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Making space to listen: engaging people with a chronic condition and various health literacy levels as citizen researchers

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Abstract

Background Despite growing calls for patient and public involvement (PPI) to improve research relevance and inclusivity, it is still too often implemented in a tokenistic way. Health inequalities persist, and vulnerable populations, such as people with chronic conditions and/or limited health literacy (LHL), remain underrepresented as active participants in research. Factors contributing to this underrepresentation include complex research language, unfamiliar settings, and social stigma. To bridge the gap, this study aims to offer practical lessons that provide researchers and policymakers with concrete strategies for creating inclusive and effective research collaboration processes.

Methods A participatory action research approach was used, guided by the first three stages of the Participatory Research to Action (PR2A) framework: readiness, discover, and define. Data were collected across five group sessions with ten individuals with type 2 diabetes and various health literacy levels. The analysis focused on process-related data to explore recruitment, facilitation strategies, and participatory experiences.

Results Effective recruitment relied on a multifaceted community outreach approach, combining online and offline channels, which improved group diversity. Clarifying expectations at the outset and balancing structure and flexibility supported meaningful contributions, and allowed sessions to be adapted to individual needs. This approach fostered factors central to motivation and group cohesion, including a collective purpose and mutual respect, while recognising the varied experiences of managing diabetes. Equitable engagement between citizen researchers and PPI facilitators was essential to valuing diverse perspectives and maintaining shared responsibility. Creative co-creation strategies, including sketching and small-group exercises, proved more effective in promoting accessible, inclusive engagement than text-based or plenary-only methods.

Conclusions The study demonstrates that recruiting and engaging citizens with type 2 diabetes and various health literacy levels as citizen researchers is feasible when conditions such as equitable partnership and engagement, clear expectations, and flexible structures are met. Creative co-creation strategies further support accessible and meaningful participation. These insights provide practical guidance for researchers seeking to implement inclusive PPI, contribute to reducing health inequalities, and inform the next stages of the PR2A framework for advancing participatory health research.

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Plain English summary

More and more researchers understand that it is important to do research together with people who have chronic conditions. Unfortunately, it still happens too often that they are not listened to enough and are not allowed to help make decisions. This is especially true for people in a vulnerable position, such as people with chronic conditions and people who find it difficult to find, understand, and use health information. Two researchers brought together ten people with a chronic condition (type 2 diabetes). They form a group that shares experiences and talks about what they feel is lacking in their diabetes care. This article describes how to start such a group and how this group can meaningfully participate in research. To find people with a chronic condition, researchers can go to places where they often spend time. Current group members can also encourage others to join. During the five meetings, the group spent a lot of time getting to know each other. This helped everyone feel free to share their thoughts about the group and the group process. It is important that researchers spend enough time creating an open and safe environment, setting clear expectations, and treating each other with respect. Depending on who is in the group, the language used must be adjusted. In this way, people with chronic conditions can take part in research and share their opinions. By doing research together with people in a vulnerable position, we hope to improve healthcare. See Additional file 1 for the Plain Dutch summary.

Keywords Patient and public involvement, Citizen researchers, Research engagement, Chronic conditions, Health literacy, Health inequalities, Type 2 diabetes

Background

Patient and public involvement (PPI) is increasingly recommended and recognised as necessary for ensuring the relevance and quality of research endeavours, particularly in the context of person-centred care for people with chronic conditions [1–3]. This approach involves conducting research “with” or “by” the population it concerns rather than merely “about” or “for” them [1]. Given that patients with chronic conditions often require continuous care, PPI can ensure that research remains relevant by aligning healthcare innovations with individuals’ changing needs and preferences [4, 5]. By involving patients, more accessible and inclusive innovations can be developed, leading to improved health outcomes and reduced healthcare costs [6]. Additionally, disseminating research findings can be more effective with the help of patients, as it allows for accessible communication and outreach beyond the borders of the scientific field, improving the public understanding [6].

Despite the benefits of PPI, its application in practice often remains superficial [7]. Patients are frequently only informed or consulted, while researchers retain control over most decision-making [8]. This is particularly true for individuals with limited health literacy (LHL) [8, 9], who tend to be underrepresented as active participants in research. In Europe, between 25 and 75% of adults have LHL, which is more common among older adults, people with lower socio-economic status, and non-native speakers [10, 11]. People with LHL often struggle to find, understand, and apply health information [12], which can create challenges with self-management of their chronic condition(s), resulting in poorer health outcomes, higher healthcare costs, and more reliance on care services [13, 14]. As health inequalities continue to rise, it is essential to involve people with LHL in research to understand

their needs and perspectives better [9]. This requires moving away from tokenistic box-ticking and engaging in more meaningful participation [15, 16]. Ultimately, such efforts can reduce disparities and inequities in healthcare, creating a more accessible and effective system that demonstrates how to empower all.

Previous studies point to several reasons why people with LHL are less engaged in PPI than more health-literate individuals. First, research opportunities are often not presented in a way that appeals to people with LHL, failing to clearly convey added value and relying on non-understandable or accessible language, making recruitment more challenging [9, 17]. Second, people with LHL tend to have greater health-related institutional mistrust, often due to prior negative experiences like poor communication with the healthcare provider, lack of social support or coping skills, or difficulties judging the quality of health-related information [18–21]. Finally, when overwhelmed by the amount and complexity of information, people with LHL may have difficulties identifying what is relevant information, making it more challenging to form personal preferences, resulting in feelings of embarrassment, shame, and reluctance to participate in research due to feeling more insecure about the value of their voices [21].

To bridge the gap between research and practice and promote greater inclusivity in research, we sought to understand how people with chronic conditions and diverse health literacy levels can be effectively engaged as citizen researchers, meaning that they actively participate in shaping and conducting research rather than only being subjects of it. We have established an expert-by-experience group consisting of people diagnosed with a chronic condition, type 2 diabetes (T2DM), who are known to have various health literacy levels [10, 22].

This study applied the first three stages of the six-stage Participatory Research to Action (PR2A) framework to guide experts-by-experience involvement. This study focuses only on the process outcomes of recruiting citizen researchers, building trust, and collaboratively identifying research priorities. Existing frameworks, like the PR2A framework, outline these stages but rarely describe how to execute them in practice; several studies call for richer process descriptions and empirical accounts of the early relationship-building steps that enable meaningful PPI [23–25]. Therefore, the aim of this study is to offer practical lessons that provide researchers and policymakers with concrete strategies for creating inclusive and effective research collaboration processes. This aim is supported by the following two research questions:

1. How can people with a chronic condition and various health literacy levels be effectively recruited as citizen researchers in health research?
2. How can people with a chronic condition and various health literacy levels be meaningfully engaged as citizen researchers in health research?

Methods

Study design

We used a participatory action research approach by applying the first three stages of the PR2A framework as a guide to engage experts-by-experience as citizen researchers [26]. The PR2A framework was chosen as suitable for adoption to address our research questions because it aims to engage experts-by-experience meaningfully throughout all steps of the research. This six-stage framework gives a structured yet flexible approach to deciding who and how someone can be engaged in what part of the research process. The first three stages, which precede the co-creation stage, outline the initial and fundamental steps that must be taken. These first three stages include *readiness*, *discover*, and *define* [26]. Fig. 1 shows the PR2A framework focusing on these first three stages.

In the *readiness* stage, the foundation is laid for equal collaboration between the citizen researchers and research PPI facilitators by creating a safe and inclusive environment, managing expectations from both sides and recognising each other’s needs and capacities when acting as co-researchers. At the *discover* stage, the focus is on understanding the research’s context. Together,

citizen researchers explore what matters to them in healthcare by sharing their experiences. At the *define* stage, shared aims and research goals are noted and prioritised before entering the co-creation stage.

Setting

This study was conducted in South-Limburg, the most southern region of the Netherlands. The region is characterised by health inequalities, which manifest in both physical and mental health outcomes [27]. A relatively high proportion of people are older and are at a higher risk of having at least one chronic condition compared to other regions of the country [27, 28]. One of these conditions is T2DM. T2DM is one of the most common and fastest-growing chronic conditions worldwide, affecting approximately 462 million individuals in 2017 [29, 30] and almost 1.1 million individuals in the Netherlands in 2022 [31]. As a result, 30% of the population in South Limburg has T2DM or prediabetes [32].

Patients with T2DM are particularly vulnerable to problems associated with LHL [10, 22], partly because socio-economic factors may contribute to the development of T2DM [33, 34]. For instance, people with lower levels of education and/or a history of migration are more likely to develop T2DM. Nationally, about 35% of adults demonstrate LHL, and people in South Limburg have a greater likelihood of poor self-rated health, limited self-sufficiency, and LHL [27, 35]. Consequently, engaging this group in the context of T2DM can lead to valuable insights that may also inform approaches to other chronic conditions.

Eligibility criteria

Eligible for this study were people with a T2DM diagnosis, aged 18 years or older, residing in South Limburg. Individuals had to be able to travel to the session location in the region and be willing to attend group sessions approximately every two months, for five sessions, lasting around three hours each.

To ensure a purposefully diverse group, we aimed to include 10–15 individuals with various health literacy levels. This group size was chosen to balance individual engagement and diversity. This allowed for a range of perspectives while ensuring that each expert-by-experience felt comfortable with actively contributing. Furthermore, including 10–15 experts-by-experience accounted for potential challenges such as illness, scheduling

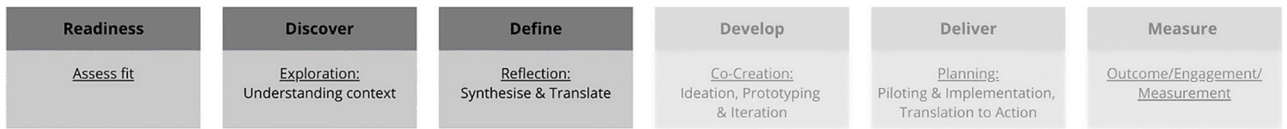


Fig. 1 PR2A framework, focusing on the first 3 out of 6 stages, adapted by Giosa et al. (2025)

conflicts, or dropouts to maintain a sufficiently diverse and engaged group throughout the study.

Recruitment

Recruitment strategies involved a multifaceted community outreach approach to help ensure the inclusion of individuals with T2DM, including people with LHL. The PPI facilitators (NdG and DH) presented themselves and their vision for engaging people with T2DM in research at a local Diabetes Café. This is a place where people with diabetes can learn more about their condition by attending presentations from nurses, specialists or others with lived experiences. The PPI facilitators were able to leverage this setting to reach people with T2DM who are already interested and engaged in learning more about their condition. Additionally, health literacy-friendly flyers were developed, incorporating tips from Pharos, the Dutch Centre of Expertise on Health Disparities, to ensure accessibility of engaging in research. Texts were further reviewed and adjusted using the Dutch LiNT tool, a digital resource designed to assess and improve linguistic accessibility [36]. The finished flyers were distributed in supermarkets, community centres, libraries, and general practitioners' offices in neighbourhoods with a lower socioeconomic status.

Beyond physical outreach, the PPI facilitators engaged in networking and digital recruitment. Multiple Dutch organisations and foundations were contacted via email to support these recruitment efforts. These included initiatives that focus on health equity, limited (health) literacy, accessible communication, and community empowerment, such as Pharos, Burgerkracht (in English

'Citizen Power'), Stichting ABC Limburg (in English 'ABC Limburg Foundation'), Stichting Makkelijk Lezen (in English 'Easy Reading Foundation'), and Stichting Lezen en Schrijven (in English 'Reading and Writing Foundation'). Discussions with other researchers in these fields also provided insights into best practices for engaging individuals with LHL. Additionally, online platforms such as the Diabetes Fonds forum (in English 'Diabetes Foundation forum') and diabetes Facebook groups were utilised to reach a broader audience. Moreover, previously engaged contacts were reapproached to determine if they knew of additional individuals interested in participating. Finally, word-of-mouth recruitment played a significant role after the initial recruitment stage, as already enrolled experts-by-experience encouraged others to join our citizen researcher group.

Data collection and analysis

Data collection and analysis covering the first three stages of the PR2A framework were embedded across five group sessions from January 2025 to September 2025. The present study focused on process-related data to explore recruitment, engagement strategies, and participatory experiences of individuals with T2DM and various health literacy levels. Process data were collected by two academic researchers (NdG and DH), who also acted as PPI facilitators of the sessions. PPI activities were reported in accordance with the GRIPP2-LF reporting checklist [37], with the completed checklist provided in Additional file 2.

Table 1 provides an overview of five group sessions organised within the first three stages of the PR2A

Table 1 Overview of group sessions, including data collection and analysis of process-related data

Session	PR2A stage	Purpose	Format(s)	Data collection & analysis of process-related data
1	Readiness	Foster introductions, build initial trust, and jointly explore the scope and fit of the research.	Personal introductions using an object/story; open group dialogue; informal setting with healthy snacks	Oral, plenary evaluations regarding group atmosphere and expectations at the end of the session.
2	Discover	Jointly identify experienced barriers in diabetes care; explore health literacy diversity within the group.	Introduction to person-centred care; individual Post-its → group discussion; completion of printed SAHL-D* questionnaire	Administration of the SAHL-D* questionnaire and oral plenary evaluation on the process is documented.
3	Discover	Revisit and refine the earlier identified barriers; explore positive diabetes care experiences and enabling factors	Visual recap of barriers; small-group discussions with individual reflections → mind maps; plenary synthesis	Oral plenary evaluation on the process is documented.
4	Define	Co-develop visions for future diabetes care and prioritise these ideas	Sketching exercise from design thinking; in pair discussions on these sketches; plenary prioritisation matrix (importance × feasibility)	Oral plenary evaluation on process is documented.
5	Define	Reflect on participation and evaluate prolonged involvement	Presentation by an external academic on an intervention for diabetes care following the vision for the future of diabetes care; PPEET** Module B (Dutch version)	PPEET** open- and closed-ended questions are analysed descriptively; oral plenary evaluations documented. Findings directly informed iterative adaptations

*SAHL-D questionnaire = Short Assessment of Health Literacy in Dutch questionnaire

**PPEET = Public and Patient Engagement Evaluation Tool

framework. Each session's specific purpose, formats, and data collection strategies are presented. This table illustrates how the sessions were structured to facilitate engagement and collaborative identification of the research direction. At the same time, process-related data was collected to support iterative adaptations and evaluation of the group process.

To explore recruitment strategies, the number of people who wanted to participate in the research was recorded per outreach method and moment in time. This visualised how, where, and when people were included and when and why people dropped out during the recruitment phase. To adapt facilitation strategies and remain responsive to possible differences in engagement or understanding, participants' health literacy levels were assessed during session 2 in the *discover* stage using the SAHL-D questionnaire (Short Assessment of Health Literacy in Dutch questionnaire) [38]. The SAHL-D questionnaire consists of 13 healthcare-related terms with multiple-choice definitions and a "don't know" option. Responses were scored according to the instrument's guidelines (1 point per correct answer; range 0–13). In line with Woudstra et al. (2019) [38], a cut-off point of 9.5 was applied to distinguish between likely limited and adequate health literacy. The SAHL-D questionnaire was presented to the citizen researchers as a tool to understand their health literacy at this moment in time. This explanation by the PPI facilitators also included the definition of health literacy and the use of the tool's results. The results of the SAHL-D questionnaire were used solely to guide adaptations in facilitation style and communication, and provide an overview of the diversity of the group in the scientific articles, and not for individual classification or exclusion. Only aggregated results were considered during analysis to protect participant confidentiality and minimise pigeonholing.

To collaboratively explore the research direction, multiple participatory formats were used across sessions. In session 2, citizen researchers were asked to write down, individually, perceived barriers, bottlenecks, and frustrations related to diabetes care on post-it notes. These notes were then discussed in plenary and inductively clustered into categories on a shared board [39]. Prior to session 3, the clustered themes were visually summarised by the PPI facilitator (NdG) and presented back to the group for validation and refinement. Sharing this visual recap of barriers also gave the citizen researchers an opportunity to reflect more deeply on the previously identified barriers and to consider additional ones. During session 3, citizen researchers worked in small groups to explore two questions: (1) what is currently working well in diabetes care, and (2) what improvements are needed for the future? Each group created a mind map to structure their ideas, which were subsequently discussed

in plenary. In session 4, a sketching exercise informed by design thinking was used to stimulate quick solution-oriented thinking [40]. The citizen researchers and PPI facilitators sketched approximately 8 ideas in 8 minutes in response to the question: "How can we improve diabetes care?" Ideas were then discussed in pairs, and each pair selected two to three ideas they preferred the most [41]. These were placed in a prioritisation matrix, with perceived importance on the y-axis and feasibility on the x-axis. The citizen science group voted democratically on positioning within the matrix. No ideas were discarded; all were documented for further consideration.

To assess how the citizen researchers experienced their involvement in research, short informal plenary oral evaluations were held at the end of each group session to discuss their experiences with structure, facilitation, and overall atmosphere. The PPI facilitators (NdG and DH) used standardised prompts such as: "What did you think of this session?", "What did you like and what could be improved about the structure or content?", "Do you have suggestions or ideas for the next session?", and "Do you have any feedback for the facilitators?". Facilitators captured responses using unstructured field notes. For each session, a summary of the discussion—focused on session activities, adaptations made, and upcoming plans—was shared with citizen researchers via email, chat, voice note, or 1-on-1 follow-ups. No participant names were recorded to ensure anonymity. These oral evaluations directly informed iterative adaptations to subsequent sessions—for example, adjusting session timing, content format, or physical arrangements to support inclusivity and engagement better. Additionally, a Dutch version of the validated Module B from the Public and Patient Engagement Evaluation Tool (PPEET) was administered during session five in the *define* phase [42]. This tool, co-designed with stakeholders including patients and translated by LUMC from the original McMaster University version, includes open- and closed-ended items. It addresses key themes, including clarity of purpose, practical support, inclusivity, communication, perceived influence, and overall satisfaction with the prolonged project engagement by citizen researchers [42]. Examples of the open-ended questions are 'In your role, what influence do you think you have had to date?' and 'What could be improved about the project?'. Responses to these open-ended questions were reviewed and summarised descriptively to identify recurring reflections relevant to the engagement process, including suggestions for improvement or expressions of value. Examples of closed-ended Likert-scale questions are 'I feel that my views are heard.' and 'The individuals participating in this project represent a broad range of perspectives.' Responses to the closed-ended questions were analysed descriptively to summarise overall evaluation patterns.

Given the small sample size and evaluative purpose of these data, no inferential statistical analyses were conducted. These reflections informed iterative adaptations to the structure and facilitation of subsequent sessions and gave insights into the needs and priorities of experts-by-experience when engaged as citizen researchers.

Ethical considerations and accessibility

Ethical procedures were embedded throughout the research process, reflecting the participatory ethos of co-ownership and mutual respect. Ethical approval was obtained from the Faculty of Health, Medicine, and Life Sciences (FHML) ethics committee of Maastricht University under FHML-REC/2025/029. After giving out an information letter during the readiness stage, informed consent was obtained, and both forms were specifically adapted from Pharos and refined using the LiNT readability tool to ensure accessibility and comprehension for citizen researchers with varying health literacy levels [36]. No audio or video recordings were made, and only data were reported at the group level to ensure confidentiality and prevent unintended labelling. Since properly valuing your citizen researchers is important, the citizen researchers were rewarded with financial compensation in consultation with the group, offering options (bank transfer, supermarket voucher, or VVV voucher of 30 euros per session). The group chose supermarket vouchers to support essential groceries. Attendance was flexible; absences were reported via WhatsApp, phone, or email.

Reflexivity statement

We, as academic researchers, were aware that engaging in citizen science required a more iterative and flexible approach. This approach runs counter to the institutional structures that often value predefined research outcomes, efficiency, and clarity of the process beforehand. Additionally, we encountered institutional constraints, including procedural and financial regulations. While we sought to remain responsive to citizen researchers' input, these constraints influenced the project's pace. In response to institutional constraints, we, in collaboration with other academic colleagues, are advocating for a broader institutional support structure for citizen science initiatives.

Throughout the project, we tried to work ethically and consciously to engage less in our initially learned academic reflexes, such as quickly forming judgments, offering advice, or steering discussions toward predetermined hypotheses, to create more space for the citizen researchers to guide the process. This required ongoing reflection on our roles and on the power dynamics inherent in facilitator-led sessions. The combination of facilitating sessions, documenting and interpreting process and

outcome data, and actively contributing to group discussions may have introduced interpretative bias. We tried to remain aware of this possible bias by reflecting on our influence during and after sessions and by discussing these reflections within the academic and citizen science research team.

Results

Recruitment

Since we aimed to include a diverse population of people with T2DM, we recruited people in various ways and places. Figure 2 shows an overview of the recruitment and dropout process of participants from May 2024 to January 2025. Recruitment methods included networking after a conference presentation on low literacy ($n=1$), a presentation at a local Diabetes Café ($n=2$), a follow-up reminder email to the Diabetes Café community ($n=5$), word-of-mouth ($n=2$), an online post via the Diabetes Foundation forum ($n=1$), a diabetes focused Facebook group ($n=1$), distribution of flyers in supermarkets, community centres, and libraries ($n=1$), and collaboration with the foundation working with language ambassadors ($n=1$).

So, a total of fourteen individuals with T2DM expressed interest in participating as experts-by-experience. Four subsequently withdrew due to physical limitations, travel distance, or scheduling conflicts, resulting in a group of ten experts-by-experience. The group ranged in age from 45 to 73 years, including four women and six men. The duration of living with T2DM ranged from 5 to 30 years, with a median of 10,5 years. Four individuals were identified as having LHL at the time they completed the SAHL-D questionnaire. The SAHL-D scores ranged from 1 to 12 (maximum score = 13), with a median score of 11.

Recruitment presented several challenges, partly due to our inclusion criteria and planning issues. All sessions were conducted in person, which fostered stronger trust and engagement through direct interaction and social breaks, but excluded those unable to travel. Sessions were held during daytime hours, co-designed with the first five citizen researchers, which limited availability for individuals with rigid work schedules or other daytime commitments. The final group consisted of ten citizen researchers, which enabled multiple perspectives to be represented during discussion while allowing room for everyone to speak up.

A further concern was achieving diversity in health literacy. To avoid pigeonholing, ensure accessibility, and because people with T2DM are more vulnerable to challenges of LHL, we did not pre-assess participants' health literacy, which carries the risk of inadvertently forming a less diverse group in terms of health literacy. Nevertheless, the final group included four experts-by-experience with LHL and the other six with moderate to high health

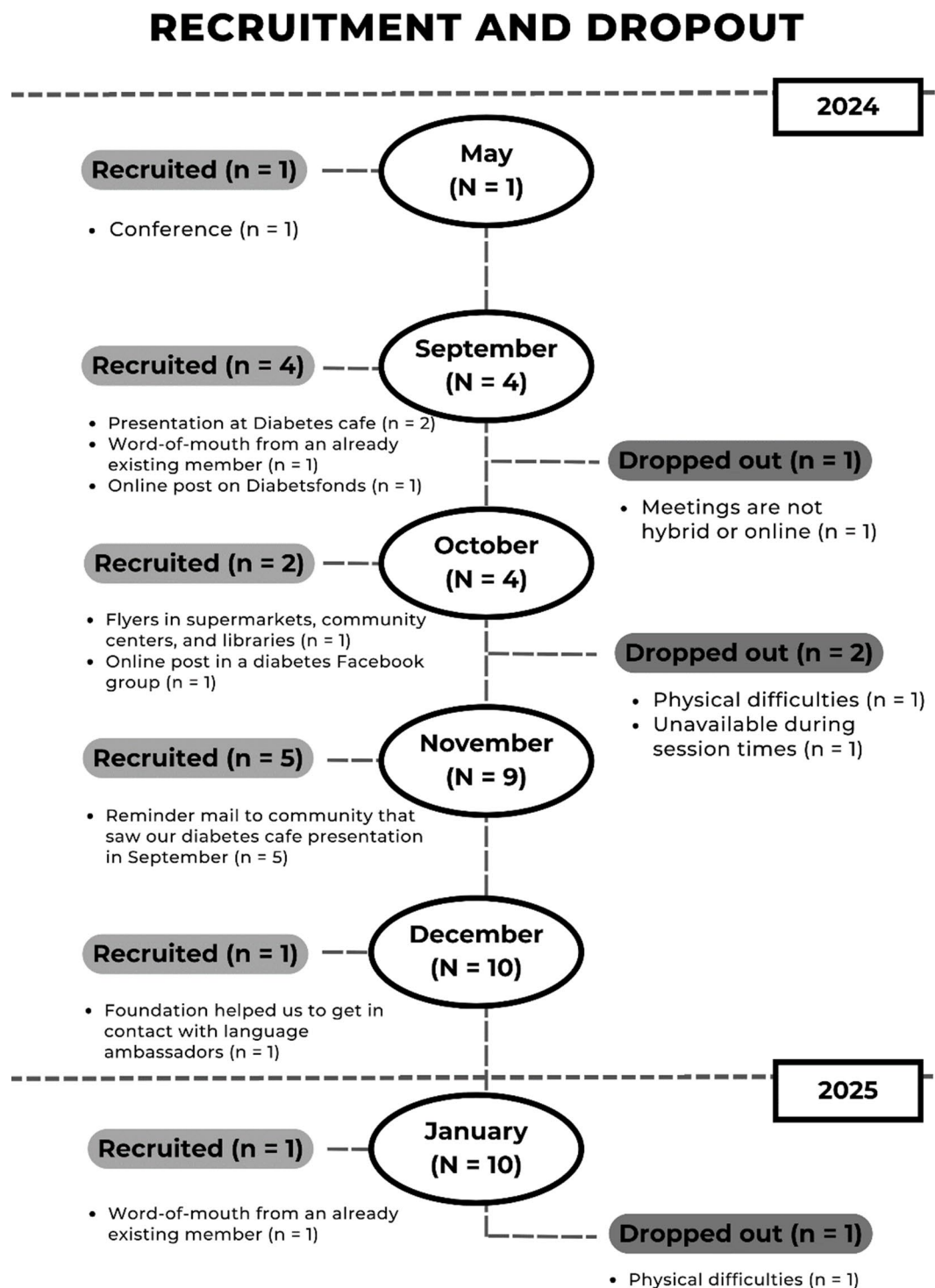


Fig. 2 Overview of recruitment and dropout of experts-by-experience over time

literacy, suggesting a reasonable range of health literacy levels.

Overview of co-research sessions categorised in the first three PR2A stages

A series of five structured group sessions of around three hours was held approximately every two months by the two PPI facilitators (NdG and DH) from January 2025 to September 2025, in alignment with the initial three stages

of the PR2A framework. These sessions functioned not only as sites of co-research but also as places for interaction and support between people with lived experiences with T2DM.

Readiness

During the kick-off session, we took the time to engage in personal stories with each other, prompted by a self-brought object. Personal storytelling was followed by increased openness in sharing experiences and engagement. Clearly communicating the research scope and the PPI facilitators' capacities from the outset contributed to managing expectations. While the intention was to define the research scope collaboratively, academic knowledge constraints set boundaries.

Discover

Discussing experienced barriers in diabetes care during session 2 helped acknowledge the weight of the struggles of living with a chronic condition and created space for the citizen researchers to voice what matters most to them. Citizen researchers recognised shared experiences, which strengthened the group bond and reinforced a feeling of not being alone. The PPI facilitators also gained deeper insight into the priorities and language of the citizen researchers, which further shaped the ongoing research process.

Selecting an appropriate health literacy assessment tool required careful consideration. We ultimately selected the SAHL-D questionnaire, developed by Woudstra et al. [38], as it is a validated tool, and we initially thought it would not be too long or burdensome. Its neutral introduction made it easier to implement without causing people to feel judged or tested. However, while filling in the questionnaire, several citizen researchers questioned the relevance of the hospital-based terminology. Their feedback pointed to a limitation of using this tool: citizen researchers did not always associate the tested vocabulary with their understanding of health literacy, which led to confusion. For example, it was unclear why it would be necessary for them to understand what "pessarium" or "plaque" means, and therefore how this could accurately describe their health literacy skills with managing their T2DM. Despite this, the SAHL-D questionnaire provided a rough sense of diversity in health literacy levels within the group, and informed accessible language use during sessions, while not using it as a diagnostic tool in this research project.

Define

During the Define stage, the plenary discussion focused on what worked well in the healthcare experiences of the citizen researchers. This conversation provided a foundation for continued dialogue about their vision for the

future of diabetes care, highlighting the importance of their lived experiences and voices in shaping research priorities. To stimulate creativity and explore ideas from a different perspective, we used the "Crazy 8's" design thinking sketching exercise, accompanied by classical background music requested by the citizen researchers. This activity encouraged participants to quickly generate eight ideas in a short period, tapping into different ways of thinking and fostering a playful, engaging environment. Beyond generating ideas, this method promoted collective reflection, helped identify shared priorities, and strengthened group cohesion by emphasising collaborative problem-solving for improving diabetes care.

During the initial sessions, oral evaluations brought forward several practical suggestions from the citizen researchers, such as modifying the length and timing of the sessions, offering more biologically sourced foods, and selecting physical spaces that felt more comfortable and welcoming. The citizen researchers also expressed appreciation for having some structure and guidance. While there was plenty of room to adapt and modify elements of the research sessions iteratively, the presence of a pre-send general agenda for each session provided the necessary direction and clarity. Creating space for meaningful input was found important, even if PPI facilitators could not always accommodate every suggestion. It also provided structure to feel efficient, and that they contributed to something bigger.

As the sessions progressed, oral evaluations increasingly centred on the emotional and social aspects of research engagement. Citizen researchers described a growing sense of shared purpose, identifying the co-improvement of diabetes care as a collective mission. Many expressed feeling less alone and more heard and valued the opportunity to connect with others facing similar experiences and challenges. The diversity of diabetes experiences within the group allowed citizen researchers to support one another, with some noting they would have appreciated access to such a group when first diagnosed.

This was further elaborated in the PPEET evaluations completed by the citizen researchers. The citizen researchers appreciated the diversity of perspectives involved in the group, which enabled the sharing and acquisition of new knowledge about their chronic condition. This was supported by the open and safe environment within the group, where people felt confident speaking and engaging, knowing they would be listened to. Besides this, the citizen researchers acknowledged the effective guidance of the PPI facilitators, providing structure while allowing for creativity and freedom, participating alongside them in the sessions, and helping to contribute to the creation of a safe space.

However, several areas for improvement were also identified by the group. Since the sessions were perceived as valuable, engaging, and educational, the citizen researchers expressed a desire to meet more frequently, even though sessions are currently held once every 2 months. On top of this, the citizen researchers expressed the need for more information regarding the following research steps, their role in the study and how the study results will be disseminated. Some citizen researchers suggested involving healthcare providers in future sessions to share the group's insights. The group also recognised the need to ensure more balanced participation, as some members tend to dominate discussions. This means creating space for everyone to engage equally, for example, by simplifying complex topics when needed and actively encouraging contributions from all members. In fostering this safe environment, the group valued respecting everyone's unique journey with T2DM. Citizen researchers appreciated exchanging successful advice with people at different stages of living with T2DM, but emphasised the need to allow space for challenges and setbacks. Differences in focus, such as managing diabetes through nutrition or without medication, sometimes created moments where discussions felt less safe for those whose experiences or approaches differed. This highlighted the need to share experiences and advice without implying a 'right' or 'wrong' way of managing T2DM, and of recognising that

everyone's experience is different to avoid a 'one-size-fits-all' mindset.

The PPI facilitators reflected on these findings, recognising and acknowledging the feedback provided by the citizen researchers, which they will implement in the future sessions.

Practice-informed considerations for meaningful PPI for researchers and citizen researchers

From five group sessions covering the first three stages of the PR2A framework, we formulated several actionable process-related recommendations for researchers on what works and why it matters when recruiting and engaging citizens in research (Table 2). These are covered by one of the following themes: purpose & clarity, recruitment & access, equity & participation, compensation & respect for time, materials & tools, transparency & expectations, and leverage diversity & experience.

We also created a handout for (prospective) citizen researchers outlining what they will gain and what they can expect from actively participating in research (Table 3). These are covered by one of the following ways of participating as a (prospective) citizen researcher: sharing your experiences, taking part in activities, receiving support, making arrangements to meet, sharing your voice and listening, contributing to research, and taking on challenges. The citizen researchers read, adjusted,

Table 2 Recommendations for researchers wanting to facilitate citizen researchers with a chronic condition and various health literacy levels

Theme	Results	Rationale
Purpose & Clarity	Establish a clear, shared mission and goal	Provides group cohesion, strengthens a sense of belonging, and reduces participant drop-out.
Recruitment & Access	Recruit experts-by-experience where they naturally gather	Marginalised or hard-to-reach groups may not seek out research opportunities; engaging them in familiar spaces improves participation.
	Engage trusted key figures and maintain a visible presence	Personal contact and familiar faces build trust, credibility, and motivation to participate in research.
	Build relationships early	Early rapport and consistent contact help participants feel valued and safe, supporting meaningful engagement.
Equity & Participation	Practice equity rather than assuming equality	Researchers and citizen researchers bring complementary expertise; responsibilities differ but are equally valued, avoiding hierarchical dynamics.
	Actively listen and respond to citizen researchers' needs	Soliciting feedback on logistics and session design ensures sessions are accessible, comfortable, and co-led.
Compensation & Respect for Time	Offer fair financial compensation, considering citizen researchers' on social benefits	Acknowledges time and effort and removes potential barriers to engagement for citizen researchers.
Materials & Tools	Adapt materials and communication to citizen researchers' health literacy	Simplifying language, using visual aids, and contextualising assessments fosters equitable participation.
Structure & Engagement	Provide structured yet flexible sessions	Pre-sent agendas and clear session boundaries allow citizen researchers to prepare while maintaining comfort and autonomy.
	Incorporate creative engagement methods	Activities like design-thinking exercises (e.g., Crazy 8's) encourage idea generation, reflection, and the identification of shared priorities.
Transparency & Expectations	Clearly communicate constraints and facilitator capacities	Explaining what can realistically be achieved from the outset manages expectations and builds trust.
Leverage Diversity & Experience	Value and integrate diverse perspectives	Combining lived experience with research expertise strengthens the relevance and quality of outcomes.

Table 3 Joining a research group as a citizen researcher: what you do, what you can gain and what to watch out for

What you do	What you can gain	What to watch out for
Share your experiences	You learn from others. Your opinion helps make the research better for people like you.	Make sure you know the goal of the group and what is expected of you. Ask for an explanation if something is not clear.
Take part in activities	You join conversations, small group tasks, or creative activities. This helps move the research forward.	Activities may be new. This may need more explanation. Facilitators and other participants can help you.
Receive support	You work in a safe, respectful group. Your contribution is important.	Not every meeting is strictly planned. Sometimes there is more space for free ideas.
Make arrangements to meet	The group meets regularly. You contribute in a way that fits your time, possibilities, and priorities.	Sometimes you may need to prepare or think later about what was discussed. Check if the schedule works for you. There are no obligations.
Share your voice and listen	There is space to talk, listen, and work together. Different insights make the group stronger.	Some people talk more than others. Try to share your opinion and give others space to speak.
Contribute to the research	You see how your ideas help with decisions in the research. You learn how research works.	Results are not always visible right away. Ask how your input is used.
Take on challenges	You learn to work with others in a group. You also learn about new topics.	Some topics can be difficult or sensitive. You can always ask for help or explanations. Facilitators pay attention to how participants are doing.

and approved the Dutch version of Table 3, which can be found in Additional file 3.

Discussion

Main findings

This paper explored the process of recruiting and engaging citizen researchers with a chronic condition (T2DM) and various health literacy levels. We illustrated not only strategies for initial engagement but also approaches to sustaining their active involvement throughout the first three stages of the PR2A framework. While the full co-creation phase is still forthcoming, we completed the first three stages before co-creation, stages that are fundamental yet remain under-reported in the literature [24, 43]. From these stages, several lessons emerged, providing valuable insights to guide future efforts in recruitment, facilitation, and the engagement of diverse citizen researchers. For instance, recruitment was most effective when a multifaceted community outreach approach was employed, reaching experts-by-experience through both online and offline channels, ensuring better diversity in the group. As a facilitation strategy, creative co-creation approaches, such as sketching and small-group exercises, proved more effective than text-based or plenary-only methods for fostering accessible, inclusive engagement. Equitable engagement between citizen researchers and PPI facilitators was essential to valuing diverse perspectives and maintaining shared responsibility throughout the process.

Reflection on main findings

Recruitment strategies, particularly via trusted key figures or acquaintances of experts-by-experience already

involved, combined with recruitment in familiar community spaces in lower socio-economic neighbourhoods, appeared more effective than passive approaches such as flyers or online postings and seemed to increase participation and diversity. This aligns with previous research, which emphasised that successful recruitment depends on collaborating with local communities, ensuring that research addresses their needs, demonstrates the value of their contributions, and fosters trust [44]. Our findings also support the notion that a more targeted recruitment strategy could help with greater diversity among citizen researchers [45]. Specifically, more personal outreach, rather than broad calls via flyers or social media, has been shown to lead to increased participation from older citizens and those with lower levels of education [45].

The variation in health literacy within our recruited group appears to suggest that recruiting based on T2DM alone could still yield a diverse group in terms of health literacy and that including people based on LHL at the start of recruitment may be unnecessary. Although the citizen researchers were purposefully recruited to achieve diversity, this diversity was primarily conceptualised through health literacy. Other factors, such as educational level, socioeconomic status, or migration background, were not assessed separately from health literacy levels and may therefore be underrepresented within the group. As these factors are known to shape experiences with healthcare access and communication, their limited representation may have constrained the transferability of our findings. However, since LHL is more prevalent among older adults, individuals with lower socioeconomic status, and non-native speakers, some of these factors of diversity may have been

indirectly represented within the group. At the same time, no one recruitment strategy can capture all possible forms of diversity within a recruited citizen researcher group, indicating the need for a combination of recruitment approaches to achieve a broader and more diverse range of perspectives to address the study aim [46]. Given the central role recruitment plays in establishing a purposefully diverse group of citizen researchers, our findings suggest that recruitment should be considered a preliminary step within the PR2A framework [26]. The authors propose formalising this initial step by providing guidance on effective recruitment strategies, such as engaging key figures and adopting a multifaceted community outreach approach. Formalising this step would acknowledge its essential contribution to forming a purposefully diverse group of citizen researchers, and ultimately, to enhancing the overall quality of participatory research.

Adapting the research facilitation strategies is essential to ensure that PPI sessions are inclusive and productive. In our project, three types of strategy appeared particularly important. First, clear communication of the research scope and the PPI facilitator's research expertise was identified as essential for managing expectations from both ends. Addressing institutional, departmental, and expertise constraints before engaging in PPI with the group helped with this. Establishing these clear roles and structures by the PPI facilitators from the outset seemed to provide the citizen researchers with a sense of direction while maintaining flexibility to adapt to their needs [6]. Second, we observed that these roles may shift during the project. Therefore, maintaining open and regular conversations about responsibilities and the project's course is necessary and balancing structure and flexibility may be important for sustaining participation [47]. Finally, creative engagement methods, such as sketching or small-group exercises, seemed to support the integration of diverse perspectives and provided opportunities for citizen researchers with LHL to contribute without fear of dismissal. This co-creation approach contributed to gradually disrupting traditional power imbalances and fostering a more open, safe space where people can share their experiences and thoughts and feel listened to [48].

Equity in PPI emerged as an important concept in our study, reflecting the need to value and balance different types of expertise: citizen researchers contribute lived experience, while the PPI facilitators contribute research knowledge and organisational navigation skills. Achieving such a balance required an open two-way dialogue between PPI facilitators and citizen researchers. Accessible language and regular feedback were important enablers of effective communication in this dialogue [49]. Our experience in practising equity echoes earlier research, which states that equitable partnerships are not

static but negotiated, with degrees of shared responsibility shifting over time between academic and non-academic partners [50]. Meaningful participation exists on a spectrum, as described in the International Association for Public Participation (IAP2) spectrum of public participation, and the level of participation can shift among partners depending on the project's phase, purpose, and resources [51]. Achieving equitable participation depends not only on balancing this expertise but also on fostering an environment that encourages contributions from diverse perspectives.

Reflection on areas for improvement

The identified areas for improvement primarily concern transparency, role clarity, and equitable participation. These findings underline that meaningful PPI requires continuous negotiation of expectations and responsibilities rather than a one-time clarification at the outset. In response, the PPI facilitators, together with the citizen researchers, co-created an overview with an anticipated timeline to more clearly communicate the subsequent steps in the research process and the intended use of their contributions.

The request for more frequent sessions and clearer information about dissemination further illustrates that engagement in PPI fosters a sense of ownership. At the same time, the need for more balanced participation highlighted the importance of actively managing group dynamics, particularly when working with individuals with T2DM who have heterogeneous experiences. To address this, future sessions will incorporate more small-group exercises, which were found to promote more equitable participation. The PPI facilitators will also continue to monitor discussion dynamics, particularly when complex or potentially sensitive topics arise, and intervene when necessary.

Limitations

There are also some limitations to consider. Although participants were not included based on health literacy, the PPI facilitators were interested in whether they had indeed included experts-by-experience with LHL. To do this, and to adapt the session content for accessibility while better accommodating everyone, we used the SAHL-D questionnaire. Although this tool is brief and validated in Dutch, some citizen researchers were uncertain how it reflected their T2DM-related health literacy. While generic health literacy tools, like the SAHL-D questionnaire, allow broader comparisons and generalisability, disease-specific tools may feel more relevant when all citizen researchers share the same condition. In participatory research, the priority is often to gain a general understanding of health literacy to adapt session content and facilitate engagement, rather than to provide a

precise assessment. Future research should carefully balance these considerations based on group composition when selecting health literacy assessments.

Additionally, our inclusion criteria were relatively narrow, including only South-Limburg residents able to attend in-person sessions to capture experiences in an area with high health inequalities and T2DM prevalence. This may have introduced selection bias, as experiences in this region may differ from other parts in the Netherlands, potentially limiting transferability of our findings. Other context-dependent elements include collaboration with the local Diabetes Café, the use of the Dutch SAHL-D questionnaire, and the feasibility of daytime, face-to-face sessions. In contrast, most identified recommendations, including the use of creative co-creation methods and the facilitation of equitable participation, are likely relevant to other participatory research settings. We therefore advise readers to consider these findings transferable to contexts with similar characteristics, such as small-group co-research with diverse lived experiences. Readers should, however, take into account factors that may vary by local infrastructure and population needs. Moreover, despite efforts to enhance accessibility, some recruitment materials may still have been challenging for participants with LHL, especially passive methods such as flyers. To improve clarity, the readability tool LiNT [36] was used to check the language of written materials. This tool does not assess texts below a certain difficulty level. As a result, some materials may still have been challenging [36], potentially favouring participation by more confident or outspoken citizen researchers, as also noted by some citizen researchers in the PPEET evaluation.

A final limitation concerns the absence of structured field notes or systematic observational data. Although process reflections were documented, no formal observation protocol was used during the five sessions. This was partly due to the multiple roles held by the PPI facilitators, who simultaneously facilitated discussions, participated in them, and documented key points on process and content-related outcomes. These overlapping responsibilities may have constrained opportunities for systematic recording of observational data and, therefore, may have limited the depth of the process data. In future studies, involving an independent researcher to conduct structured observations could strengthen methodological rigour. However, the presence of an additional observer may also influence group dynamics and potentially affect the sense of safety within participatory settings, particularly when working with citizen researchers. Careful consideration is therefore needed to balance methodological rigour with relational and participatory integrity.

Conclusions

Our study shows that recruiting and engaging people with T2DM and various health literacy levels as citizen researchers is feasible when certain conditions are met. Effective recruitment requires a multifaceted community outreach approach and the involvement of trusted key figures, rather than relying solely on passive strategies. Eliciting expectations and providing clear yet flexible structures can help make participation accessible and manageable. One way to support accessibility is through creative cocreation methods such as small-group exercises. To ensure sustainable and inclusive engagement, an environment of equity must be created, where lived and research expertise are valued equally, and diverse voices are listened to. Together, these lessons provide a practical foundation for advancing to the next stages of the PR2A framework and for strengthening meaningful PPI in health research more broadly.

Abbreviations

PPI	Patient and Public Involvement
LHL	Limited Health Literacy
PR2A framework	Participatory Research to Action framework
GRIPP2-LF	Guidance for Reporting Involvement of Patients and the Public Long Form
T2DM	Type 2 Diabetes Mellitus
LINT tool	Leesbaarheidsinstrument voor Nederlandse Teksten
SAHL-D questionnaire	Short Assessment of Health Literacy in Dutch questionnaire
PPEET	Public and Patient Engagement Evaluation Tool
LUMC	Leiden University Medical Centre
FHML	Faculty of Health, Medicine, and Life Sciences
VVV	Vereniging Vreemdelingen Verkeer
IAP2	International Association for Public Participation

Supplementary Information

The online version contains supplementary material available at <https://doi.org/10.1186/s40900-026-00873-w>.

Additional file 1: .pdf, Plain Dutch summary, Dutch variant of the plan English summary read, adjusted and approved by the citizen researchers.

Additional file 2: .pdf, GRIPP2 reporting checklist, the completed GRIPP2 long form checklist about this study.

Additional file 3: .pdf, Dutch Table 3, Dutch variant of Table 3 read, adjusted and approved by the citizen researchers.

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Author contributions

This article was written as part of a PhD project by NdG under the internal supervision of DFLH, DR, and AMJE and the external supervision of JMC. NdG wrote the first draft of the manuscript, and all co-authors commented on all versions of the manuscript. All authors read and approved the final manuscript. The PPI group “Samen de diabeteszorg verbeteren” read, adjusted, and approved the final plain Dutch summary in Additional file 1 and the Dutch Table 3 in Additional file 3.

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Data availability

Process-related outcome data generated during this study are included in this published article. Content-related outcome data will be presented in the subsequent paper, which covers the next three steps of the PR2A framework.

Declarations

Ethics approval and consent to participate

Ethical approval was obtained from the Faculty of Health, Medicine, and Life Sciences (FHML) ethics committee of Maastricht University under FHML-REC/2025/029. All citizen researchers provided written, informed consent to participate.

Consent for publication

All authors and contributors have given consent for publication.

Competing interests

The authors declare no competing interests.

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