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From participation to partnership: why citizen science matters in osteoarthritis research

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Abstract

Patient and stakeholder engagement is increasingly promoted to improve the relevance, feasibility and ethical quality of osteoarthritis research. The scoping review by Rucci et al. provides a useful map of this emerging field, showing that active patient involvement in OA research remains limited, inconsistently reported and concentrated mainly in priority setting and study design. However, citizen science should not be used as a simple synonym for patient and public involvement, patient engagement or co-production. This commentary argues that citizen science may represent a more participatory extension of established engagement models, but that its value in OA research should be tested rather than assumed. Future studies should clarify terminology, avoid tokenism, address representativeness and conflicts of interest, compensate contributors appropriately, and evaluate engagement using measurable indicators and reporting frameworks such as GRIPP2 and PEIRS.

Introduction

The scoping review by Rucci, Caldo and Ferracini addresses an underdeveloped area in osteoarthritis (OA) research: the transition from patients as study participants to people with lived experience as contributors to research decisions[1]. Its main value is to show that this field is still early, heterogeneous and incompletely reported.

Only a small number of OA-specific sources described active involvement beyond study participation. Engagement was concentrated mainly in priority setting and protocol development, with less evidence of sustained influence in governance, analysis or interpretation[1]. This should temper strong claims that citizen science represents a ready-made paradigm shift. It is better framed as a promising approach whose value still needs to be specified, tested and measured.

Conceptual boundaries

A necessary first step is conceptual precision. Patient and public involvement (PPI) generally refers to research conducted "with" or "by" patients rather than merely "on" them[2,3]. Patient engagement is broader and may include consultation, advisory roles, dissemination or shared decision-making[4,5]. Patient partnership implies a sustained reciprocal relationship, while co-production suggests shared influence over design, conduct, interpretation and implementation[6,7].

Citizen science should not be used simply as a more attractive synonym for these terms. In OA research, it may be understood as the most participatory end of this spectrum, particularly when non-professional contributors help generate, refine and translate knowledge[8]. It should therefore complement, rather than replace, established PPI frameworks.

What the evidence shows — and what it does not

The review supports the plausibility that patient involvement can improve research relevance, feasibility, recruitment materials, outcome selection and dissemination[1,4,5,9]. However, plausibility is not proof of superiority. Much of the available literature is descriptive, qualitative or based on case examples, and the OA-specific evidence base remains small[1,9,10].

The key question is therefore not whether involvement is desirable in principle, but which model works best for which research question. More participatory approaches may be especially useful when lived experience directly affects validity: choosing outcomes that matter to patients, assessing the acceptability of exercise and weight-loss programmes, designing conservative care pathways, supporting adherence, clarifying arthroplasty decision-making and translating results into community practice[11-16].

Risks and limitations

Patient involvement is not automatically meaningful. Tokenism may occur when contributors are invited after major decisions have already been made, when their role is symbolic, or when their feedback has no visible effect on the study[3,6,17]. Selection bias is another concern. Contributors may be highly educated, digitally connected and advocacy-oriented, and may not represent people with severe disability, low health literacy, socioeconomic disadvantage, multimorbidity or limited access to care[3,17].

Conflicts of interest also require explicit management, particularly when patient organizations receive industry funding or when contributors have strong treatment preferences. Engagement also requires money, time and administration. Recruitment, onboarding, training, compensation, accessibility measures and facilitation increase workload and may slow decision-making[3,4,9]. These costs are not arguments against involvement; they are reasons to plan and evaluate it rigorously.

Practical implementation

A pragmatic model for OA studies should be proportionate to the project. At minimum, investigators could establish a Patient Advisory Board at project inception, define responsibilities in written terms of reference, and include one or two patient research partners on steering committees, especially in studies of rehabilitation, conservative care, digital tools or surgical decision-making[4,7,18].

Contributors should receive orientation on study aims, methods, confidentiality and expected workload. Compensation should be budgeted from the beginning and should cover time, travel, parking, caregiving costs and digital access when relevant[3,4,9]. Researchers should also close the feedback loop by explaining which suggestions were adopted, which were not, and why. Without this step, involvement remains consultative rather than influential.

Measuring impact and equity

Future OA studies should move beyond stating that patients were involved. Process indicators may include timing of involvement, diversity of contributors, training provided, compensation offered, attendance and the proportion of patient suggestions implemented[6,19-21]. Research-impact indicators may include changes to eligibility criteria, intervention burden, recruitment strategy, outcome measures, dissemination formats and patient-facing materials[4,9,20,21].

Qualitative evaluation should examine whether contributors felt respected, prepared and able to influence decisions. The Guidance for Reporting Involvement of Patients and the Public 2 (GRIPP2) can improve transparent reporting, while the Patient Engagement In Research Scale (PEIRS) can help assess engagement quality from the patient perspective[19,20]. Equity should be measured rather than assumed, including representation of older adults, people with multimorbidity, low digital literacy, mobility limitations and under-resourced communities[3,17].

Feasibility across settings

Feasibility will vary across healthcare systems. In low- and middle-income countries (LMICs), and in under-resourced research environments, formal boards, repeated meetings, paid roles and digital platforms may be difficult to sustain. Citizen science models may therefore need to be simplified: smaller advisory groups, community-based recruitment, telephone or hybrid meetings, reimbursement of direct costs and collaboration with local patient organizations may be more realistic[3,4,17].

The aim should not be to impose one universal model, but to define a transparent, proportionate and non-tokenistic approach for each study.

Conclusion

The review by Rucci et al. highlights an important gap: patient involvement in OA research is increasingly discussed, but its implementation remains uneven, incompletely reported and rarely evaluated with standardized tools[1]. Citizen science may offer a useful extension of PPI when it implies sustained contribution to agenda-setting, governance, interpretation and dissemination. However, its value should not be assumed.

The next phase of OA research should test which models work best, in which contexts, and at what cost. A practical example is the APPROACH consortium, where patient input helped adapt procedures to reduce participant burden, including changes to blood-sampling logistics[9]. This illustrates the strongest argument for patient involvement: not rhetorical endorsement, but concrete improvement of research feasibility. If implemented with methodological caution, adequate resources and equity safeguards, citizen science can become a practical route toward more relevant, inclusive and translatable OA research.

Statement on use of AI

ChatGPT, an AI-based language model developed by OpenAI (San Francisco, CA, USA), was used to assist with language refinement and editorial restructuring of selected parts of the manuscript. All intellectual content, critical interpretation, bibliographic selection, and final decisions remained under the responsibility of the authors, who reviewed and approved the final manuscript.

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