

Research Methods

Involving older people in co-designing an intervention to reverse frailty and build resilience

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Abstract

Background: An essential consideration in health research is to conduct research with members of the public rather than for them. Public and patient involvement (PPI) of older people in research can improve enrolment, relevance and impact. However, few studies with PPI in frailty research have been identified. PPI has fallen during the Covid-19 pandemic.

Objective: We aimed to involve older people in co-designing a randomised control trial (RCT) intervention to reverse frailty and build resilience. We also wished to encourage wider use of PPI with older people by outlining our approach.

Methods: Involvement of older people was undertaken in three stages. Eighteen over 65-year-olds helped co-design an exercise intervention in two group discussions using the Socratic education method. Ninety-four contributed intervention feedback in one-on-one telephone interviews over nine months. Ten contributors helped optimise the intervention in three online workshops. Multidisciplinary team input and systematic review supported co-design.

Results: Eleven home-based resistance exercises were co-designed by group discussion contributors (mean age 75, 61% female). Frailty intervention format, gender balance and GP follow-up were shaped in telephone interviews (mean age 77, 63% female). Dietary guidance and patient communication were co-designed in workshops (mean age 71, 60% females). Technology proved no barrier to PPI. The co-designed frailty intervention is being evaluated in a definitive RCT.

Conclusions: We enabled meaningful the involvement of 112 older people in the co-design of an intervention to reverse frailty and build resilience in diverse ways. Inclusive involvement can be achieved during a pandemic. Feedback enhanced intervention feasibility for real-world primary-care.

Lay Summary

Our research paper describes how we involved 112 older adults in the co-design of an intervention aiming to reverse frailty and build resilience. Involving participants in research can improve its feasibility and impact. However, there have been few studies involving older people in frailty research and involvement has fallen further during the Covid-19 pandemic. Involvement of older people was undertaken in three stages. Eighteen over 65-year-olds helped co-design an

Key Messages

- Public and patient involvement is an essential consideration in health research.
- There are few guidelines or studies involving older people in frailty research.
- PPI has fallen further during the Covid-19 pandemic.
- Meaningful patient involvement can be achieved during a pandemic.
- Communication technology proved no barrier to contribution.
- A co-designed intervention, founded on PPI, improved its feasibility.

exercise intervention in two group discussions. Ninety-four older adults contributed intervention feedback in one-on-one telephone interviews over nine months. Ten contributors helped optimise the intervention in three online workshops. The co-designed intervention involved resistance exercises and dietary guidance and will be tested in a full randomised control trial. We enabled the meaningful involvement of 112 older people in our research in diverse ways. Inclusive involvement can be achieved during a pandemic.

Key words: Frailty, older people, PPI, primary-care, public and patient involvement, resilience

Introduction

Public and patient involvement (PPI) in health involves undertaking research *with* members of the public rather than *for* them (1). It has become an essential consideration in health research culture and is a requirement for funding in several countries (2–4). However, evidence for how to conduct PPI in health research remains limited (5,6). Few studies implementing PPI with older people in frailty research have been identified (7–10), despite benefits that can be achieved such as improved enrolment, relevance and dissemination (6). Furthermore, recent evidence highlights a drop in public and patient involvement during the Covid-19 pandemic (11,12).

We set out to involve older people in co-designing a randomised control trial (RCT) intervention to reverse frailty and build resilience. We aimed to ensure their priorities were at the intervention's core to increase its feasibility in a real-world primary care (PC) setting. We also wished to encourage wider use of PPI in research with older people by outlining our approach.

Boote *et al.* describe three key arguments for conducting effective PPI (13). The benefit of informing research design with the experience and insights of patients underpins the epistemological argument (14). The right of the public to be involved in research that may shape publicly funded health care underlines the moralistic argument (15). Involvement of patients and public in improving the quality, relevance and impact of research reinforces the consequentialist argument (16).

A review of PPI approaches has identified six factors that contribute to effectiveness (17): a shared understanding of the PPI purpose; a key individual co-ordinating PPI; a diversity of PPI contributors; a positive attitude in the research team to PPI; and PPI effectiveness evaluated by the team.

Frailty has been described as the most problematic expression of population ageing (18). It is a state of vulnerability to external stressors that increases the risks of serious illness, falls, dependency and disability (18,19). Prevalence is estimated at 11% in adults aged over 65 and 50% in those aged over 80 (20). The challenge of frailty is heightened by our aging population and increased life expectancy. Physical resilience may be regarded as the opposing end of a health spectrum with frailty (21). Resilience reflects the capacity to recover

following exposure to external stressors (22). Screening for frailty by General Practitioners (GPs) is now an established international best practice. However, there has been little guidance on the best interventions to address frailty and improve resilience until recently.

A recent systematic review of frailty interventions in PC (23), followed by meta-analysis (24), found that frailty can be delayed and even reversed. Interventions with both muscle strength training and protein supplementation consistently scored highest for effectiveness and ease of implementation and demonstrated significant health benefits. These interventions are rarely offered to older people with frailty or sarcopaenia (25).

We aimed to build on these review and meta-analysis findings and involve patients and public in co-designing a definitive intervention to reverse frailty and build resilience. We aimed to develop such an intervention, founded on inclusive PPI, for trial and ultimately encourage mainstream adoption of an approach to improve health outcomes for all older people attending primary care.

Methods

Involvement of older people in co-designing our RCT intervention was undertaken in three stages (a schematic is shown in Fig. 1). Their involvement overlapped with the Covid-19 pandemic. No prior relationship with participants had been established before the study. Study and investigator information was provided to participants. The research team comprised a GP, two geriatrician consultants and a university expert in PPI of older people in medicine. We ensured a diversity of involvement opportunities as outlined below.

Firstly, 27 community-dwelling adults, aged 65 and over, attending a weekly health education programme in a hospital on aspects of ageing (26) were invited to join dedicated discussions on frailty and to co-design an exercise intervention. Eighteen agreed to be involved in two, hour-long, group discussions, facilitated by JT. We discussed four key aspects of frailty, namely: definition, risks, screening and interventions. The Socratic education method (27) was used in discussions. This dialectical method involved using open questions to clarify people's beliefs and assumptions, then build enhanced insight into frailty and resilience. We assessed practicality

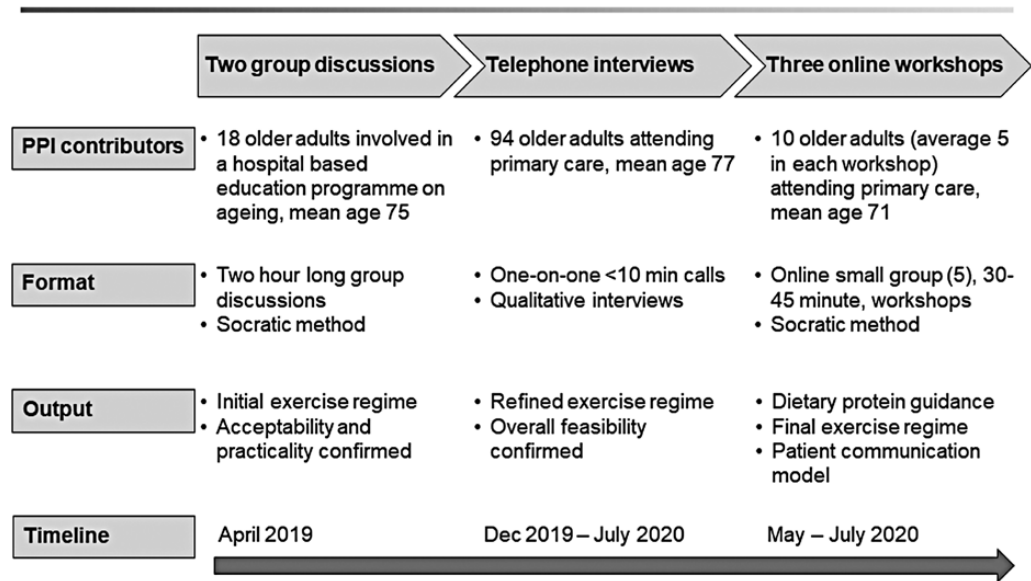


Figure 1 Public and patient involvement stages in co-designing a primary care frailty intervention with community-dwelling adults, 2019–20

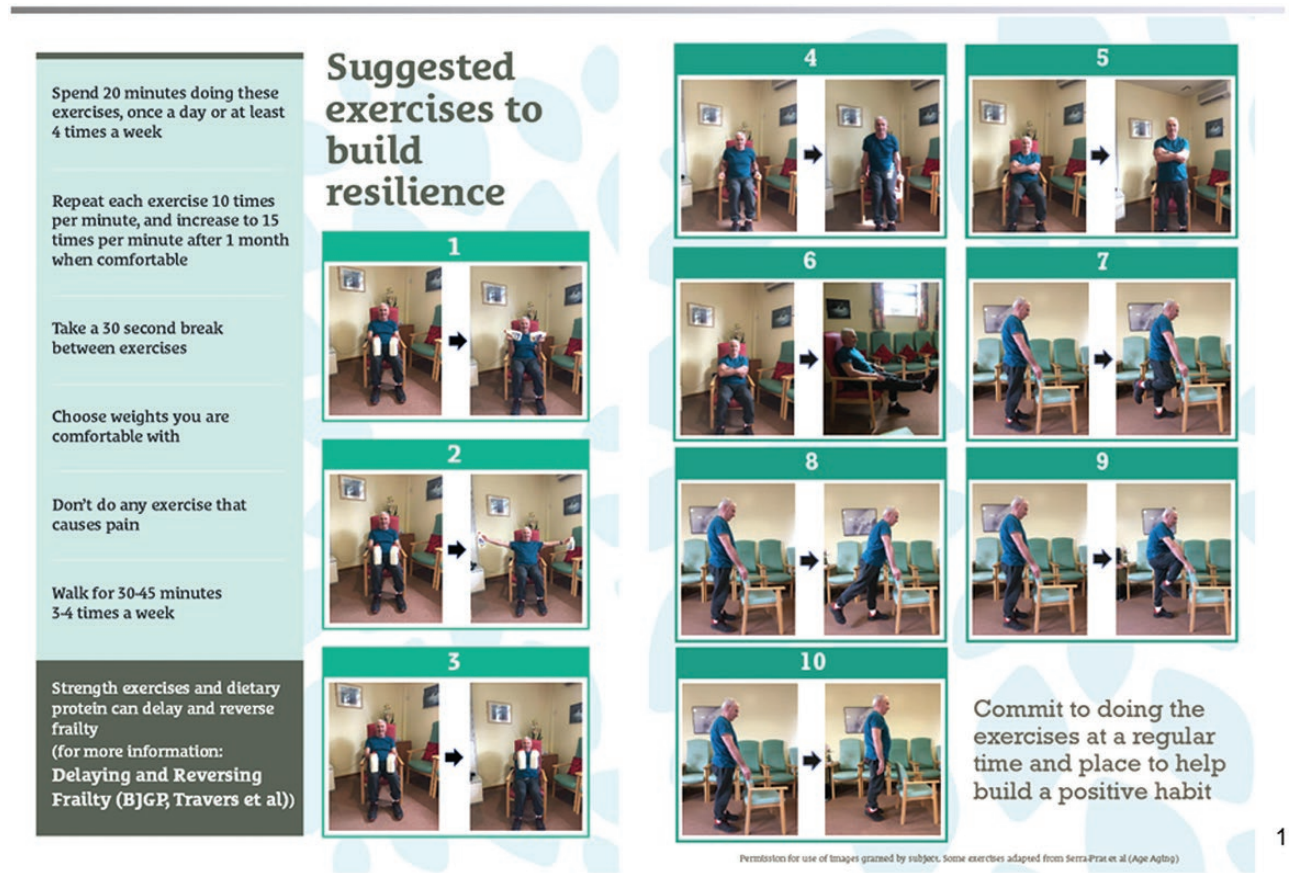


Figure 2 Exercise intervention co-designed with public and patient involvement of community-dwelling older adults, 2019–20

and demand for an exercise intervention. We designed a regime and format based on feedback. We involved a physiotherapist in refining exercises that had been drawn from the interventions that scored highest for effectiveness and ease of implementation in the

systematic review and meta-analysis. We provided and demonstrated the draft regime (Fig. 2) in the second meeting and sought feedback. Secondly, 94 older adults agreed to be involved in contributing feedback on the exercise regime over nine months, helping to refine

Workshop 1**Themes: Introduction, definitions and communication**

- Welcome and thanks. Introductions of participants and ice-breaker (10 mins)
 - Can you each say your name, where you come from and what your favourite form of exercise is?
- Review of the workshops aims and objectives
- Discussion on what frailty and resilience mean and the benefits of exercise and protein consumption (15 mins)
- Discussion on how people would like GPs to engage/ communicate on the topics of frailty and resilience (20 mins)
 - Do you think it is reasonable for a GP to raise the topics of frailty and resilience during a consultation?
 - Does it matter whether a GP, nurse or physio engages on these topics?
 - How do you think these topics can be discussed in a way that is most helpful? (probe: helpful language)
 - What other advice would you have on engaging people on these topics?

Workshop 2**Theme: Content of the exercise intervention**

- Shaping an exercise regime (30 mins)
 - Considering the exercise regime offered for the feasibility study: What works well? What would you change?
 - How would you like the exercises to be presented? (probe as needed: paper leaflet vs. video vs. mix vs. other?)
 - How should we consider gender in the portrayal of the exercises?
 - How important is it for the exercises to be demonstrated?
 - How helpful would an initial group demonstration session be?

Workshop 3**Theme: Dietary guidance and follow up support**

- Discussion on how dietary protein can support resilience (15mins)
 - What forms of protein do you think are easily available/ affordable? What are your favourite protein foods?
 - Do you have suggestions for how we can share information on having sufficient protein in a diet?
- Clinical follow-up and support (15mins)
 - Once a person has started the intervention, what follow up contact from the GP is acceptable and helpful (probe as needed: follow up call(s) vs. text vs. online engagement; appropriate frequency)?

Figure 3 Public and patient involvement workshop themes and questions, 2020

the regime prior to RCT. We offered the exercise regime to consecutive older adults presenting for routine consultations at a PC centre [aged 65 and over, with a score of 5 (mildly frail) or less on the Clinical Frailty Scale (CFS) (28); not in need of emergency care, residential care or diagnosed with dementia]. Participation rate was 88% (94/107). They were offered the pictorial leaflet with resistance-based exercises developed in stage one (Fig. 2). The GP (JT) described the syndrome of frailty, how resistance exercises can help strengthen muscles and bones and demonstrated the exercises. Demographic details and health indicators [vital signs, BMI, handgrip strength, multi-morbidities, SHARE Frailty Instrument (SHARE-FI) score and CFS] were recorded.

The principal investigator (PI), JT, conducted one-on-one telephone interviews with all 94 contributors at two months, listening to feedback on the exercises. We sought feedback on ease of doing the exercises, compliance, self-reported benefits to general health on a Likert scale and asked an open question as to how the exercise regime could be improved or changed. Feedback was transcribed in pseudo-anonymised format by JT, synthesised and codified in Microsoft Excel and key themes were identified by Framework analysis (29).

Thirdly, we convened three online focussed workshops with an average of five older adults, to optimise our patient communication model, develop dietary protein guidance and refine the exercise regime for the RCT. Two researchers (JT and MTC) co-chaired the discussions.

Twelve contributors who were familiar with the exercise from the second stage and represented a diversity of age and gender were invited to join the workshops. Ten agreed to join. The average workshop attendance of five PPI contributors and two researchers aligned

with the best practice of group size 6–10 for conducting both group-based action learning (30) and focus group activity (30,31).

The online format was chosen to facilitate safe gathering of older people during the Covid-19 pandemic and to conform to national health care guidelines. An audio dial-in facility was provided using secure 'MeetUpCall' software (32) and was free to use for contributors. Contributors were called and invited by the automated message to press one button to join the meeting. The first workshop was designed for 45 minutes and the subsequent two workshops for 30 minutes each.

Key themes and questions for each workshop were prepared in advance (Fig. 3). A Socratic approach of open questions with active listening was used in order to ensure the voices of the non-researchers were primarily heard. The content of workshops was transcribed in pseudo-anonymised format by the PI in Microsoft Word. Summaries of the workshops were validated by the supervisor (MTC). Content analysis was undertaken by JT and MTC.

Key PPI feedback was synthesised and codified through a collaborative effort of the research team under the headings of: 'patient engagement and communication model', 'exercise regime' and 'dietary guidance'. Analysis used both an inductive and deductive approach.

Finally, in order to inform co-design in parallel with PPI, we secured multidisciplinary involvement from physiotherapists, dieticians, geriatricians/gerontologists and GPs. Our proposed exercise regime was shared by email for feedback with a public health team of 80 physiotherapists. A physiotherapy manager and the lead physiotherapist for older people and frailty interventions synthesized feedback from email responses and a group zoom meeting. Two nutritionists for older people were consulted in the design of the protein dietary guidance. Six GPs at two PC centres provided input into



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Figure 4 Exercise intervention refined with the female model and one exercise removed

shaping the intervention and its communication to patients. Three geriatric medicine consultants at three teaching hospitals provided input and supervision in developing the intervention. Input from these helped to inform our PPI activities.

Results

Eighteen over-65-year-olds attended the initial group discussions [mean age 75, 11 females (61%)]. They confirmed patient demand for information and interventions on frailty and resilience. A regime of eleven resistance-based exercises was developed and shared with the group for feedback.

One-on-one telephone calls conducted with 94 contributors aged 65 and over [mean age 77, 59 females (63%)] provided a strong endorsement for the exercise intervention and insights for further improvement.

Contributors described the exercises as easy to follow and do. 87% described exercises as either 'very easy' or 'somewhat easy', 7% 'neither easy nor hard' and 6% either 'somewhat hard' or 'very hard' after two months. A majority reported improvements to general health as a result of the exercises. 66% felt either 'much better' or 'slightly better', 34% 'about the same', 0% 'slightly worse' or 'much worse'. Many reported mental health benefits, including reduction of anxiety during the Covid-19 pandemic lockdown.

We discussed formats for sharing the exercises, including leaflets or videos. Universal preference was for exercises shown on a leaflet. Several contributors described how the leaflet was a helpful physical reminder. One left it at their bedside and exercises became part of their waking routine; another left the leaflet beside his daily

medications and said that he felt the exercises gave him more benefit than any of the pills.

Two female participants commented they would prefer photos of a woman doing the exercises. This led us to produce leaflets with male and female models (Fig. 4). Feedback from contributors and physiotherapy colleagues highlighted one exercise involving shoulder abduction that we removed to reduce the risk of rotator cuff strain (no adverse event had been reported).

Contributors described the follow-up telephone call from a GP as helpful motivation and suggested this be incorporated in the intervention design for the RCT.

The three online workshops provided input in co-designing the protein dietary guidance, refining the exercise regime and optimising the patient communication model. The three workshops involved 10 participants in total with an average of five present per workshop [mean age 71, 6 female (60%)].

The key messages from contributors in designing dietary protein guidance were:

1. There had previously been little understanding of recommended daily amounts of dietary protein and how this contributed to muscle strength and general health.
2. The clear preference for means of information sharing was a well-illustrated/pictorial leaflet with information on sources of protein, amounts per serving, daily intake guidance, suggested meals and recipes (being mindful of cost).
3. Participants were open to the idea of taking a protein supplement. While recognizing that sufficient protein could be consumed in a balanced diet, protein supplements may be helpful to

some to ensure habitual consumption and to others to 'top up' if diet were occasionally lacking.

4. The environmental impact of various food sources was not of large concern. Cost was a concern.

The key messages from contributors in refining the exercises were:

1. The exercises are valued by everyone. They are easy to do and make a difference to energy, mobility, strength and an overall feeling of wellness.
2. The regime can create a new mindset to stay physically healthy and strong, see opportunities to exercise in daily tasks and take up complementary forms of exercise.
3. Consider changing the pictures to a more appealing setting and ensure a gender balance.
4. A video might be appealing to some. However, the leaflet is the primary means to share the exercises. It is a daily visible reminder to do them and can be incorporated in daily routine.
5. Home-based exercises are preferred over a group setting to maintain personal autonomy in how they are done.

The key messages from contributors in designing the patient communication model were:

1. It is appropriate and reasonable for a GP to raise the topics of resilience and frailty in a regular consultation and the interest taken is welcome.
2. It would not matter which health care professional raised the topics.
3. The approach used to engage participants on resilience and frailty was seen as appropriate: i.e. raising the topics during a normal consultation, offering a brief educational discussion on frailty and resilience, inviting a person to try the intervention (without pressure), calling (with consent) to check in on progress.
4. Frailty is not a negative concept. Engage on this topic as it can be of benefit.
5. The intervention leaflets are appropriate and easy to follow.

We found that the use of communication technology helped to overcome restrictions to physical meetings during the Covid-19 pandemic and proved no barrier to involvement. Contributors readily agreed to be involved and gave positive feedback about being invited to contribute. No technical difficulties were encountered. Contributors universally preferred audio rather than video gatherings. Several expressed how they would miss the gatherings on completion.

Discussion

Involvement of public and patients in research is distinct from participation. Contributors to our research were actively involved in early design and direction of our RCT intervention in the three PPI stages, prior to actual trial recruitment, participation or feedback. Involvement is also distinct from engagement, which might include outreach activities, media publications or research open days for public and patients (33). Mindful of terminology, community-based participatory research (CBPR), more often applied in North American studies has similarity to PPI, more typically described in UK/European studies. Both involve community members in early design and guidance of research. However, while the PPI approach has been described as formal and 'top-down' with contributors often sitting on research committees (34), CBPR involves contributors in more informal community settings, beyond the constraints of research or medical settings, an advantage we sought to apply in our approach.

We noted a common belief among contributors that frailty was an inevitable consequence of growing older. It was the source of hopeful encouragement for all involved to be able to unpack assumptions and achieve shared insight that frailty may in fact be delayed or reversed with simple interventions.

Positive contributor feedback reinforced the team's motivation to advance an RCT (35) of the co-designed intervention involving 180 participants in six PC centres in Ireland.

It is hoped results can encourage mainstream adoption both of interventions to reverse clinical frailty and build resilience in primary care and also PPI in health research with older people.

Comparison to existing literature

Four studies undertaking PPI in frailty research have been identified (7–10). Only two were community-based (9,10). All used a single means of engagement – workshops or interviews. One study, co-designing delivery of care for frail patients in an Irish hospital, involved ten PPI contributors in six workshops over 18 months (7). A UK hospital study examined how care participation of frail patients could be enhanced in 19 patient interviews (8). A Puerto Rican community-based study on care needs of older adults was explored in five workshops over five years with an average 9.5 contributors (9). Lastly, a UK community-based study exploring rehabilitation potential in frail adults conducted five workshops with 28 contributors, including clinicians, over two months (10).

Characteristics of our study that appear to be unique in the literature include use of telephone or online communications technology to enable PPI; use of more than one format of engagement; and the scale of participation, with 112 contributors.

Strengths and limitations

A key strength of this study was realisation by patients of the importance of their role in improving health outcomes. Patients were placed at the heart of research that affected them directly. The diversity of ways to contribute and settings (hospital/community) as well as the large number of contributors enabled diverse feedback, meaningful involvement and avoidance of PPI exclusivity or tokenism (36).

The risk of selection bias existed in each of the three PPI stages. Contributors to stage-one group discussions were already attending an existing hospital-based education programme. Contributors to the telephone interviews and online workshops were limited to patients attending a single PC centre. A limited number of contributors were invited to join the workshops to keep to group size best practice (30,31). Although the hospital and centre serve diverse socio-economic groups, this limited data geographically and increased the risk for unconscious investigator bias. Efforts were made to reduce this bias by offering group discussion and telephone interview participation to every single person presenting, and by ensuring diversity of age and gender in the workshops. High participation rates of 18/27 (67%) in the hospital, 94/107 (88%) for telephone interviews and 10/12 (83%) for workshops in the PC centre also mitigated potential bias.

Measuring benefits to health resulting from the intervention was limited to self-reporting rather than objective efficacy measures as the emphasis of this study was on the subjective feedback. The measurement was recorded by the same person who was involved in co-design and delivery of the intervention. This bias was mitigated by using the same question wording with each contributor and using open questions in interviews. These limitations will be addressed in the definitive, multi-centre RCT (35).

Conclusions

We enabled the meaningful involvement of 112 older people in the co-design of an intervention to reverse frailty and build resilience in diverse ways, such as group discussions, one-on-one interviews and focussed workshops.

Our paper demonstrates that inclusive involvement can be achieved during a pandemic, despite physical restrictions.

Contributions shaped the format for sharing the intervention, gender balance in portraying the exercises, the content of dietary guidance and the language and approach for patient communication. This feedback enabled us to enhance the feasibility and relevance of a real-world PC intervention for a definitive RCT (35).

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Ethical approval: ethical approval was granted by the Irish College of General Practitioners research ethics committee on 9 November 2019.

Conflict of interest: there are no conflicts of interest.

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