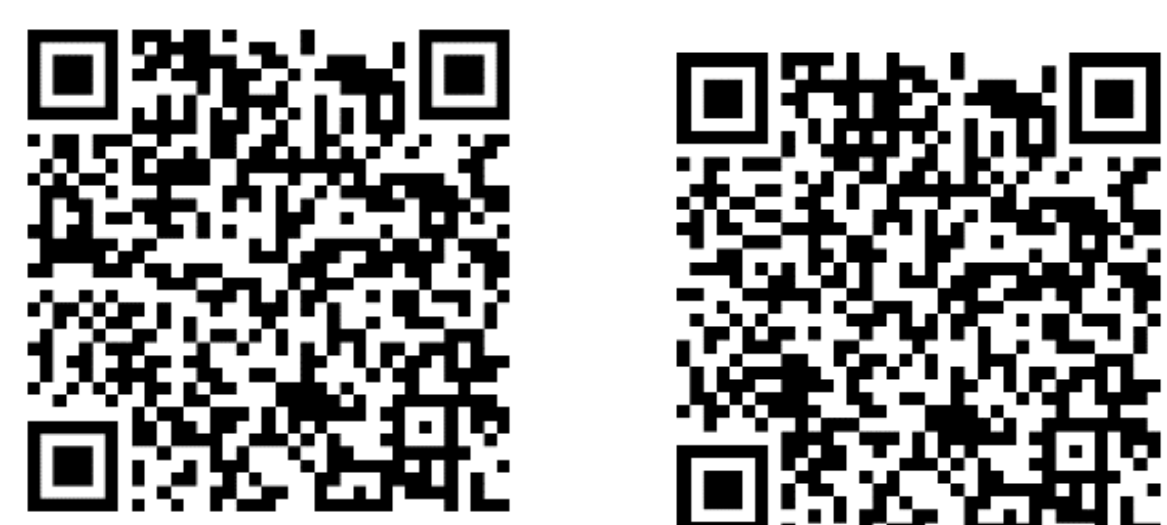
The **MRC Framework** for developing complex interventions was used to guide the process. (QR codes below link to associated content)

Review published literature, identify key uncertainties



Systematic review: Studies with poor methodological quality; low quality evidence for effect of physiotherapy interventions on pain, function and QoL in PWH.

Understand context



Qualitative Inquiry: Pain is a lifetime experience, part of identify alongside haemophilia. Pain management is discordant with haemophilia care. Exercise is acceptable if done with someone who understands their condition.

Work with stakeholders to develop and refine programme theory

Programme theory: Identified needs, barriers & activities for recruitment/ study participation, plus outcome measures of interest.



Refine and describe intervention



Study protocol: Behaviour change techniques mapped to theory, protocol refined and study registered: ISRCTN 17454597 = The '**RE**habilitation for **M**anaging **A**rthritic **P**ain' in Haemophilia Study

METHODS – The 'REMAP-Haemophilia' feasibility study

Study Design: Multi-site, non-randomised, pre-post feasibility study with explanatory, sequential nested qualitative study.

Population: PWH (Severe), >18 years, living with chronic pain

Intervention: 12 individualised, low impact/moderate intensity exercise sessions (6 individual, 6 group) and 3 knowledge sharing/discussion sessions. Real time delivery over MS Teams.

Primary Objectives: Feasibility and acceptability: safety recruitment rate, adherence, fidelity of delivery and intervention acceptability

Secondary Objectives: Preliminary evaluation on outcomes of pain (BPI-SF, PSEQ), function (HAL, PSFS) and quality of life (EQ5D-5L, MSK-HQ)

RESULTS – Feasibility and acceptability

Quantitative results

- Ten male PWH, aged 39-67 were recruited from 2 sites (100% recruitment rate); 8 people had 4 or more joints with arthropathy
- Overall virtual attendance was 68.3% (Threshold for success = 75%). Individual/group session attendance was 84.5%/52.1% respectively
- Study protocol: Delivered as described 80.4% of the time (19.6% delivered over telephone not webcam).
- No serious adverse events were reported
- Outcome measures completion: 100% at baseline and 70% post intervention. (Threshold for success = 75%)
- Group median showed minimal change in all outcome measures post intervention

Qualitative results

- Nine PWH and 2 physiotherapists were interviewed
- Virtual delivery: Minimal burden on time and travel for PWH – but created extra administration and time required for the physiotherapists
- Condition specific, individualised exercises enabled inclusion and sense of safety in taking part
- Group sessions: Personal preference for attendance
- Feeling a change in physical ability, exercise skills and fitness over time helped increase enjoyment
- Outcome measures: Too generic, failing to capture other positive subjective experiences
- Participants felt benefits in general wellbeing, mood, and motivation to do more than change in their pain

CONCLUSIONS

- Exercise-based telerehabilitation is safe, feasible and acceptable for PWH with chronic pain
- Further work should determine which outcome measures are most suitable for interventions such as this with PWH