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Identifying the right phase—increasing the impact of patient involvement in quality improvement

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ABSTRACT

Objectives: Involving patients in quality improvement is often suggested as a critical step for improving healthcare processes. However, this comes with challenges related to resources, tokenism, validity, and competence. Therefore, to optimise the use of available resources, there is a need to understand at what stage in the improvement cycle patient involvement is most beneficial. Thus, the purpose of this study was to identify the phase of an improvement cycle in which patient involvement had the highest impact on radicality of improvement.

Design: An exploratory design was used.

Setting and methods: A questionnaire was completed by 155 Swedish healthcare professionals who had trained and had experience in patient involvement in quality improvement. Based on their replies, the impact of patient involvement on radicality in various phases of the improvement cycle was modelled using the partial least squares method.

Results: Patient involvement in quality improvement might help to identify and realise innovative solutions; however, there is variation in the impact of patient involvement on improvement radicality depending on the phase in which patients become involved. The highest impact on radicality was observed in the phases of *capture experiences* and *taking action*, while a moderate impact was observed in the *evaluate* phase. The lowest impact was observed in the *identify and prioritise* phase.

Conclusions: Involving patients in improvement projects can enhance the quality of care and help to identify radically new ways of delivering care. This study shows that it is possible to clearly define at what point in an improvement cycle patient involvement has the highest impact, which will enable more efficient use of the resources available for patient involvement.

Keywords: patient involvement, improvement project, quality management, radicality

Strengths and limitations of the study:

- The research team has practical and academic experience from both health care and quality improvement
- Radicality has been sparsely used as a measure for patient involvement in quality improvement
- The model allows for a prioritizing of when to involve patients in improvement projects
- Patients were not asked the same questions as health care professionals to validate results
- How the impact of patient involvement on radicality might be affected by the type of healthcare setting was not examined

BACKGROUND

Healthcare today faces an imminent challenge originating from the paradox of survival—namely, a higher demand for care without additional budget [1]. Stretching available resources to cover more individuals while simultaneously pursuing new possibilities for treatment often using expensive methods has demanded radical changes in the organisation and improvement of existing healthcare systems. As a response to this challenge, patient involvement in quality improvement (QI) has increasingly been viewed as a means to generate more radical ideas for new healthcare services [2-5]. Radicality can be defined as the potential or novelty of a QI idea for meeting new needs of patients, thus generating solutions or innovations that range from incremental ('the same but better') to radical ('really different') [6,7]. Note that radicality does not necessarily refer to solutions that are new to the world, but solutions that allow for addressing previously unmet patient needs.

It is believed that patient involvement can lead to radically new and more resource-efficient ways of delivering healthcare [1]. These changes do not necessarily need to be on a large scale, it is often small things that can be questioned and pointed out by patients that can lead to effective new ways of working. To generate radical as opposed to incremental innovation, there needs to be a sense of urgency and a tension for change [8]. The fundament for the creation of a sense of urgency is a disconfirmation of taken-for-granted implicit assumptions. Potentially, this leads to organisational members experiencing the current conditions as inadequate and developing motivation for change. Utilising patients' experiences wisely (i.e. for the right purpose at the right time) can contribute to such a tension for change. For example, methods that involve customers in design activity [9] emphasise the need for coping with conflicting interests; thus, when staff is exposed to patients' first-hand experiences, this provides an insight into the need for change, i.e. it explicates the tension for change.

However, the impact of patient involvement on radicality per se has been questioned, and arguments have been put forth that patient involvement lends itself to more incremental rather than radical change [9].

Patient involvement has been criticised for being exclusive and cosmetic, and for tokenism [2,10,11]. Furthermore, efforts to achieve greater involvement have been patchy and slow. Thus, it cannot be neglected that patient involvement imposes challenges in terms of resources [12], tokenism [13,14], validity [15], and competence [16]. Firstly, involving patients is time- and resource-consuming [15], and requires careful management to reach its full potential [10]. Secondly, if patients are asked but not listened to, tokenism might ensue in order to simply 'tick the boxes' [14], with hierarchical structures and asymmetrical patterns of power remaining unchallenged [13,17]. Thirdly, there may be validity issues with patient involvement studies where academic dissemination is preceded and therefore more rigorous evidence are desirable (15), or the validity of such studies needs to be confirmed to be accepted as high-quality research. Finally, in terms of competence, Batalden et al. [12] stressed that each level of shared work in co-creation between staff and patients requires specific knowledge of the subject matter, know-how, dispositions, and behaviours, thus pointing to a need for healthcare competence in QI work.

Despite these challenges, there are promising examples of patient involvement in QI, for example in acute care [18], development of patient education materials [17], and neonatal care [19]. The positive effects of patient involvement include enabling patients to act as intermediaries between other patients and clinicians, which may help to convince healthcare professionals of a need for change [10]. Additionally, patient involvement may improve care efficiency and decrease costs, among other aspects [20]. However, overall, there is rather poor-quality evidence and few measurements to evaluate the impact of patient involvement [10,21,22].

Thus, there are contradictory views on the potential of patient involvement to contribute to radical improvements in healthcare. A reason for this controversy lies in the uncertainty regarding how to work with patient involvement [2], in particular in terms of the most beneficial stage to involve patients in QI. Accordingly, the purpose of this study was to identify the phase of an improvement cycle in which patient involvement had the highest impact on the radicality of the improvement. This will aid in the optimisation of resource allocation to best support the contributions of patient involvement to radically new and improved ways of organising and delivering healthcare. For this purpose, we evaluated *when* patient involvement is most beneficial in an improvement cycle, which we divided into four phases according to the work of Bate and Robert [23]: *capture experiences*, *identify and prioritise*, *taking action,* and *evaluate*. The first phase involves capturing patient experiences, e.g. through interviews, films, diaries, etc. The second phase involves identifying and prioritising areas for improvement in the care process. Active involvement in QI is considered to comprise the third phase, *taking action,* while in the fourth phase, *evaluate,* patients can be involved in the follow-up and evaluation of improvements [23,24].

METHODS

Sample

Data were collected through an online survey using a web-based survey tool provided by fluidsurveys.com. The original sample consisted of 472 participants who had training and practical experience in patient involvement in QI. The participants came from 3 (out of 20) Swedish healthcare regions, responsible for the provision of primary care, healthcare, dental care, etc. in a specific geographical area. Nineteen additional participants were added by using snowball sampling. In total, 491 participants were included and received an e-mail with an introductory message and a link to the survey. Following two e-mail reminders, 155 participants completed the entire questionnaire (response rate 32%). However, a number of participants (n=32) no longer worked in healthcare or were unable to answer the questionnaire for various reasons (e.g. long sick-leave); after excluding these individuals from the original sample, the adjusted response rate was 34%. This study was conducted in accordance with the ethical code of research in healthcare [25], and the relevant ethical board acknowledged that no formal ethical approval was needed.

Measures

The questionnaire comprised a cover letter and 44 questions. The questions were based on three validated questionnaires on the evaluation of improvement initiatives [26], experience-based co-design [27], and customer involvement in service innovation [28]. The first questionnaire [26] was chosen because it examines how improvement projects can be evaluated, the second [27] investigates how to evaluate patient involvement in improvement projects specifically, and the third questionnaire [28] examines how to study radicality of improvements in a service area. Most of the questions were close-ended (examples can be seen in Table 1), with a few being open-ended, and covered the participants' demographic and background information, experiences of patient involvement in QI, and perceived results of QI. A pilot questionnaire was evaluated by a focus group consisting of five healthcare professionals from different healthcare organisations with training and practical experience in patient involvement in QI.

Seven items were used to operationalise the independent latent constructs of the phases of an improvement cycle (Table 1).

Table 1. Latent variables, items, and scale

Latent variable/ Phase of improvement cycle	**Items**	**Acronym**	**Scale**
Capture experiences	To what extent did patients/relatives participate in capturing experiences about the process?	Sharing experiences	5-point scale from 1 (to a small degree) to 5 (to a large degree)
	To what extent did patients/relatives participate in the identification of improvement areas?	Identifying improvement areas	
Identify and prioritise	To what extent did patients/relatives participate in the planning of the quality improvement project?	Project planning	
	To what extent did patients/relatives participate in prioritising possible improvement areas?	Prioritising	
Taking actions	To what extent did patient/relatives participate in generating improvement suggestions?	Generating suggestions	
	To what extent did patient/relatives participate in the implementation of improvement suggestions?	Implementing suggestions	
Evaluate	To what extent did patient/relatives participate in the evaluation of the results of the quality improvement project?	Evaluating results	

The dependent variable—radicality of improvement—was measured using a self-report single-item measure: ‘To what extent do you agree with the following statement: with the new way of working (resulting from the quality improvement project) we can meet patient needs that we did not try to meet earlier’. The item is rated on a 5-point scale ranging from 1 (completely disagree) to 5 (fully agree). Radicality hence focuses on the potential of the new way of working to meet prior unmet patient needs. This is similar to the definitions of radical innovations proposed by Tidd and Bessant [29] and Hertog [30].

Data analysis

This study was exploratory and relied on a formative measure of radicality of improvement, for which the partial least squares (PLS) method is well suited [31]. Moreover, the PLS method can be used in situations where there could be strong correlations between items [28], as could be the case in this study. The validity of the model was checked by examining the average variance extracted [32], which measures the relation between the variance captured by the construct and the variance caused by measurement error [33]. Good discriminant validity in PLS is established if the off-diagonal values are lower than the diagonal values [28].

RESULTS

The participants in this study all had training as well as experience of QI involving patients, moreover 63.9 % of the participants reported that they had experiences as facilitators of projects with patient involvement. One participant reported on an improvement project involving patient conducted already in 1979, but most of the mentioned projects were conducted after year 2010. The participants represented a variety of professions; the distribution of gender and occupation of the participants is shown in Table 2.

Table 2. Characteristics of respondents (n=155)

Gender	
Female	117 (75.5%)
Male	36 (23.2%)
Missing data	2 (1.3%)
Profession	
Nurse	71 (45.8%)
Physician	19 (12.3%)
Physiotherapist	5 (3.2%)
Occupational therapist	2 (1.3%)
Social worker	1 (0.6%)
Psychologist	2 (1.3%)
Other	51 (32.9%)
Missing data	4 (2.6%)

Following standard procedures, the first step in assessing the measurement model focused on examining the loadings to assess the reliability of all measured items. The measured items, displayed in Table 1, are assessed to ensure that they apply correctly to their latent variable i.e. *capture experiences*, *identify and prioritise*, *taking action*, or *evaluate*. The recommended threshold value of 0.707 [28] was applied and all measured items had loadings that exceeded this threshold; hence, good reliability was confirmed.

Moreover, the results revealed that the discriminant validity of the model was sufficient, meaning that the latent variables (in this study Phase of improvement cycle) have stronger relationship to its own measured items (see Table 1) than to measured items related to another latent variable. The discriminant validity was evaluated by the average variance extracted (AVE) method, stating that the off-diagonal values should all be lower than the diagonal values [28]. Following thus method the model's latent constructs have good discriminant validity (see Table 3).

Table 3. Assessment of validity of the model (average variance extracted)

	Capture experiences	**Evaluate**	**Identify and prioritise**	**Radicality**	**Taking action**
Capture experiences	0.912				
Evaluate	0.557	1.000			
Identify and prioritise	0.603	0.547	0.886		
Radicality	0.457	0.402	0.402	1.000	
Taking action	0.658	0.619	0.706	0.464	0.877

The model was estimated using PLS, Figure 1 displays the model and its four paths. From left to right, each path consists of the measured items and the associated latent variable, all modelled to assess the potential impact on the radicality of the solution resulting from the QI project.

- Insert Figure 1 about here.

Starting from top to bottom, the path coefficients were 0.220, 0.063, 0.200, and 0.121 for *capture experiences*, *identify and prioritise*, *taking action*, and *evaluate*, respectively. The coefficients reflect the magnitude of the potential impact on radicality, in other words the extent to which involvement in respective phase can lead to improvements that address previously unmet patient needs. This meant that the phases with most impact on radicality appeared to be *capture experiences* and *taking action,* whilst least impact was to be found in the phase *of identify and prioritise.*

Focusing the phases with most impact and looking at the underlying measured items, patient involvement in the *capture experience* phase means to include patients in the process of understanding (not only reporting on) patients' experiences and based on this involve patients in identification of improvement areas. In later parts of the improvement cycle, most impact is related to patient involvement in the phase *taking action*, meaning generating and implementing improvement suggestions.

DISCUSSION

The present study showed that the involvement of patients in QI might be a key to identifying and realising more radical solutions; however, the impact of patient involvement on radicality varied depending on the point at which patients were involved in a QI project. The impact of patient involvement on radicality appears to be highest in the phases of *capture experiences* and *taking action*. In contrast, patient involvement had the lowest impact on radicality in the *identify and prioritise* phase. These results are in accordance with previous studies in other disciplines that have systematically investigated the role of customer participation in development projects [35].

The shift towards an outside-in perspective might explain why patient involvement influences radicality. Traditionally, QI has been carried out by staff within organisations. However, a central problem with this approach is that staff's insight into various solutions may be constrained by their own experience [36]. Furthermore, healthcare staff are trained in evidence-based medicine, where changes are more often incremental per se, and one first learns something and then applies it. It is therefore unlikely that a QI team with only healthcare staff will generate and implement ideas that conflict with their own assumptions. However, if QI teams interact with patients in the phases of *capturing experiences* and *taking action*, a new understanding of needs, anchored in patients' experiences rather than current healthcare practices, might be identified. This can lead to a sense of urgency and a tension for change (8). In such QI projects, patients' views would balance the inside-out perspective of staff.

However, as previously argued, patient involvement presents several challenges, such as the need for resources [12], and problems related to tokenism [13,14], validity [15], and competence [16]. Firstly, dividing an improvement cycle into distinct phases and identifying the stages in which patient involvement has the greatest impact on the radicality of the improvement will enable the allocation of resources required for patient involvement to the most relevant phases. Secondly, minimising the risk of tokenism requires conditions for authentic patient involvement that can lead to a sense of urgency and a tension for change. This can best be provided in the *capturing experiences* and *taking action* phases, where this study shows that PI has most impact on radicality. Thus, patient involvement in these phases can help to reduce the risk of tokenism and our study, therefore, supports the notion that patients' active participation in practical QI projects lays a foundation for real impact. Thirdly, in contrast with previous studies suggesting validity problems when involving patients [15], this study measured healthcare professionals' perception of patients' influence and experience, and showed that patient involvement may increase the likelihood of finding a radical solution. The task of the QI team is to translate patients' expressed experiences and needs into solutions to meet these needs. Thus, the question is not to do merely what the patients say, but rather to actively listen to them and carefully consider the possible alternatives. This might also explain why patient involvement in the *identify and prioritise* phase was not so strongly linked to radicality, as these tasks are better performed by the QI team. Fourthly, concerns have been raised as to the competence of patients to contribute to QI. This can be due both to a lack of professional knowledge [12] and to the sharing of power, which challenges current power relations [13,17]. According to Gaventa and Cornwall [37] the relationship between power and knowledge can be regarded from at least three perspectives: (1) knowledge owned by powerful experts and transferred to the powerless as truth yielded by objective research; (2) knowledge as controlled by the powerful, where the powerless may be occasionally invited to produce and act upon a set agenda of knowledge creation; and (3) an emphasis on participation in the knowledge production, where co-production builds greater awareness and self-consciousness of capacities for action [37]. According to this, only in the third perspective can healthcare staff perceive patient's perspectives as equally important, and knowledge about what needs to be improved as co-created without a set agenda. Having such an approach means that the patient is regarded as a capable person with unique knowledge [38] and a partner in developing care through participation in QI. The findings in our study support this view while still respecting the professional knowledge held by healthcare staff (i.e. given that the *identify and prioritise* phase had the lowest impact on radicality, it should be developed by professionals based on their broader healthcare experience).

The findings in this study have practical implications for improvement projects that involve patients. A particularly important implication of this study is that QI teams should consider involving patients, especially in the *capture experiences* and *taking action* phases of a project, as this will likely influence the radicality of the solutions. However, as healthcare is co-created and produced within the interactions between patients and health professionals [12], the staff's perspective should be balanced with that of patients. As discussed above, power and ethics could be a barrier to forging a true partnership between patients and staff, but our results can nevertheless help by defining when patient involvement is most beneficial for radicality. At the same time, this knowledge can help to save resources spent on patient involvement by identifying which phases are best handled by healthcare professionals alone.

This study has several limitations. Firstly, it clarifies the effects of patient involvement in QI initiatives in the specific context of Swedish healthcare. Secondly, as patient involvement in QI is a relatively new practice, the sampling strategy involved choosing participants who were trained and had experience in QI. When these practices have been in use for a longer time and by more healthcare professionals, a different sampling strategy might be used. Furthermore, it would be of interest for future research to study how the impact of patient involvement on radicality is affected by the type of healthcare setting, such as acute vs. chronic care, or standardised simple procedures vs. complex care. Another potential area for future research would be to identify what methods could be used to support patient involvement in the different phases of QI. For instance, well established methods such as concept mapping [39], where there is a clear distinction between stakeholders' and researchers' responsibilities within the cycle, could be tested in patient involvement in healthcare.

Conclusion

In conclusion, before considering involving patients in improvement initiatives, it is essential to decide how and when to involve them. Consideration should be given to the phase in which patients have the potential to co-create radical and valuable insights for improvement initiatives. This study showed that patient involvement has the greatest impact on radicality in the phases *capture experiences* and *taking action*, a moderate impact in the *evaluate* phase, and the lowest impact on the *identify and prioritise* phase.

Contributors

IG, ME and SG developed and directed the survey. IG and ME performed the statistical analysis. IG, ME and FS designed this specific study and did the draft and editing of the manuscript. All authors approved the manuscript.

Competing interests

None declared.

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Data sharing statement

The database is held at the host institution and analysis and access to the data are limited to on-site access. More detailed analysis results are available on request to the corresponding author.

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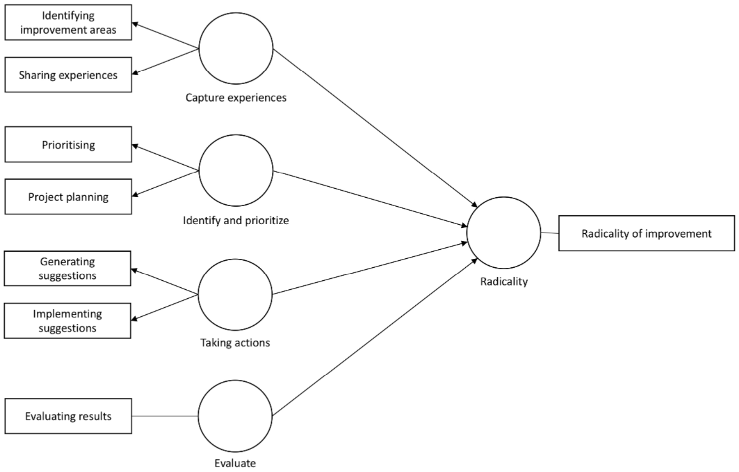
Figure 1. Model of radicality of improvement. Latent variables are the phases of an improvement project: *capture experiences*, *identify and prioritise*, *taking action*, and *evaluate*.



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Exploring the phase for highest impact on radicality—a cross-sectional study of patient involvement in quality improvement in Swedish health care

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Exploring the phase for highest impact on radicality—a cross-sectional study of patient involvement in quality improvement in Swedish health care

ABSTRACT

Objectives: Involving patients in quality improvement is often suggested as a critical step for improving healthcare processes. However, this comes with challenges related to resources, tokenism, validity, and competence. Therefore, to optimise the use of available resources, there is a need to understand at what stage in the improvement cycle patient involvement is most beneficial. Thus, the purpose of this study was to identify the phase of an improvement cycle in which patient involvement had the highest impact on radicality of improvement.

Design: An exploratory cross-sectional survey was used.

Setting and methods: A questionnaire was completed by 155 Swedish healthcare professionals (response rate 34%) who had trained and had experience in patient involvement in quality improvement. Based on their replies, the impact of patient involvement on radicality in various phases of the improvement cycle was modelled using the partial least squares method.

Results: Patient involvement in quality improvement might help to identify and realise innovative solutions; however, there is variation in the impact of patient involvement on perceived radicality depending on the phase in which patients become involved. The highest impact on radicality was observed in the phases of *capture experiences* and *taking action*, while a moderate impact was observed in the *evaluate* phase. The lowest impact was observed in the *identify and prioritise* phase.

Conclusions: Involving patients in improvement projects can enhance the quality of care and help to identify radically new ways of delivering care. This study shows that it is possible to suggest at what point in an improvement cycle patient involvement has the highest impact, which will enable more efficient use of the resources available for patient involvement.

Keywords: patient involvement, improvement project, quality management, radicality

Strengths and limitations of the study:

- The research team has practical and academic experience from both health care and quality improvement
- Radicality has been sparsely used as a measure for patient involvement in quality improvement
- The model allows for a prioritizing of when to involve patients in improvement projects
- Patients were not asked the same questions as health care professionals to validate results
- How the impact of patient involvement on radicality might be affected by the type of healthcare setting was not examined

BACKGROUND

Healthcare today faces an imminent challenge originating from the paradox of survival—namely, a higher demand for care without additional budget [1]. Stretching available resources to cover more individuals while simultaneously pursuing new possibilities for treatment often using expensive methods has demanded radical changes in the organisation and improvement of existing healthcare systems. As a response to this challenge, patient involvement in quality improvement (QI) has increasingly been viewed as a means to generate more radical ideas for new healthcare services [2-5]. Radicality can be defined as the potential or novelty of a QI idea for meeting new needs of patients, thus generating solutions or innovations that range from incremental ('the same but better') to radical ('really different') [6,7]. Note that radicality does not necessarily refer to solutions that are new to the world, but solutions that allow for addressing previously unmet patient needs within specific contexts.

The notion of patient involvement includes a variety of influences that has led to its development, including democratisation, challenges to professional power, and welfare rights social movements. It is also believed that patient involvement can lead to radically new and more resource-efficient ways of delivering healthcare [1]. These changes do not necessarily need to be on a large scale, it is often small things that can be questioned and pointed out by patients that can lead to effective new ways of working. To generate radical as opposed to incremental innovation, there needs to be a sense of urgency and a tension for change [8]. The fundament for the creation of a sense of urgency is a disconfirmation of taken-for-granted implicit assumptions. Potentially, this leads to organisational members experiencing the current conditions as inadequate and developing motivation for change. Utilising patients' experiences wisely (i.e. for the right purpose at the right time) can contribute to such a tension for change. For example, methods that involve customers in design activity [9] emphasise the need for coping with conflicting interests; thus, when staff is exposed to patients' first-hand experiences, this provides an insight into the need for change, i.e. it intensifies the tension for change. However, the impact of patient involvement on radicality per se has been questioned, and arguments have been put forth that patient involvement lends itself to more incremental rather than radical change [9].

Patient involvement has been criticised for being exclusive and cosmetic, and for tokenism [2,10,11]. Furthermore, efforts to achieve greater involvement have been patchy and slow as healthcare QI personnel experience several obstacles and sometimes even do not value patient involvement at all. It cannot be neglected that patient involvement imposes challenges in terms of resources [12], tokenism [13,14], validity [15], and competence [16]. Firstly, involving patients is time- and resource-consuming [15], and requires careful management to reach its full potential [10]. Secondly, if patients are asked but not listened to, tokenism might ensue in order to simply 'tick the boxes' [14], with hierarchical structures and asymmetrical patterns of power remaining unchallenged [13,17]. Thirdly, there might be validity issues with patient involvement studies and therefore, more rigorous evidence of their outcome is desirable (15), for such studies to be confirmed and accepted as high-quality research. Finally, in terms of competence, Batalden et al. [12] stressed that each level of shared work in co-creation between staff and patients requires specific knowledge of the subject matter, know-how, dispositions, and behaviours, thus pointing to a need for healthcare competence in QI work.

Despite these challenges, there are promising examples of patient involvement in QI, for example in acute care [18], development of patient education materials [17], and neonatal care [19]. The positive effects of patient involvement include enabling patients to act as intermediaries between other patients and clinicians, which may help to convince healthcare professionals of a need for change [10]. Additionally, patient involvement may improve care efficiency and decrease costs, among other aspects [10]. However, overall, there is rather poor-quality evidence and few measurements to evaluate the impact of patient involvement [10, 20,21].

Thus, there are contradictory views on the potential of patient involvement to contribute to radical improvements in healthcare. A reason for this controversy lies in the uncertainty regarding how to work with patient involvement [2], in particular in terms of the most beneficial stage to involve patients in QI. Accordingly, the purpose of this study was to identify the phase of an improvement cycle in which patient involvement had the highest impact on the radicality of the improvement. This will aid in the optimisation of resource allocation to best support the contributions of patient involvement to radically new and improved ways of organising and delivering healthcare. For this purpose, we evaluated *when* patient involvement is most beneficial in an improvement cycle, which we divided into four phases according to the work of Bate and Robert [22]: *capture experiences*, *identify and prioritise*, *taking action,* and *evaluate*. These four phases are also generally found in other forms of patient involvement in quality improvement cycles [8]. The first phase involves capturing patient experiences, e.g. through interviews, films, diaries, etc. The second phase involves identifying and prioritising areas for improvement in the care process. Active involvement in QI is considered to comprise the third phase, *taking action,* while in the fourth phase, *evaluate,* patients can be involved in the follow-up and evaluation of improvements [22,23].

METHODS

Sample

Data were collected through an online cross-sectional survey using a web-based survey tool provided by fluidsurveys.com. The original sample consisted of 472 participants who had training and practical experience in patient involvement in QI. The training ranged from a two-week course to a two-year part-time university education. All training consisted of a combination of theoretical elements (focusing QI and patient involvement in healthcare) as well as practical improvement projects. Regarding the practical experience of QI and patient involvement (besides the projects being part of the training), the experience ranged from one to more than 10 completed projects; the projects focusing e.g. the eating environment at hospitals, decreasing compulsory care in psychiatry, and improvements in cancer care. The sampling frame was given by access to e-mail lists from three of the largest providers of courses on QI in healthcare, the e-mail lists included all their previous participants

The participants came several Swedish healthcare regions, responsible for the provision of primary care, healthcare, dental care, etc. in a specific geographical area. Nineteen additional participants were added by using snowball sampling. In total, 491 participants were included and received an e-mail with an introductory message and a link to the survey. Following two e-mail reminders, 155 participants completed the entire questionnaire (response rate 32%). However, a number of participants (n=32) no longer worked in healthcare or were unable to answer the questionnaire for various reasons (e.g. long sick-leave); after excluding these individuals from the original sample, the adjusted response rate was 34%. This study was conducted in accordance with the ethical code of research in healthcare [24], and the *Regional Ethical Review Board in Gothenburg* granted exemption from a formal ethical approval.

Patient and public involvement statement

Patients were not included in the sampling for this study. It is considered appropriate [25,26] for evaluation of improvement projects to choose people with a long track record of experience with a specific process, in our case the QI-staff. Patients have invaluable knowledge of the experience from other dimensions, but have less knowledge about the organization, and what can be considered as radical might thereby have a completely different meaning than for the QI personnel and should therefore not be compared.

Measures

The questionnaire comprised a cover letter and 44 questions. The questions were based on three validated questionnaires on the evaluation of improvement initiatives [27], experience-based co-design [28], and customer involvement in service innovation [29]. The first questionnaire [27] was chosen because it examines how improvement projects can be evaluated, the second [28] investigates how to evaluate patient involvement in improvement projects specifically, and the third questionnaire [29] examines how to study radicality of improvements in a service area. Most of the questions were close-ended (examples can be seen in Table 1), with a few being open-ended, and covered: the participants' demographic and background information, motivation and organisation of improvement projects, experiences of patient involvement in QI, the organisational culture, and the perceived results of patient involvement in QI. A pilot questionnaire was evaluated by a focus group consisting of five healthcare professionals from different healthcare organisations with training and practical experience in patient involvement in QI. This contributed to clarifications of questions and instructions in the survey, and ensured an understanding of the survey and its item among the focus group participants.

Seven items were used to operationalise the independent latent constructs of the phases of an improvement cycle (Table 1).

Table 1. Latent variables, items, and scale

Latent variable/ Phase of improvement cycle	**Items**	**Acronym**	**Scale**
Capture experiences	To what extent did patients/relatives participate in capturing experiences about the process?	Sharing experiences	5-point scale from 1 (to a small degree) to 5 (to a large degree)
	To what extent did patients/relatives participate in the identification of improvement areas?	Identifying improvement areas	
Identify and prioritise	To what extent did patients/relatives participate in the planning of the quality improvement project?	Project planning	
	To what extent did patients/relatives participate in prioritising possible improvement areas?	Prioritising	
Taking actions	To what extent did patient/relatives participate in generating improvement suggestions?	Generating suggestions	
	To what extent did patient/relatives participate in the implementation of improvement suggestions?	Implementing suggestions	
Evaluate	To what extent did patient/relatives participate in the evaluation of the results of the quality improvement project?	Evaluating results	

The dependent variable—radicality of improvement—was measured using a self-report single-item measure: 'To what extent do you agree with the following statement: with the new way of working (resulting from the quality improvement project) we can meet patient needs that we did not try to meet earlier', building upon Cooper [30]. The item is rated on a 5-point scale ranging from 1 (completely disagree) to 5 (fully agree). Radicality hence focuses on the potential of the new way of working to meet prior unmet patient needs. This is similar to the definitions of radical innovations proposed by Tidd and Bessant [31] and Hertog [32].

Data analysis

This study was exploratory and relied on a formative measure of radicality of improvement, for which the partial least squares (PLS) method is well suited [33]. Moreover, the PLS method can be used in situations where there could be strong correlations between items [29], as could be the case in this study. The validity of the model was checked by examining the average variance extracted [34], which measures the relation between the variance captured by the construct and the variance caused by measurement error [35]. Good discriminant validity in PLS is established if the off-diagonal values are lower than the diagonal values [29].

RESULTS

The participants in this study all had training as well as experience of QI involving patients, moreover 63.9 % of the participants reported that they had experiences as facilitators of projects with patient involvement. One participant reported being involved in an improvement project involving patient conducted already in 1979, but most of the mentioned projects were conducted after year 2010. The participants represented a variety of professions; the distribution of gender and occupation of the participants is shown in Table 2. The distributions of gender and professions are in line with the total distributions in Swedish healthcare.

Table 2. Characteristics of respondents (n=155)

Gender	
Female	117 (75.5%)
Male	36 (23.2%)
Missing data	2 (1.3%)
Profession	
Nurse	71 (45.8%)
Physician	19 (12.3%)
Physiotherapist	5 (3.2%)
Occupational therapist	2 (1.3%)
Social worker	1 (0.6%)
Psychologist	2 (1.3%)
Other, e.g. public health scientists, psychotherapist, and quality manager	51 (32.9%)
Missing data	4 (2.6%)

Following standard procedures, the first step in assessing the measurement model focused on examining the loadings to assess the reliability of all measured items. The measured items, displayed in Table 1, are assessed to ensure that they apply correctly to their latent variable i.e. *capture experiences*, *identify and prioritise*, *taking action*, or *evaluate*. The recommended threshold value of 0.707 [29] was applied and all measured items had loadings that exceeded this threshold; hence, good reliability was confirmed.

Moreover, the results revealed that the discriminant validity of the model was sufficient, meaning that the latent variables (in this study Phase of improvement cycle) have stronger relationship to its own measured items (see Table 1) than to measured items related to another latent variable. The discriminant validity was evaluated by the average variance extracted (AVE) method, stating that the off-diagonal values should all be lower than the diagonal values [29]. Following thus method the model's latent constructs have good discriminant validity (see Table 3).

Table 3. Assessment of validity of the model (average variance extracted)

	Capture experiences	**Evaluate**	**Identify and prioritise**	**Radicality**	**Taking action**
Capture experiences	0.912				
Evaluate	0.557	1.000			
Identify and prioritise	0.603	0.547	0.886		
Radicality	0.457	0.402	0.402	1.000	
Taking action	0.658	0.619	0.706	0.464	0.877

The model was estimated using PLS, Figure 1 displays the model and its four paths. From left to right, each path consists of the measured items and the associated latent variable, all modelled to assess the potential impact on the radicality of the solution resulting from the QI project.

- Insert Figure 1 about here.

Starting from top to bottom, the path coefficients were 0.220, 0.063, 0.200, and 0.121 for *capture experiences*, *identify and prioritise*, *taking action*, and *evaluate*, respectively. The coefficients reflect the magnitude of the potential impact on radicality, in other words the extent to which involvement in respective phase can lead to improvements that address previously unmet patient needs. This meant that the phases with most impact on radicality appeared to be *capture experiences* and *taking action,* whilst least impact was to be found in the phase *of identify and prioritise.*

Focusing the phases with most impact and looking at the underlying measured items, patient involvement in the *capture experience* phase means to include patients in the process of understanding (not only reporting on) patients' experiences and based on this involve patients in identification of improvement areas. In later parts of the improvement cycle, most impact is related to patient involvement in the phase *taking action*, meaning generating and implementing improvement suggestions.

DISCUSSION

The present study showed that the involvement of patients in QI might be a key to identifying and realising more radical solutions. However, the impact of patient involvement on radicality varied depending on the point at which patients were involved in a QI project. The impact of patient involvement on radicality appears to be highest in the phases of *capture experiences* and *taking action*. In contrast, patient involvement had the lowest impact on radicality in the *identify and prioritise* phase. These results are in accordance with previous studies in other disciplines that have systematically investigated the role of customer participation in development projects [36]. The finding should not be interpreted as a non-existing need to involve patient in those two latter phases. The results point to a relatively higher influence of patient involvement in the phases of *capture experiences* and *taking action* when focusing on radicality.

The shift towards an outside-in perspective might explain why patient involvement influences radicality. Traditionally, QI has been carried out by staff within organisations. However, a central problem with this approach is that staff's insight into various solutions may be constrained by their own experience [37]. Furthermore, healthcare staff are trained in evidence-based medicine, where changes are more often incremental per se, and one first learns something and then applies it. It is therefore unlikely that a QI team with only healthcare staff will generate and implement ideas that conflict with their own assumptions. However, if QI teams interact with patients in the phases of *capturing experiences* and *taking action*, a new understanding of needs, anchored in patients' experiences rather than current healthcare practices, might be identified. This can lead to a sense of urgency and a tension for change [8]. In such QI projects, patients' views would balance the inside-out perspective of staff.

However, as previously argued, patient involvement presents several challenges, such as the need for resources [12], and problems related to tokenism [13,14], validity [15], and competence [16]. Firstly, dividing an improvement cycle into distinct phases and identifying the stages in which patient involvement has the greatest impact on the radicality of the improvement will enable the allocation of resources required for patient involvement to the most relevant phases. Secondly, minimising the risk of tokenism requires conditions for authentic patient involvement that can lead to a sense of urgency and a tension for change. This can best be provided in the *capturing experiences* and *taking action* phases, where this study shows that patient involvement has most impact on radicality. Thus, patient involvement in these phases can help to reduce the risk of tokenism, i.e. ensuring that the patients voice is listened to and acted upon. Our study, therefore, supports the notion that patients' active participation in practical QI projects lays a foundation for real impact. Thirdly, in contrast with previous studies suggesting validity problems when involving patients [15], this study measured healthcare professionals' perception of patients' influence and experience, and showed that patient involvement increase the likelihood of finding a radical solution particularly in certain phases of a QI project. Fourthly, concerns have been raised as to the competence of patients to contribute to QI. This can be due both to a lack of professional knowledge [12] and to the sharing of power, which challenges current power relations [13,17]. According to Gaventa and Cornwall [38] the relationship between power and knowledge can be regarded from at least three perspectives: (1) knowledge owned by powerful experts and transferred to the powerless as truth yielded by objective research; (2) knowledge as controlled by the powerful, where the powerless may be occasionally invited to produce and act upon a set agenda of knowledge creation; and (3) an emphasis on participation in the knowledge production, where co-production builds greater awareness and self-consciousness of capacities for action [38]. According to this, only in the third perspective can healthcare staff perceive patient's perspectives as equally important, and knowledge about what needs to be improved as co-created without a set agenda. Having such an approach means that the patient is regarded as a capable person with unique knowledge [39] and a partner in developing care through participation in QI. The findings in our study support this view while still respecting the professional knowledge held by healthcare staff (i.e. given that the *identify and prioritise* phase had the lowest impact on radicality, it should be developed by professionals based on their broader healthcare experience).

As it is based on data from a variety of QI projects cross different specialities of care, the findings from this study have practical implications for improvement projects that involve patients. Generally, as healthcare is co-created and produced within the interactions between patients and health professionals [12], the staff's perspective should be balanced with that of patients. Power and ethics could be a barrier to forging a true partnership between patients and staff, but our results can nevertheless help by defining when patient involvement is most beneficial for radicality. Besides proving the criticality and usefulness of patient involvement, this knowledge can help prioritise resources spent on patient involvement. Hence, current change models (e.g. Nolan's model for quality improvement, PDSA) and more specific patient involvement frameworks (e.g. Experienced Based Co-Design, tracer methodology) may benefit from infusing the findings from the present study in their work. Further, the findings can be used in order to identify specific methods, e.g. process mapping and fishbone analyses, where incorporation of the patient might be efficient.

In further research, a general question to be asked in relation to these frameworks and methods is if patients are invited to participate in various phases and activities and if they are effectively engaged. The findings can also be used as basis for understanding the relative importance of various patient activities in co-creation models where patients are involved as representatives in trial management groups, steering committees, and data monitoring teams [40]. Furthermore, it would be of interest for future research to study how the impact of patient involvement on radicality is affected by the type of healthcare setting, such as acute vs. chronic care, standardised simple procedures vs. complex care, as well as type of speciality. Another potential area for future research would be to identify what methods could be used to support patient involvement in the different phases of QI. For instance, well established methods such as concept mapping [41], where there is a clear distinction between stakeholders' and researchers' responsibilities within the cycle, could be tested in patient involvement in healthcare.

This study has several limitations. Firstly, it clarifies the effects of patient involvement in QI initiatives in the specific context of Swedish healthcare. Secondly, as patient involvement in QI is a relatively new practice, the sampling strategy involved choosing participants who were trained and had experience in QI [25,26]. When these practices have been in use for a longer time and by more healthcare professionals, a different sampling strategy might be used and also include patients with experience from QI work.

Conclusion

In conclusion, before considering involving patients in improvement initiatives, it is essential to decide how and when to involve them. Consideration should be given to the phase in which patients have the potential to co-create radical and valuable insights for improvement initiatives. This study showed that patient involvement has the greatest impact on radicality in the phases *capture experiences* and *taking action*, a moderate impact in the *evaluate* phase*,* and the lowest impact on the *identify and prioritise* phase.

Contributors

IG, ME and SG developed and directed the survey. IG and ME performed the statistical analysis. IG, ME and FS designed this specific study and did the draft and editing of the manuscript. All authors approved the manuscript.

Competing interests

None declared.

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Data sharing statement

The database is held at the host institution and analysis and access to the data are limited to on-site access. More detailed analysis results are available on request to the corresponding author.

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Figure 1. Model of radicality of improvement. Latent variables are the phases of an improvement project: *capture experiences*, *identify and prioritise*, *taking action*, and *evaluate*.

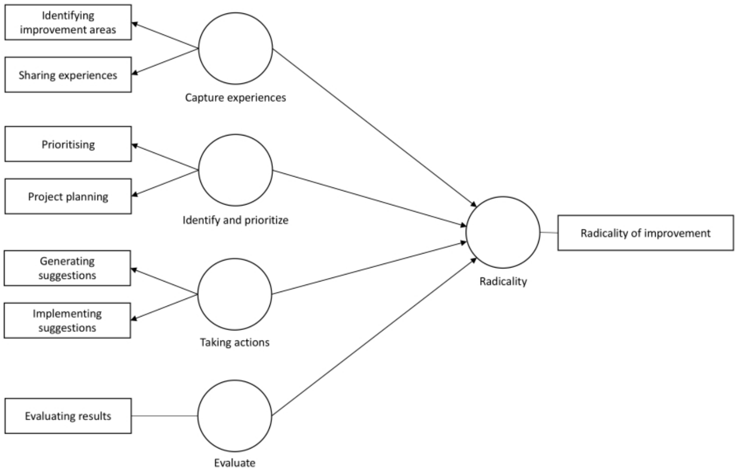

Figure 1. Model of radicality of improvement. Latent variables are the phases of an improvement project: capture experiences, identify and prioritise, taking action, and evaluate.

297x209mm (300 x 300 DPI)

STROBE Statement—Checklist of items that should be included in reports of ***cross-sectional studies***

	Item No	Recommendation	Page no
Title and abstract	1	(*a*) Indicate the study's design with a commonly used term in the title or the abstract	1, 2
		(*b*) Provide in the abstract an informative and balanced summary of what was done and what was found	2
Introduction			
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported	3, 4
Objectives	3	State specific objectives, including any prespecified hypotheses	4
Methods			
Study design	4	Present key elements of study design early in the paper	5
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	5
Participants	6	(*a*) Give the eligibility criteria, and the sources and methods of selection of participants	5
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable	6, 7 (Table 1 plus the paragraph after the table)
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group	5
Bias	9	Describe any efforts to address potential sources of bias	5
Study size	10	Explain how the study size was arrived at	N/A
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why	7
Statistical methods	12	(*a*) Describe all statistical methods, including those used to control for confounding	7
		(*b*) Describe any methods used to examine subgroups and interactions	N/A
		(*c*) Explain how missing data were addressed	N/A
		(*d*) If applicable, describe analytical methods taking account of sampling strategy	N/A
		(*e*) Describe any sensitivity analyses	9
Results			
Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed	N/A
		(b) Give reasons for non-participation at each stage	5
		(c) Consider use of a flow diagram	N/A
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders	8
		(b) Indicate number of participants with missing data for each variable of interest	N/A

Outcome data	15*	Report numbers of outcome events or summary measures	9 (Figure 1)
Main results	16	(*a*) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included	9 (Figure 1)
		(*b*) Report category boundaries when continuous variables were categorized	N/A
		(*c*) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period	N/A
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses	9 (Table 3)
Discussion			
Key results	18	Summarise key results with reference to study objectives	10
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias	11, 12
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence	10, 11
Generalisability	21	Discuss the generalisability (external validity) of the study results	11
Other information			
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based	No funding to report

*Give information separately for exposed and unexposed groups.

Note: An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at http://www.plosmedicine.org/, Annals of Internal Medicine at http://www.annals.org/, and Epidemiology at http://www.epidem.com/). Information on the STROBE Initiative is available at www.strobe-statement.org.