

Original Article

Perspectives of patient and public partners on their involvement in research

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ABSTRACT

INTRODUCTION. Patient and public involvement (PPI) in research integrates patient and public perspectives to improve research relevance and quality. The experiences of PPI partners have revealed mixed findings in countries where PPI is well established, but accounts from areas less accustomed to PPI in research are limited. This study aimed to explore the knowledge, motivations, expectations and experiences of PPI representatives in such a setting.

METHODS. This was a qualitative study based on semi-structured interviews. Patient and public partners who had recently been engaged in a PPI collaboration to redesign the written patient material for a clinical study were interviewed. The interviews were analysed using inductive content analysis in which quotations were extracted, coded, categorised and interpreted into themes.

RESULTS. Interviews indicated a lack of knowledge concerning PPI in research. Despite their motivation to collaborate, the PPI partners expressed anxiety and doubts about their abilities as laypeople. A sense of societal obligation to collaborate was noted. Groups-based, repetitive sessions fostered productivity, while challenges included off-topic discussions and skepticism.

CONCLUSIONS. The findings provide valuable insights for shaping PPI processes and recruitment strategies in regions that are new to PPI. This highlights the need to describe the PPI concept when recruiting participants elaborately and to utilise repetitive group-based sessions in the design.

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Patient and public involvement (PPI) in research is often defined as research being conducted “by” or “with” patients or members of the public rather than “about”, “for” or “to” them [1]. Collaborating with patients is proposed to improve the quality and relevance of research by including their perspectives [1, 2]. Patient perspectives may be rooted in lived experiences with different diseases, reflect prior experiences with the healthcare system or simply experiences being a member of the public [3, 4].

The research process consists of several phases, from the generation of a research question through design, practical conduct and analysis to the research presentation. PPI can be included in all or some of these phases. The involvement can take on various forms, from offering advice to engaging in active collaboration. Still, the central focus is always the active involvement of representatives of the patients and the public [3].

Throughout this manuscript, the term “partner” is used to address the individual (patient or member of the

public) who collaborates with the researchers. The term is also meant to separate PPI partners from patients engaging in a clinical study as study participants.

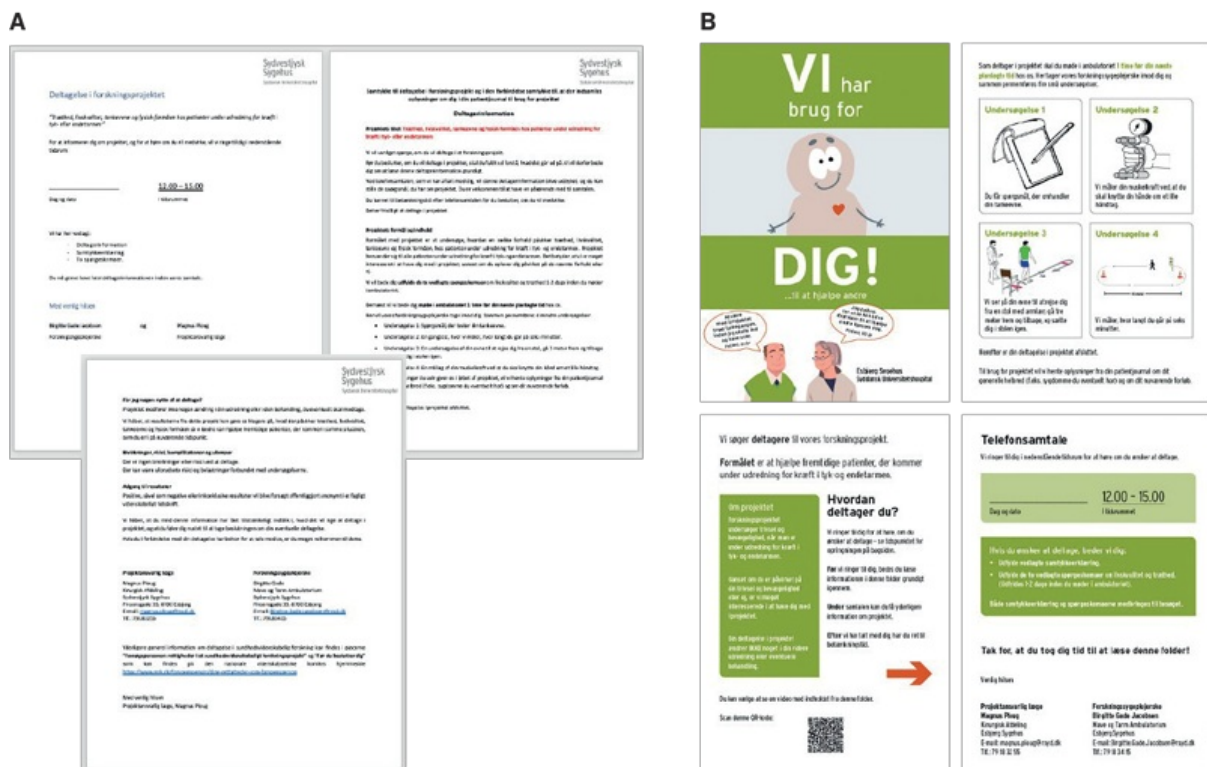
Studies on how PPI partners experience involvement have revealed positive and negative findings [1, 4-6]. While some experience an equal partnership with the researchers, others express negative experiences when included only as checkmarks of PPI inclusion rather than as actual collaborators [7, 8]. A systematic review found that for PPI partners to have a positive experience, they must feel engaged in the research process [7]. These studies originate from countries such as Australia, Canada, England and the USA where PPI is an established part of healthcare research and are primarily based on already existing PPI groups or partners with prior PPI experience [5, 6]. Contrary to this, PPI is a relatively new discipline in Denmark, and the perception of involvement will likely differ.

We aimed to investigate the prior knowledge, expectations, experiences and motivations of PPI partners about PPI in research. Given the relative novelty of PPI in research in Denmark, we aimed to uncover insights on partner perspectives that may aid in the successful organisation of future PPI processes.

Methods

This was a qualitative interview study with partners recently engaged in a PPI process to redesign a clinical study's written patient information materials (**Figure 1**). Information on the PPI process is included as **Supplementary Material** [9-11] to contextualise the findings in the interview study. The reporting followed the Standards for Reporting Qualitative Research [12].

FIGURE 1 The patient information material. **A.** the original material on A4 pages. **B.** the result of the patient and public involvement process (A5 leaflet).



Participants

All individuals who collaborated as PPI partners were eligible for inclusion in this interview study. As detailed in the [Supplementary Material](#), the partners consisted of adult individuals identified based on a current or former patient relationship with the hospital and restricted to individuals without difficulty speaking or understanding the Danish language.

After completing the PPI process, the facilitators informed the partners about the planned interview study. The interviews were held in June 2022 after obtaining oral and written informed consent. The characteristics of the PPI partners are detailed in **Table 1**.

TABLE 1 Characteristics of patient and public involvement (PPI) partners and the PPI process.

Variable	Characteristic
Partners, N	10
Time of first PPI group meeting	May 2022
Time of second PPI group meeting	June 2022
Age, range, yrs	52-77
<i>Sex, n</i>	
Females	3
Males	7
<i>Disease/symptoms prior to PPI collaboration, n</i>	
Initially referred for diagnostic colonoscopy	10
Subsequently underwent surgery for colorectal cancer	1
Had no malignant findings on diagnostic colonoscopy	9
Time of interview	June 2022

Interview structure

The interviews were conducted by telephone by the first author and audio recorded. Interview topics were included to explore the partners' prior knowledge, expectations, experience and motivations about PPI in research. Based on these topics, a semi-structured interview guide was developed. This guide consisted of broad questions to encourage participants to articulate freely, like: "When speaking about PPI in general, what comes to mind regarding what it entails?" and specific questions to pinpoint areas of the study aim, like: "Please describe what made you say yes to participating?" This dual approach facilitated an exploration of the study's aim. The structure of the interviews was kept flexible to enable a natural conversational flow and to allow for input opportunities [13, 14]. The interview guide was not pilot tested but developed through discussions within the group of authors to ensure its relevance and comprehensiveness.

Data analysis

An inductive content analysis, inspired by the work of Graneheim & Lundman, was used to gain a deeper understanding of the interviews [15]. This consisted of a stepwise process beginning with several read-throughs of the transcribed interviews to obtain an overall understanding and acquaintance with the material. Then, in accordance with the Graneheim and Lundman approach, meaning units (i.e. statements or quotations) related to the four core objectives of the study aim were identified, condensed and coded. The codes were then grouped into sub-themes according to their similarities and differences, and, finally, a comparison of the sub-themes led to the identification of the themes around which best to capture the output of the interviews [15]. This analytical process is exemplified in **Table 2**.

TABLE 2 Example of the inductive content analysis process.

Theme	Meaning unit	Condensed meaning unit	Code	Sub-theme
Knowledge, expectation, and motivation prior to collaboration	"I thought maybe I was going to talk about how I experienced my journey at the colonoscopy. That we should share some of the experiences we had"	The partners felt uncertain about what the collaboration would entail	Uncertain about what to expect	Uncertainty and expectation
	"I believe we all have a responsibility towards society and contributing to enhancements that benefit everyone – that is positive"	Responsibility to society and contribution to enhancement that benefits everyone	Motivational factors	Responsibility and contribution as motivational factors
Experiences from collaboration	"I actually thought the group sizes were quite adequate. I might have been a bit afraid that if the group had been too large, you wouldn't really have that feeling of relationship that we got"	The partners found that the size of the focus group was suitable and felt a connection within the group	Experiences in relation to the focus groups	Adequate size of groups Relationship with the members
	"Initially, I actually believed that the existing material was sufficient. I hope that a better material has come out of it now. But that doesn't change my opinion that the original material was good enough"	Believed that the original material was good enough Hope that better material has come out of the collaboration	Experiences in relation to the material	The existing material was sufficient
Outcome and motivation for PPI in the future	"The language in the material should not be too elevated, but it should also not be set too low. It should be just below the middle line. And I think we have hit the mark with what we have created"	The language in the material is sufficient Satisfied on what is created in the group	Satisfaction on the outcome in relation to the material	Satisfied with outcome of the material
	"In the beginning, I had no expectations, but I was pleasantly surprised by the course of events. I feel the same way about the results – we achieved something good. So, I wouldn't hesitate to participate in something similar if the opportunity arose"	The partner had a positive experience collaborating Felt the result was satisfactory and was open to future collaboration	Outcome of the collaboration and motivation for future PPI	Positive overall experience Satisfactory result Motivated for future PPI

PPI = patient and public involvement.

Trial registration: not relevant.

Results

All PPI partners agreed to participate and were interviewed (average length 16 min. (range: 12-24 min.)). Three overall themes emerged from the analysis process. Quotes selected from the original transcripts are provided as examples to illustrate the identified themes (**Table 3**).

TABLE 3 Citations from the partners (P) categorised under each of the three themes: Knowledge, expectation and motivation prior to collaboration, Experiences from collaboration, Outcome and motivation for patient and public involvement (PPI) in the future.

Partner	Citation ^a
<i>Knowledge, expectation and motivation prior to collaboration</i>	
P4	"I have to admit that I was a little like – didn't quite know what I was really getting myself into. So, in principle, I had no expectations other than thinking it could be an exciting project to be part of"
P2	"I guess user involvement is about listening to users to see if there is something that could be done better or if there is something that has been overlooked. It might make life easier for future patients, if the information material becomes more readable and manageable"
P6	"I didn't have high expectations because when I read the material, I had difficulty seeing what I could actually contribute with since they didn't find anything in the examination"
P1	"I discovered that what you were seeking were ordinary people's reactions and attitudes"
P2	"I believe we all bear a responsibility to society, and contributing to enhancements that benefit everyone – that is positive"
P9	"It is entirely in line with the current trend of involving citizens so that decisions are not made solely by others on our behalf"
<i>Experiences from collaboration</i>	
P4	"At that moment, it struck me. I realised that it was something to be taken seriously. It wasn't just some empty stuff. It really was relevant"
P9	"Well, it's completely natural that we all have some kind of anxiety about not being good enough – and that's even the case when you meet in a group where you don't know everyone, so you have to warm up a bit"
P2	"I think it's fine in groups because you also hear other opinions. You can change your perception because some people have something that sounds right, and others have something that you might disagree with. And I also think that everyone felt more relaxed by sitting together as a group of 4-6 people instead of sitting alone face to face with you"
P9	"It has been a good experience, I must say. However, you [the researchers] have been a part of it in the way that you have supported us. It doesn't happen on its own. It's simply the way you have set up the task – and that's why it works"
P7	"There were many who shared their personal experiences and progress, which is great, but that wasn't exactly what we were looking for. We were actually seeking ways to make the material better"
P6	"Initially, I actually believed that the existing material was sufficient. I hope that a better material has come out of it now. But that doesn't change my opinion that the original material was good enough."
<i>Outcome and motivation for PPI in the future</i>	
P9	"Well, based on the final creation, I think we have improved something"
P2	"The language in the material should not be too elevated, but it should also not be set too low. It should be just below the middle line. And I think we have hit the mark with what we have created"
P5	"It's easier to read now that it has been condensed to just one piece of paper instead of three or four pages. It could have made a difference for me if I had the opportunity to participate today. I'm sure it will be really helpful for other patients"
P4	"In the beginning, I had no expectations, but I was pleasantly surprised by the course of events. I feel the same way about the results – We achieved something good. So, I wouldn't hesitate to participate in something similar if the opportunity arose"

a) Some of the quotations are included in the column titled "meaning units" in Table 2; this serves to provide an example of the process from quotation to theme.

Knowledge, expectation and motivation prior to collaboration

The participants had no prior experience with PPI, only a few were familiar with the concept and most found it challenging to understand the precise purpose of the invitation. This caused some uncertainty about what to expect (Table 3, P4). Even so, most participants held optimistic expectations that PPI would contribute positively to future patients (Table 3, P2).

None of the partners were undergoing colorectal cancer investigation at the time of the PPI intervention, leading some to doubt their ability to contribute. (Table 3, P6) Also, some partners initially questioned their suitability as non-healthcare professionals, but later came to recognise that the goal was precisely to gather insights and input

from laypeople (Table 3, P1).

Partners were motivated to create a more user-friendly patient information material. For many, this was driven by personal experiences with complex and irrelevant health information. Also, a sense of societal obligation to collaborate emerged from the interviews (Table 3, P2, P9).

Experiences from collaboration

As the facilitators explained the significance of the clinical study, partners realised its importance, which helped them appreciate their contributions as meaningful and relevant (Table 3, P4).

Due to their unfamiliarity with PPI and the other partners, many felt anxious and needed time to establish a sense of comfort in the group (Table 3, P9). Therefore, partners found it beneficial to have two group meetings instead of one. The comfortable group sizes promoted discussions and were preferred to one-on-one interactions with researchers (Table 3, P2). When asked, none of the partners felt restricted in expressing themselves or sensed any influence from fellow partners pushing them in a specific direction (Table 3, P9).

However, some partners felt that certain group members did not contribute sufficiently as they shared personal medical experiences that were not directly relevant to the aim. This placed a greater burden on other members to guide discussions in the desired direction (Table 3, P7). Furthermore, not everyone saw a need for change in the original material and expressed skepticism about its effect (Table 3, P6).

Outcome and motivation for patient and public involvement in the future

Based on the drafts formulated following the group meetings, there was a belief that the final patient information material had significantly improved (Table 3, P9 & P2).

One partner, who had initially undergone colorectal cancer treatment, declined the invitation to participate in the primary study. The original patient information material was considered too text heavy and difficult to understand. Had the new material been available, this would have increased the likelihood that the partner would have participated (Table 3, P5).

All partners expressed a strong motivation to collaborate in similar PPI activities in the future (Table 3, P4).

Discussion

Partners had minimal knowledge and no prior experience with PPI. They were motivated to collaborate but also expressed anxiety and doubts about their abilities as laypeople. The format with group-based and repeated sessions fostered a productive environment, and the facilitation was considered important for the PPI's success. Challenges included off-topic discussions and skepticism about the need for involvement.

The partners doubted their abilities to contribute and believed that PPI required specialised knowledge or expertise. They were uncertain as to what degree their medical history within the study field was a prerequisite. In hindsight, we should have detailed this better in our PPI recruitment material. Motivated by the researchers' enthusiasm for hearing their opinions, they believed the collaborative process would benefit future patients by incorporating laypeople's insights and experiences. Many had encountered overly complex patient information materials, filled with dense text and jargon, and were thus motivated to improve the presentation and readability of the material. This is consistent with those who argue that there is a pervasive information overload within healthcare and that a significant amount of this "waste" could be prevented by patient involvement [16]. The partners also felt a societal obligation to collaborate and to improve healthcare through the PPI process.

The motivations identified in this study may be comprehended by applying the theory of Ryan and Deci [17] on

how a combination of internal and external motivation can lead to increased engagement in collaborative healthcare initiatives. Our results, where both an inner motivation (desire to contribute and share opinions and experiences) and an external motivation (improving materials for future patients) were described, fit very well with this theory [17]. Also, our understanding of what drives the motivation to collaborate aligns with studies in which the primary motivation for participants is the sense of giving something back [5] and studies describing the desire to help other patients and improve research as the primary motivation [7]. Our results also support those studies where the experience of not being heard has been associated with decreased motivation and engagement [8].

The partners expressed that the sense of trust grew as the group reconvened and that time was essential for relaxing. With the repetitive group meetings, we achieved just that – and while more than two sessions might be valuable, our results indicate that researchers should not rely on single-session collaboration. Consistent with other studies, PPI partners believed that it is essential to foster a sense of community in the groups to enjoy conversing and collaborating [5, 18]. Emphasis was placed on the importance of competent facilitation, which is in line with the significant responsibility of the facilitator to foster a positive partner experience described by others [18].

Concerning the data-analysis process, the resulting three themes do, by nature, align with the four prespecified core objectives defined in the research aim. The themes were, however, not predefined, and the analysis process could have resulted in either fewer or more themes had the content of the interviews been different. Also, an example of the analytical process is the division of the core objective of motivation into a “motivation prior to collaboration” and a “motivation for future PPI”, thus being included in two of the final three themes.

Limitations and strengths

The clinical study for which the written material was produced was not a clinical trial and was thus not guided by the stringent demands of Danish legislation [19]. Had it been a clinical trial, this legislation would have enforced that detailed information on the trial was added, including any foreseeable risks and detailed information on methodology, economy and potential benefits and discomfort. It was therefore possible to modify and reduce the contents of the written patient information based on the the PPI partners’ preferences. This introduces the limitation that partners might be less positive if their ideas and inputs are discarded based on legal requirements. Similarly, experiences or motivations might be different if studied in other phases of the research process.

The PPI partners were all recruited from the same department, and the sample size might be considered small. Even so, our data contain valuable perspectives from partners, considering that within qualitative methods, variation is not related to clinical or demographic characteristics but to variations in perspectives and that sampling is not only about size but quality [14, 20]. For future studies to examine the uncovered perspectives in more detail, longer or more repeated interviews would likely be needed.

Several actions were taken to ensure trustworthiness. Data credibility was increased through interaction with the partners in connection with the PPI process and obtaining their confirmation of the data collected during the interviews. Data dependability was achieved through a step-by-step description of the recruitment of partners, data collection, analysis and the extensive [Supplementary Material](#). Discussion between the authors throughout the analysis process was sought to increase data confirmability. Validity was established by presenting quotations from the transcribed data to illustrate the themes.

We chose not to pay our partners for their collaboration. This is contrary to practices in other countries, where payment demonstrates the value of the partners [7]. This decision allowed us to explore the partners' genuine experiences and motivations without financial incentives.

Conclusions

PPI partners are motivated to use their free time to improve healthcare research and feel obligated to collaborate when called upon. A general lack of familiarity with the concept of PPI was uncovered, and the results highlight the importance of communicating the need for laypeople as partners and clarifying whether lived experience with a certain disease is required. Group work with a repetitive design and with competent facilitation was found to foster trust and engagement. These results provide important guidance when designing PPI processes and recruitment campaigns in countries where PPI in research is relatively new.

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<https://content.ugeskriftet.dk/sites/default/files/2024-06/a12230790-supplementary.pdf>

REFERENCES

1. Crocker JC, Ricci-Cabello I, Parker A, et al. Impact of patient and public involvement on enrolment and retention in clinical trials: systematic review and meta-analysis. *BMJ*. 2018;363:k4738. <https://doi.org/10.1136/bmj.k4738>
2. Finderup J, Buur LE, Tscherning SC, et al. Developing and testing guidance to support researchers engaging patient partners in health-related research. *Res Involv Engagem*. 2022;8(1):43. <https://doi.org/10.1186/s40900-022-00378-2>
3. Greenhalgh T, Hinton L, Finlay T, et al. Frameworks for supporting patient and public involvement in research: systematic review and co-design pilot. *Health Expect*. 2019;22(4):785-801. <https://doi.org/10.1111/hex.12888>
4. Russell J, Greenhalgh T, Taylor M. Patient and public involvement in NIHR research 2006-2019: policy intentions, progress and themes. Oxford, UK: National Institute for Health Research, 2019
5. Cullen M, Cadogan C, George S, et al. Key stakeholders' views, experiences and expectations of patient and public involvement in healthcare professions' education: a qualitative study. *BMC Med Educ*. 2022;22(1):305. <https://doi.org/10.1186/s12909-022-03373-z>
6. Boote JD, Dagleish M, Freeman J et al. 'But is it a question worth asking?' A reflective case study describing how public involvement can lead to researchers' ideas being abandoned. *Health Expect*. 2014;17(3):440-51. <https://doi.org/10.1111/j.1369-7625.2012.00771.x>
7. Lauzon-Schnittka J, Audette-Chapdelaine S, Boutin D, et al. The experience of patient partners in research: a qualitative systematic review and thematic synthesis. *Res Involv Engagem*. 2022;8(1):55. <https://doi.org/10.1186/s40900-022-00388-0>
8. Richards DP, Poirier S, Mohabir V, et al. Reflections on patient engagement by patient partners: how it can go wrong. *Res Involv Engagem*. 2023;9(1):41. <https://doi.org/10.1186/s40900-023-00454-1>
9. National Institute for Health Research. Briefing notes for researchers: public involvement in NHS, public health and social care research. Oxford, UK: National Institute for Health Research, 2021. www.invo.org.uk/wp-content/uploads/2014/11/9938_INVOLVE_Briefing_Notes_WEB.pdf (19 Mar 2024)
10. Public involvement in research: values and principles framework. National Institute for Health Research, 2016
11. Region Hovedstaden. Center for Patientinddragelse (CPI). www.regionh.dk/patientinddragelse/Sider/default.aspx (12 Dec 2023)

12. O'Brien BC, Harris IB, Beckman TJ, et al. Standards for reporting qualitative research: a synthesis of recommendations. *Acad Med*. 2014;89(9):1245-51. <https://doi.org/10.1097/ACM.0000000000000388>
13. Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *Int J Qual Health Care*. 2007;19(6):349-57. <https://doi.org/10.1093/intqhc/mzm042>
14. Brinkmann S, Kvale S. *Doing interviews*. 2 ed. Los Angeles: SAGE, 2018
15. Graneheim UH, Lundman B. Qualitative content analysis in nursing research: concepts, procedures and measures to achieve trustworthiness. *Nurse Educ Today*. 2004;24(2):105-12. <https://doi.org/10.1016/j.nedt.2003.10.001>.
16. Khaleel I, Wimmer BC, Peterson GM, et al. Health information overload among health consumers: a scoping review. *Patient Educ Couns*. 2020;103(1):15-32. [10.1016/j.pec.2019.08.008](https://doi.org/10.1016/j.pec.2019.08.008)
17. Deci EL, Ryan RM. The "what " and "why" of goal pursuits: human needs and the self-determination of behavior. *Psychol Inq*. 2000;11(4):227-68. https://doi.org/10.1207/S15327965PLI1104_01
18. Bombard Y, Baker GR, Orlando E, et al. Engaging patients to improve quality of care: a systematic review. *Implement Sci*. 2018;13(1):98. <https://doi.org/10.1186/s13012-018-0784-z>
19. Indenrigs- og Sundhedsministeriet. Bekendtgørelse om information og samtykke til deltagelse i sundhedsvidenskabelige forskningsprojekter samt om anmeldelse af og tilsyn med sundhedsvidenskabelige forskningsprojekter. BEK nr 498 af 13/05/2018. www.retsinformation.dk/eli/ta/2018/498 (13 Dec 2023)
20. Norlyk A, Harder I. What makes a phenomenological study phenomenological? An analysis of peer-reviewed empirical nursing studies. *Qual Health Res*. 2010;20(3):420-31. <https://doi.org/10.1177/1049732309357435>