DISCUSSION
This chapter presents the conclusions of this thesis, which were guided by the following research question:

*How can knowledge co-creation and empowerment processes enhance patient-centred care?*

These intertwined processes were studied through five case studies which have been described in the previous chapters. To answer the main research question, three sub-research questions (as described in Chapter 3) were formulated:

RQ3: *How can knowledge co-creation strengthen patient-centred care, and vice versa?*

RQ1: *How can knowledge co-creation strengthen patient empowerment, and vice versa?*

RQ2: *How can health professional empowerment strengthen knowledge co-creation and patient empowerment?*

This chapter addresses these research questions based on the findings of five case studies as presented in Chapter 4 to 8. Subsequently, the theoretical implications of the findings are discussed, as well as the recommendations for practice, the validity and opportunities for future research.

**9.1 | MUTUALLY REINFORCING KNOWLEDGE CO-CREATION AND PATIENT-CENTRED CARE**

Insights into how knowledge co-creation processes could enhance patient-centred care were obtained directly through the second case study (Chapter 5). The primary focus of the other four case studies was not directly related to patient-centred care. However, these case studies indirectly aimed to create care that is patient-centred. How patient-centred care could stimulate knowledge co-creation processes was studied in all five cases.

The case studies highlighted that knowledge co-creation could be enhanced by patient-centred care services through ‘genuinely’ involving patients. Conversely, knowledge co-creation processes can lead to more patient-centred care by providing services which are responsive to patients’ needs.

**9.1.1 | ENHANCING KNOWLEDGE CO-CREATION BY ‘GENUINELY’ INVOLVING PATIENTS**

The findings of the case studies demonstrate that at an individual level, patient-centred care services can stimulate knowledge co-creation by ‘genuinely’ involving patients in decision-making processes. With ‘genuine’, we refer to ‘meaningful’ involvement as formulated by Gallivan *et al.* (2012), mentioned in Chapter 2. Conversely, knowledge co-creation processes were impeded when involvement was limited or there was only tokenistic involvement. In all five case studies, patients and patients’ parents highlighted that they experienced difficulties in becoming involved in the care process, because communication was lacking, unclear or not provided in a timely fashion. Communication was often restricted to the current status and care steps (Chapters 4, 5 and 7). Patients missed, however, information on future care steps (Chapters 5 and 7) and underlying considerations of decisions (Chapters 4 and 7), needed for being able to look for additional
information about their condition and take an active role in decision-making processes. In the case studies described in Chapters 4 and 6 the lack of communication about transfers were specifically mentioned. Communication was also lacking during acute situations (Chapter 5) or in relation to ‘insecurities’ about for instance the prognosis or future care steps (Chapter 4). Fried (2016) showed that the greater the uncertainty relating health-related decisions, the more likely it is that patients are asked to make the decision, stressing patients’ need for being well-informed about these uncertainties. Previous findings indicate that current communications are not well aligned with patients’ information need to become empowered. Ha and Longnecker (2010) also indicated a gap between the preferred and actual patient-health professional communication and stressed that health professionals currently overestimate their communication skills.

In addition, the difficulties patients experience in sharing their perspectives and questions were described in the case studies as a barrier to become involved at an individual level. Even though health professionals assume patients have the opportunity and feel free to ask questions and share their perspectives, patients’ stories showed differently. Various situations were described in which patients felt constrained to ask questions or share their perspectives due to for instance health professionals’ high work load (Chapter 6). In the case study described in Chapter 8 patients mentioned that they do not discuss their problems because they are amongst others unaware of the possibilities of professional support. Such situations hinder collaborative communication in which two-way exchange of information takes place, limiting knowledge co-creation processes. A lack of family involvement was also directly mentioned in the case studies described in Chapters 4, 5 and 8.

At a collective level, patients were invited by health professionals to evaluate the care services by, for instance, satisfaction questionnaires. This invitation to articulate their knowledge was regularly experienced by patients as a box-ticking exercise (Chapters 5 and 7) instead of truly listening to their feedback and subsequently implementing improvement measures. Such tokenistic use of patients’ perspectives has also been highlighted in the literature (Ocloo and Matthews, 2016; Trujols et al., 2014; Hahn et al., 2017; Supple et al., 2015). Forbat et al. (2009) suggest that involving patients in integrating and embedding the integrated knowledge into e.g. improvement measures, could help in dissolving patients’ concerns about tokenism. However, in several of our case studies patients mentioned that knowledge integration and embedding was hindered by defensive and patronizing responses on the part of health professionals (Chapters 4, 5 and 7).

Throughout the case studies, patients were involved by joining the research team and by inviting them to the co-creation sessions. Process facilitation largely prevented tokenistic involvement, by establishing the right conditions to stimulate integration and embedding of knowledge, and in line with Pittens (2013). The facilitators created an atmosphere of trust, enabling patients to share their knowledge and provided time and opportunities to reflect on the articulated knowledge.
### 9.1.2 | ENHANCING PATIENT-CENTRED CARE THROUGH RESPONSIVENESS

The case studies show that to enhance patient-centred care, the care provided should be responsive to patients’ and – in the case of young children – parental needs. Current initiatives to enhance patient-centred care focus primarily on involving patients to determine their needs (Castro et al., 2016; Zucca et al., 2017; Scholl et al., 2014). Responsiveness refers to the recognition of patients’ individual experiences and needs (Sidani and Fox, 2014). Being responsive does not mean that the care services fulfil or exceed patients’ expectations, but that there is flexibility to adapt to patients’ individual needs at a certain moment in time. Following the findings of the case study presented in Chapter 5, responsiveness is required at all four levels of patient-centred (or client-centred) care: (1) patient, (2) interaction, (3) health professional, and (4) health care organization. This means that the roles of both patients and health professionals, the patient–health professional interaction and the organization of care should enhance patient-centred care by stimulating a partnership relationship (Maassen et al., 2017) in which knowledge is co-created.

Involving patients in the entire process of knowledge co-creation (not solely articulation) was found to be useful to become responsive to patients’ needs and thus to enhance patient-centred care. A lack of knowledge integration will lead to different outcomes, which are expected to be less responsive and therefore less patient-centred (Ocloo and Matthews, 2016).

At an individual level, responsiveness to patients’ needs was achieved when health professionals took women’s background into account, communicated openly, showed a caring attitude and provided continuous care within a cohesive team (Chapter 5). In some cases, patients felt that they did not have a real choice in their care process (Chapters 5 and 7). Patients lacked involvement in decision-making processes regarding, among others, the planning of transfers (Chapters 4 and 6) and treatment options and steps (Chapter 7).

At a collective level, the integration of patients’ articulated knowledge enabled the formulation of specific improvement measures (Chapters 4, 6 to 8) and empowering interventions (Chapter 7 and 8) that were in line with patients’ needs and therefore patient-centred. The areas of improvement were used as an input to improve current clinical guidelines (Chapters 4 and 8) and care pathways (Chapter 6). The interventions consisted of complete transparent, personal and ultimately empowering patient information. By being in line with patients’ needs, and so being more patient-centred, these interventions are expected to empower patients by increasing their knowledge and shared decision-making and self-management skills (Coulter and Ellins, 2007, 2006) and improve patient involvement in knowledge co-creation.

### 9.2 | MUTUALLY REINFORCING KNOWLEDGE CO-CREATION AND PATIENT EMPOWERMENT

The mutual relationship between knowledge co-creation and patient empowerment were studied in the five case studies at different levels (individual and/or collective) and to varying degrees. Where the first case studies (Chapters 4 and 5) studied the processes mainly at an individual level by articulating patients’ knowledge, more attention was paid to knowledge integration and embedment
of patients’ articulated knowledge at a collective level in the other three chapters. Empowerment also became a more important focus in the case studies presented in Chapters 6 to 8.

The case studies showed that knowledge co-creation and patient empowerment processes can be mutually reinforcing at both an individual and collective level. Knowledge co-creation was found to stimulate patients’ empowerment state through mutual learning. Knowledge co-creation processes, in turn, were improved by patients’ empowerment behaviours.

9.2.1 | REINFORCING PATIENTS’ EMPOWERMENT THROUGH LEARNING

As stressed by other authors (Pittens, 2013; Regeer and Bunders, 2009), the case studies show that knowledge co-creation processes stimulate mutual learning. Single-, double- and triple-loop learning (Argyris and Schön, 1978) – described in Chapter 3 – took place to a varying extent. At both an individual and collective level, mostly single-loop learning took place. The learnings induced patient empowerment as suggested in previous studies (Stang and Mittelmark, 2009; Fumagalli et al., 2015).

By being involved in decision-making at an individual level, patients learned about their disease and care process (single-loop learning). These learnings increased patients’ knowledge and skills regarding self-management, treatment options or caring tasks in the case of patients’ parents’, which contributed to the extent they perceived personal control and thus felt empowered (Chapters 4 and 7). The case described in Chapter 7 showed that involvement of patients in decision-making processes through for instance the use of decision-aids increased patients’ knowledge about the considerations of possible treatments and so contributed to their control in deciding about a future treatment. Perceived personal control was also increased by the use of a birth plan in maternity care (Chapter 5). These decision-aids and birth plan helped patients to become more aware of their own values and needs. According to (Feste and Anderson, 1995) such awareness can enhance patients’ empowerment. However, these tools were often not consistently used or in a tokenistic way, hindering double- and triple-loop learning and consequently empowerment. In addition, decision aids were mostly used after the consults by patients themselves. This could be explained by the fact that decision aids are not well-designed for the patient-health professional encounter (Stiggelbout et al., 2012). Similar to Hargraves et al. (2016), we found that to enhance patient empowerment, offering information and choices is not sufficient, but a dialogue between patients and health professionals should be facilitated. Such a dialogue has the potential to generate learnings, as also stressed by Nygårdh et al. (2012). Examples of double- and triple-loop learning at an individual level were, however, not brought forward in patients’ stories.

Patients were involved at a collective level by joining the knowledge co-creation processes of the case studies. Throughout the case studies, patients were involved by the use of the participatory tools Interactive Learning and Action (Chapters 6 and 7) and Participatory Action Research (Chapter 8). Through these participatory processes in which knowledge was co-created, single-, double- and triple-loop learning was stimulated. As also found by Regeer and Bunders (2009), these learning processes were valuable for integrating the different types of knowledge and embedding the
integrated knowledge. Through their participation, patients learned about their disease and care process (*single-loop learning*). Patients in the last case study (Chapter 8), for instance, learned about the sexual problems related to their disease and how these could be solved. Another example is provided by the third case study (Chapter 6) where patients became more knowledgeable about the care logistics, such as the transfer to a specialized centre.

Patients also learned about their own and health professionals’ perspectives and assumptions (*double-loop learning*), enhancing their self-awareness and changing their attitudes and the meaning they attributed to their disease. For example, in the case described in Chapter 8 patients became aware that sexuality is more than sexual intercourse and that it is important to introduce the topic from an early age. The patients involved in the development of the care pathway of Sarcoma (Chapter 6) became aware of the underlying reasoning of health professionals’ for not making the radiology reports directly available. Patients also became more aware of their own knowledge and that their knowledge was additional to that of health professionals (and vice versa). This was strengthened by recognizing the similarities with other patients’ experiences, also addressed by Pittens (2013). As suggested by Elberse *et al.* (2011), this awareness could help patients to become more empowered. In the case study described in Chapter 7, patients discovered their specific experience of the lack of written information focused on women’s situation, e.g. using pictures of female body parts, which was of additional value for developing empowering patient information. By including this information, female patients were better able to apply the information to their own situation and were therefore expected to become more empowered.

Last, patients learned about the way they could be involved in knowledge co-creation and how they can contribute (*triple-loop learning*). These learnings seemed to enhance patients’ perceived personal control and self-efficacy and thus their empowerment.

The extent to which double- and triple-loop learnings took place were however limited compared to single-loop learning. This hindered the embedding of the integrated knowledge as well as the structural involvement of patients, also highlighted by Pittens (2013). An ongoing-process of knowledge integration and embedment, in which double- and triple-loop learning is fostered, is required for patients to become empowered in the long run and thus to initiate incremental change as described by Peschl (2007).

**9.2.2 | REINFORCING KNOWLEDGE CO-CREATION BY EMPOWERMENT BEHAVIOURS**

The findings of the case studies demonstrate that by showing more empowered behaviours, the involvement of patients in knowledge co-creation processes was improved both at an individual and collective level.

At an *individual level*, patient involvement in decision-making was expected to be enhanced by increased help- and information seeking, and shared decision-making behaviour, influenced by patients’ empowerment ‘state’ as described by Bravo *et al.* (2015). Help-seeking behaviour was, for instance, shown to be increased by patients’ knowledge on how potential psychological and sexual problems could be managed (Chapters 7 and 8), which is regarded as a first step
for patients to become involved in decision-making with health professionals regarding their own care. Chapters 7 and 8 furthermore showed that knowledge about relevant resources and self-management tools could in principle stimulate information-seeking behaviour and patients' skills in self-managing their illness. Having more knowledge about the disease and how to manage their illness, could subsequently be helpful for taking an active role in decision-making processes by better understanding the pros and cons regarding different options. Chapters 7 and 8 furthermore showed that examples of questions for shared decision-making could help patients to pose the 'right' questions and articulate their perspectives, and so have a more balanced interaction with the health professional, in which knowledge is articulated, integrated and embedded at an individual level. Empowered patients could also ensure that an equal relationship is established by testing health professionals' knowledge via other resources (Chapter 7). At the same time, patients regularly felt that they were unable to make an informed decision. Half of the patients in the fourth case (Chapter 7) and some patients in the fifth case (Chapter 8) felt that they were not sufficiently informed, resulting in a more reactive attitude during the consult. Information materials were not always provided or do not contain the necessary information for making a well-informed decision, such as information on different diagnostic and treatment options and their pros and cons. Specifically, information about the impact of treatment decisions on their quality of life were addressed to a limited degree. A need for patient information that empowers patients and their families, has also been addressed by e.g. Wilkes et al. (2000). Furthermore, feeling respected was seen as critical for involvement in decision-making at an individual level (Chapters 7 and 8), empowering patients' to talk freely. The other way around, not feeling respected due to authoritarian behaviour can restrain patients to become involved fully in their own care, also found by Frosch et al. (2012).

At a collective level, empowered behaviours of both individual patients and patient organizations improved knowledge co-creation processes. Conversational skills, the skill to think at a more abstract level, knowledge of medical terms and jargon, and a more assertive attitude were found to enhance empowered behaviour among individual patients involved in the knowledge co-creation processes of the case studies described in Chapters 4, 6-8. These skills stimulated behaviours such as posing questions, asking for explanations and being able to articulate their knowledge. A patient involved in the case study in Chapter 7, for instance, highlighted that his extended knowledge about the illness and fellow sufferers' experiences, which he obtained as a patient representative of the patient organization, helped him to make a valuable contribution in the knowledge co-creation process. Feeling respected by other participants also helped patients to share their views more easily (Chapters 6 and 7), which enabled knowledge integration. The other way around, less empowered behaviours, such as a reactive attitude due to a lack of assertiveness or feelings of insecurity, hindered knowledge articulation and integration (Chapter 6). The researchers' facilitation of the process by reiterating knowledge, explicitly allowing patients to speak-up, helped patients to feel respected and to have the skills to play a more active role within the co-creation process (Chapters 6 and 7). As stressed by Ocloo and Matthews (2016), facilitation could assist a dialogue (and thus knowledge co-creation) by e.g. building on people's strengths and creating reciprocal relations. Reciprocal relations are strengthened by facilitators' support in fostering inclusive conditions by becoming more familiar with each other's perceptions and developing mutual trust (Pittens, 2013;
Broerse, 1998; de Wit et al., 2015). Patient organizations’ network and tools such as a forum through which the experiences of a broad group of patients could be collected, helped the organization to contribute in the knowledge co-creation process. A lack of time to consult grassroots’ support, which is necessary to validate patients’ input among fellow-sufferers, was however mentioned by another patient organizations as a barrier to integrate knowledge.

9.3 | RELATION BETWEEN PROFESSIONAL EMPOWERMENT AND KNOWLEDGE CO-CREATION

Health professional empowerment in relation to enabling patients to become involved in knowledge co-creation processes, was directly studied at an individual level in the fifth case (Chapter 8) and indirectly in the other four cases. At a collective level, this relation was studied directly in the third and fifth case study (Chapters 6 and 8) and indirectly in the other case studies.

Patient empowerment is constructed in the interaction with the health professional (Aujoulat et al., 2007). To establish a collaborative interaction (in which knowledge is co-created) and the decision-making power is shared, demands new responsibilities and roles of health professionals (Ocloo and Matthews, 2016; Gagliardi et al., 2008; de Wit et al., 2015). Anderson and Funnell (2010), for instance, suggested that patient empowerment implies a paradigm shift in professionals’ notion of patients as being dependent on their advice towards becoming critical patients who make autonomous informed decisions. The findings of our case studies confirm the hypotheses of existing literature that empowerment of health professionals greatly influences their ability to take up these new tasks and roles (Ocloo and Matthews, 2016; Goedhart et al., 2017) and consequently the empowerment of patients (Igoumenidis et al., 2019). In order to be able fulfil these new roles, health professionals have the following empowerment needs: (1) knowledge; (2) reflection skills; (3) conversational skills; (4) rule orientation skills; (5) extended role perceptions; and (6) time. The first five needs refer to the elements ‘competence’ (1-4) and ‘meaningfulness’ of health professionals’ psychological empowerment (Thomas and Velthouse, 1990). The element ‘time’ relates to health professionals’ structural empowerment (Kanter, 1987). In relation to these needs, reflection is mentioned as a skill, but also as a desirable outcome reached through achieving some of the other empowerment needs. For example, health professionals need certain conversational skills and time in order to be able to have a reflective interaction with patients.

Knowledge

The case studies illustrated health professionals’ empowerment need for knowledge on the psychosocial aspects of care and how they could empower patients to become involved in knowledge co-creation processes. Various situations were mentioned in which health professionals were insufficiently able to empower patients to become involved at both an individual and collective level because they were not aware of patients’ empowerment needs. In line with this finding, Nygårdh et al. (2012) state that health professionals show a lack of knowledge about and understanding of the meaning of patient empowerment, impacting their abilities to empower patients. Knowledge on patients’ empowerment ‘state’ and ‘behaviours’ and how these are related, is expected to be helpful in being responsive towards patients’ empowerment needs. For example,
health professionals’ awareness of patients’ fear for a non-empathetic response which could cause difficulties to broach certain topics (Chapter 8), could motivate behaviours to ensure that patients feel safe and respected. Another example is that informing health professionals about patients’ potential unawareness about their ability to join the decision-making process, could stimulate health professionals to give information on decision options. In accordance, Stiggelbout et al. (2012) stress the need for ‘creating awareness of equipoise’, making patients aware that they have a choice and that a decision has to be made.

In addition, the case studies highlighted the inability of health professionals to empower patients at an individual level because of their lack of knowledge on psychosocial aspects of care, such as sexuality or psychology. A lack of knowledge of health professionals on sexual issues, as consequences of the illness or treatments, has also been addressed in other studies (Stead et al., 2003; Byrne et al., 2010; Moore et al., 2013). According to Odey (2009) psychosocial issues are normal aspect of holistic care. To be able to deliver patient-centred care, health professionals should thus be knowledgeable about these topics. Educating health professionals on sexual health was addressed in Chapter 8 as a way to enable health professionals to pose the ‘right’ questions needed to start a conversation on the topic of sexual health and for patients to articulate their knowledge. In addition, knowledge about self-management tools was highlighted to assist health professionals in supporting patients to control their illness (Chapters 7 and 8). Last, information on the possibilities of professional support for psychological or sexual problems (Chapters 6 to 8), pelvic-related problems (Chapters 5 and 8) or breastfeeding (Chapter 5) could empower health professionals in transferring patients in a timely fashion. Health professionals who provide such support were often not contacted or at a very late stage.

Reflection skills

Chapters 5 and 6 highlighted the need for health professionals to acquire skills for having interactive reflections at both an individual and collective level in order to be responsive towards patients’ needs. Reflection helps health professionals to make sense of complex situations and enables learning (Mann et al., 2009). By asking reflective questions (such as requesting patients to list and describe the meaning of health problems in their everyday life) and listening to their feedback, health professionals could stimulate the articulation and integration of patients’ implicit knowledge at an individual level (Kettunen et al., 2003; Poskiparta et al., 2001).

Moreover, a few health professionals in the case study presented in Chapter 6 indicated that reflections at a collective level helped them to become more aware of their own action-oriented attitude which could impede the reflective activities necessary for obtaining worthwhile insights. However, this case study also showed that reflection was seen by most health professionals as yet another activity in addition to their ‘normal’ work activities. They were not motivated to participate in the sessions and as a result double- and triple-loop learning were constrained. These learnings are, however, essential for knowledge co-creation processes (see Regeer and Bunders, 2009). The Dynamic Learning Agenda (Regeer and Bunders, 2009; Hoes et al., 2010) was initially used in this case to stimulate these learning processes. This tool has been found to be useful for practice-based learning in complex innovations, such as sustainability (van Mierlo et al., 2010), agriculture
and development programmes (van Veen et al., 2014), supporting change agents by drawing out encountered challenges and solving these through reflection (Regeer et al., 2009). This case study, however showed that the tool may be less useful for supporting reflection when working with health professionals in the context of care pathways. First of all because the health professionals did not take the initiative but were asked to do so by the management. Moreover, they generally preferred to keep the status-quo. This assumption is in line with a value assessment which was conducted in parallel to determine patients’ and health professionals’ values. This assessment showed that although their values correspond to each other, patients and health professionals held different ideas about the current situation regarding these values; where patients still consider improvement necessary, health professionals were already satisfied. The need for intrinsic motivation to successfully reflect, has also been put forward by Thompson and Thompson (2018). They stress that commitment could be enhanced by documenting learning, showing examples and addressing accountability. These actions will increase health professionals’ understanding of what reflection is and why it is important, consequently stimulating their empowerment.

Conversational skills
Third, conversational skills were identified as a way to empower health professionals to involve patients in decision-making processes at an individual level. For instance transparent communication – also addressed by Ocloo and Matthews (2016) – was emphasised in several cases (Chapters 4, 5 and 7) as a necessity for patients to become empowered. A lack of transparency on the other hand – for instance on the progress and possible choices – resulted in feelings of a loss of control among patients. Better conversational skills were found by a study of Levinson et al. (2010) to be positively correlated with patients’ self-management.

The case studies illustrated in Chapters 6 to 8 suggested that health professionals should also be able to invite patients to ask questions. Patients involved in the case study of Chapter 6 stressed that they felt they had only limited space to ask questions during a consult and felt uncomfortable about doing so afterwards due to the health professionals’ busy schedule. In the context of sexual health, patients did not dare to bring up the topic (Chapter 8). These barriers among patients for posing their questions and bringing up problems, were an eye-opener for health professionals. According to Skagerström et al. (2017), health professionals should invite patients to participate in decision-making by indicating they are happy to answer questions and informing them that there is time to ask questions. Ocloo and Matthews (2016) go even further by stating that health professionals should expect all patients to ask questions. By asking the right questions, health professionals become knowledgeable about what patients need in becoming empowered to join the shared decision-making process (Stiggelbout et al., 2012). Health professionals in the last case (Chapter 8) stressed, however, that they experienced difficulties in addressing sexual health issues.

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22 This value assessment has been based on the method of Richard Barrett (www.valuescentre.com) developed to measure people’s individual values and has been used as a tool for organizational development and change and measuring values of population groups at national and international level.
during a consult, not knowing what questions to ask. Training in conversational skills can enhance health professionals’ self-efficacy, as found by Nørgaard et al. (2012), consequently improving their communications. In line with Stewart et al. (2000), we argue that communication education should even go beyond skills training to enable health professionals to be responsive to patients’ needs.

At a collective level, the conversational skills of health professionals can empower patients to be involved in knowledge co-creation processes. Health professionals’ encouragement to give input by asking questions or explicitly giving them the floor, helped patients who were involved in the case studies to share their knowledge (Chapter 6). These behaviours empowered patients to overcome their reactive and hesitant attitude caused by a lack of knowledge and the fact that they are invited into the medical world which is unfamiliar to them (Chapters 7 and 8). In addition, health professionals felt hesitant about criticizing patients’ input because of their efforts throughout the project (Chapter 6). The ability to facilitate an open climate in which power is shared has also been identified as a way to build a relationship of trust and overcome power imbalances in other studies (Skagerström et al., 2017; Faulkner, 2001).

**Rule orientation**

The ability to determine when and how to deviate from established protocols and tasks, and thus put the patient at the centre, were brought forward in various cases as a necessary skill of health professionals when involving patients in decision-making processes at an individual level. McCormack (2003) calls this skill rule orientation. As Thompson and Thompson (2018: p.140) state: “Simply following procedures is not a workable response in the helping professions. This is because the work involves working with people, and therefore incorporates a significant degree of uncertainty and unpredictability.” The ability to determine when and how to deviate from established protocols and standards requires health professionals to balance patient and organizational values in delivery or care services (McCormack, 2003). The case studies presented in Chapters 5 and 7 describe situations in which a lack of flexibility in taking personal factors into account and/or act in relation to a specific situation led to patients’ disempowerment. In situations where patients’ concerns were not taken seriously, because they did not fit the protocol or general situation, patients experienced little respect. This was for instance described in Chapter 5 in relation to paediatric clinics when they compare the development of individual babies against statistics on ‘average’ child development and do not take individual circumstances into account. The other way around, patients appreciated it when there was flexibility regarding standard procedures – for example when primary care midwives remained during delivery after the transfer from primary to secondary/tertiary care, which is uncommon in the Netherlands. Regarding the second case study (Chapter 5) health professionals recognized these areas for improvement, but mentioned that they did not know how to improve the situation within current protocols and logistics.

At a collective level, a lack of rule flexibility challenged the embedment of integrated knowledge. For example, integrating the empowerment tools with existing information materials and patient records was found to be challenging because of a lack of flexibility to deviate from standard formats (Chapter 7). Embedment of inputs and involvement of patients in care pathway management (Chapter 6) was hindered by difficulties in aligning this step with current procedures for evaluating
patient outcomes. Such a change of procedures requires a system innovation, affecting existing knowledge and structures (see Geels, 2006).

**Extended role perceptions**

Limited role perceptions of health professionals were also mentioned as a barrier to involving patients in knowledge co-creation, having a disempowering effect on patients. At an **individual level**, some health professionals said that providing elaborate (written) information (Chapter 7) — needed to empower patients to become involved — was not part of their work activities. In addition, all case studies indicated that psychosocial problems related to the illness were often not discussed during consults. For example, the case study of Chapter 5 stressed that non-pregnancy-related aspects such as patients’ mental health were not addressed at the hospital. Health professionals did regularly not regard discussing mental (Chapters 6 and 7) or sexual health (Chapter 8) as part of their job description. This supports the hypothesis of Zucca *et al.* (2017) that most health professionals regard discussion of the physical aspects of patients’ illness as their primary responsibility. Readiness of health professionals is needed to perceive themselves as facilitators of patients’ empowerment (Nyatanga and Dann, 2002), being responsive towards patients’ specific needs even though these ask them to go beyond their ‘traditional’ role.

Restricted role responsibilities were also highlighted at a **collective level** in Chapter 6. In this case study, reflection processes were impeded because health professionals did not see reflecting on the process of involving patients in care pathway management as their responsibility, or even a waste of time since their focus is on treatment. Thompson and Thompson (2018) underline the need to incorporate time for reflection, conceptualizing reflection as part of health professionals’ work rather than an additional activity on top of their work. In addition, embedment of patient involvement in care pathway management was hindered by uncertainties about responsibilities and a lack of accountability. These barriers to knowledge co-creation were not experienced in the last case studies (Chapters 7 and 8). A possible explanation is that health professionals’ participation in these case studies was on a voluntary basis. They joined the studies because they were enthusiastic about the initiative, both the topic and the involvement of patients. In Chapter 6 the participating health professionals were obliged to do so, because senior management asked them to.

**Time**

A lack of time was shown in various cases to be a barrier in involving patients in knowledge co-creation. At an **individual level**, Chapter 7 showed that health professionals avoid involving patients in decision-making processes because they experience it as challenging to answer ‘even more questions’ in the limited available time. Limited time was also identified by Vennik *et al.* (2016) as a barrier to involving patients in decision-making. A study by Skagerström *et al.* (2017) however stressed that taking sufficient time is a prerequisite for facilitating patients’ involvement in decision-making.

The findings presented in Chapter 6 show difficulties in knowledge articulation and integration at a **collective level** as well as restricted reflection processes due to a lack of time. Due to a high pressure of work, health professionals were not very motivated to join the care pathway management process.
and even less motivated to reflect on it (Chapter 6). Health professionals experienced the reflection tool as very time-consuming. In order to stimulate the reflection necessary to have meaningful patient involvement, a more concrete, results-oriented tool might be helpful. This, however, remains at odds with the inherent time-consuming nature of a reflective process (Thompson and Thompson, 2018). In addition, time is also needed for health professionals to develop the skills mentioned in the previous sections, such as conversational and reflexive skills.

**Overall Conclusions**

By answering the three sub-research questions, three elements were identified as essential for enhancing patient-centred care through co-creation and empowerment: (1) responsiveness, (2) mutual learning, and (3) empowerment behaviours. We therefore conclude that in order to enhance patient-centred care, services should be more responsive to patients’ needs by empowering patients and health professionals to engage in knowledge co-creation through mutual learning. To integrate different types of knowledge and embed integrated knowledge, single-loop learning is not sufficient and double- and triple loop learning should take place, thus necessitating reflection.

**9.4 | THEORETICAL IMPLICATIONS**

This thesis explored and elaborated on the processes of involving patients in knowledge co-creation and patients’ and health professionals’ empowerment to enhance patient-centred care. In a recent publication of Castro et al. (2016), a reciprocal relationship between patient involvement and empowerment was also suggested and they developed a process model for the concepts of patient empowerment, patient involvement and patient-centredness in health care (see Figure 8). In this model, patient involvement is seen as a way to achieve patient-centred care, which could subsequently stimulate patients’ empowerment and vice versa. Regarding the conceptualization of

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**Figure 8:** Process model for concepts of patient empowerment, patient participation and patient-centredness in health care (Castro et al., 2016)
patient involvement, Castro et al. (2016) also address the right and opportunity of patients to be involved in a dialogue in which both patients’ experiential knowledge and expert knowledge are included at both an individual and collective level. These authors specifically mention the act of ‘combining’ these types of knowledge. The concept of knowledge co-creation goes even further by describing the act of integration which is not just bringing the different types of knowledge together.

This thesis adds to understanding how these relations between the concepts (the gears) are established and thus what enables the gears to work. It specifically indicates that knowledge co-creation, by genuinely involving patients in reflection processes, could lead to responsiveness and empowerment through learning. These elements of knowledge co-creation were not yet incorporated in the model of Castro et al. (2016). By stimulating responsiveness and learning, the gears will start to turn through which the involvement of patients in co-creation processes will actually lead to more patient-centred care services and subsequently empowerment.

Moreover, this thesis incorporates the concept of health professionals’ empowerment which influences patient involvement in knowledge co-creation processes both directly and indirectly by patient empowerment. Previous literature on health professional empowerment mainly focused on work empowerment related to job satisfaction and burnout (Spence Laschinger et al., 2009; Gilbert et al., 2010; Ahmad and Oranye, 2010; Ning et al., 2009; Lautizi et al., 2009) and patient safety (Lin and Liang, 2007; Armellino et al., 2010; Dirik and Intepeler, 2017). A literature review undertaken by Goedhart et al. (2017) suggested that empowering work conditions for nurses could enhance patient-centred care. This assumption was based on a study by Donahue et al. (2008), which showed that when nurses were more structurally empowered, patients were more satisfied with the care provided. To date, insights into health professionals’ empowerment and patient involvement in the context of patient-centred care have been limited (Goedhart et al., 2017; DiNapoli et al., 2016). This study adds to this knowledge base by showing that knowledge, reflection, conversational and rule orientation skills, extended role perceptions, and time could empower health professionals to establish a partnership relationship with patients that stimulates knowledge co-creation, which is necessary to enhance patient-centred care through responsiveness.

**Patient-Centred Care Enhancement Cycle**

Based on the explored interrelation between patient-centred care, patient involvement in knowledge co-creation and empowerment, obtained through the five case studies, the conceptual framework (presented in Chapter 2) was adapted into the PCC Enhancement Cycle (PCCEC). This model (see Figure 9) shows a direct and indirect route to enhance patient-centred care. The direct route is depicted by the large loop from patient-centred care to empowerment. This loop shows that by placing patients’ needs more centrally, care services will be more empowering. Conversely, the empowerment of patients and health professionals could stimulate patient-centred care by introducing a patient-centred culture. The indirect route is illustrated by the two smaller loops from knowledge co-creation to patient-centred care and empowerment. The first small loop demonstrates that patient-centred care stimulates patient involvement in knowledge co-creation, which subsequently lead to more responsiveness towards patients’ needs and makes care more patient-centred. The second small loop shows that patients’ involvement in knowledge co-creation
stimulates learning processes which enhance patients’ and health professionals’ empowerment, leading to empowerment behaviour. This empowerment behaviour in turn improves knowledge co-creation processes. Empowered health professionals could also directly stimulate patients’ empowerment by for instance providing patient education. Patient-centred care can thus also be enhanced indirectly by improving the quality of the process, serving as a guide for operationalizing the direct route. This model could be helpful for justifying the complexity of involving patients in the health care context as highlighted by Tritter and McCallum (2006).

Figure 9: Patient-Centred Care Enhancement Cycle (PCCEC)

In Chapter 2 the following definition of PCC, based on the definition of IOM (2001), was formulated: “a partnership to ensure that health-related decisions include patients’ preferences and needs”. Based on the findings of the research described in this thesis, brought together in the PCCEC Model, we propose a new definition: “Being responsive towards patients’ preferences and needs by empowering patients to become involved in knowledge co-creation processes”. By using this definition attention is given to both the process and outcome of patient-centred care. By including the process-component, more guidance will be given to health groups who would like to implement patient-centred care in how this can be realized.

To date, assessing the impact of patient-centred care and patient involvement initiatives have been found to be challenging (Xochelli et al., 2019; Mockford et al., 2011), because of the absence of reliable and valid tools (Phillips et al., 2016) and the limited impact of involvement activities on
decision-making processes (Boivin, 2012; Staniszewska et al., 2008). Following Lusk and Fater (2013), further insights into the contextual factors influencing the provision of patient-centred care are needed in order to overcome current difficulties in shifting towards patient-centred care (Rashid et al., 2017; Bensing, 2000). Because the value of the concepts exists within their relationships, mapping these relationships is expected to be worthwhile for evaluating these initiatives.

9.5 | RECOMMENDATIONS FOR PRACTICE

The previous sections described that to successfully implement patient-centred care, health professionals should be responsive to patients’ needs by involving patients in knowledge co-creation processes. The findings of this thesis do not clearly indicate a need for a partnership relationship, in which power is shared. Such a relationship has been described by e.g. Guilliland and Pairman (1995) and Sidani and Fox (2014). Rather than equality in roles, equality in the involvement in decision-making by adding knowledge are suggested as a means to enhance responsiveness, as also highlighted by Pittens (2013). Health professionals have the responsibility to establish such relationships with patients, such as supporting patients to become so called ‘e-patients’. This term has been introduced by Ferguson (2007) to indicate that patients are ‘equipped’, ‘enabled’, ‘empowered’ and ‘engaged’ in decision-making processes.

Health care organizations should empower health professionals to support patients to establish relationships in which knowledge is co-created (Palumbo, 2017). To empower health professionals to create such a relationship at an individual level, health care organizations are advised to allocate time during consults for empowering patients to join decision-making processes, having interactive reflections and paying attention to the psychosocial aspects of care. These investments of time are expected to save time in the long run by making ‘better’ decisions (Coulter and Collins, 2011). Involving patients in decision-making processes also demands new social skills on the part of health professionals over and above their current technical skills (Delaney, 2018). First, conversational skills are needed to discuss psychosocial aspects and empower patients by e.g. inviting them to articulate their knowledge. This also includes obtaining knowledge on the meaning and importance of discussing these aspects and paying attention to patients’ empowerment ‘states’ and ‘behaviours’ and how these are related in teaching programmes. To encourage health professionals to address the psychosocial aspects of care, health care organizations should also stimulate the shift towards a more social model of care by allocating accountability for providing holistic care services (Schofield et al., 2006). Skills are also required for deviating from existing protocols, guidelines, roles and job descriptions as necessary to adapt to patients’ values and needs. Health professionals need to be able to balance patients’ and organizational values’ in tailoring care services to specific circumstances (McCormack, 2003). Health care organizations are advised to allocate resources (time and money) to enable professional training to develop such skills. Such trainings should be organized repeatedly since health professionals tend to lose their communication skills and their focus on holistic patient care in time (Ha and Longnecker, 2010).

To involve patients in co-creation processes at a collective level, health care organizations are recommended to allocate time for participatory reflections in addition to health professionals
existing work to stimulate knowledge co-creation processes. To guide these reflections the Dynamic Learning Agenda (Regeer and Bunders, 2009; Hoes et al., 2010) or similar tools could be used. To involve patients in knowledge co-creation processes, health professionals need conversational skills to express themselves in layman’s terms and actively invite patients to join the conversation. Additionally, reflection skills are needed for stimulating second- and triple-loop learning, required for integrating and embedding knowledge. Activities that stimulate reflection are increasingly integrated into the medical training curriculum in various health professions (Mann et al., 2009). However, these activities mainly address reflection skills in relation to self- and peer-reflection and medical decision-making processes (Taylor and White, 2000; Wollersheim, 2008; Oostveen, 2008) and do not include reflection on participatory processes with patients. Education programmes should also pay attention to reflecting on intersubjective dynamics between health professionals and patients (Kettunen et al., 2003). In addition, formally evaluating these skills could stimulate health professionals’ motivation to change.

Patient organizations are advised to make the experiential knowledge of their members and other fellow-sufferers more explicit by collecting experiences through e.g. online forums, questionnaires or weblogs. This articulated knowledge could facilitate in communicating patients’ wishes and needs to the health care organizations. To be able to collect these experiences, patient organizations need sufficient tools and skills. In addition, patient organizations could play a role in empowering their members to become more involved in knowledge co-creation related to health care decision-making. At an individual level, health care organizations could empower their members, such as by communicating examples questions which patients could ask during consults and mentioning the possibility for asking a second-opinion. To empower members to become involved at a collective level, mentioning possible opportunities and communicating success stories could be helpful as well as enhancing professional networks.

9.6 | VALIDITY OF THE FINDINGS

In this section the validity of the research findings is reviewed. Regarding internal validity, the research design, the role of the researchers and the inclusiveness and representativeness of the participants will be discussed. With regard to external validity, this section will reflect on the generalizability within the Dutch health care context, but also beyond the Dutch context and the health care domain.

9.6.1 | INTERNAL VALIDITY

Research design

This thesis used an emergent research design (see Ohman, 2005). Through an iterative and analytical process, the research activities were adapted to the emerging findings. This flexibility of the research process, made it possible to unravel complex real-time challenges both in the case studies and throughout the thesis. In, for example, the case study described in Chapter 6 the focus shifted from ‘how to involve patients in co-creating care pathway management’ to ‘how to overcome barriers to knowledge co-creation by using reflection strategies’. During the process, we
discovered that the reflection strategies applied to overcome expected and encountered barriers were insufficient to stimulate double- and triple-loop learning in the specific context of the study. In the last case study (Chapter 8) a shift in focus took place from ‘how the sexual support for patients with Anorectal Malformations and Hirschsprung Disease could be improved’ to investigate ‘how patients and health professionals could be empowered to improve this support’. This shift was caused by advancing insights into the difficulties in using existing tools.

Throughout the thesis the focus also changed, digging deeper into the underlying mechanisms of enhancing patient-centred care. We started to study how patient involvement could enhance patient-centred care and shifted towards knowledge co-creation and empowerment processes and ultimately health professional empowerment. Not only did the focus of the case studies change, but also the way patients were involved throughout the process. In time, the study approach became more participatory. The methodologies of Interactive Learning and Action (applied in the case studies described in Chapters 6 and 7) and Participatory Action Research (see Chapter 8) were found useful to stimulate the participatory processes needed for enhancing knowledge co-creation among the different stakeholders – patients and health professionals – having different perspectives and roles. Both methodologies were helpful in structuring the processes from identifying the key problems to implementing measures and generated a learning cycle by continuous monitoring. The case study described in Chapter 5 was conducted in a less participatory/transdisciplinary manner than the other case studies. The perspectives of health professionals were not included in the project which hampered the implementation of the recommendations for improvement suggested by patients. Health professionals recognized the points for improvement, but indicated that they did not know how to change the current situation. Knowledge integration, including both patients’ and health professionals’ knowledge, would have been helpful for moving from patients points for improvement to developing concrete improvement measures.

The case studies focused on different processes. Where one case study was more focused on involving patients in knowledge co-creation processes, another paid attention to empowering patients and health professionals. By using a multiple case study design, which was partly sequential, learnings from one case study could be integrated in the subsequent one(s). Advancing insights were, for instance, applied in determining the theoretical focus and the research design. As a result, it was possible to go more deeply into the underlying barriers to implementing patient-centred care in practice. A disadvantage of using an emergent design, is that certain processes were not tested in various contexts. In addition, the differences in focus between the case studies challenged the alignment of the conceptualization of the different concepts. However, various case studies did focus on multiple processes and their findings were compared with existing literature on multiple occasions.

**Researchers’ roles**

Within the research of this thesis the researchers had various roles; changing from being a scientist, process facilitator, change agent to a reflexive practitioner (explained in more detail in section 3.5). The different roles demanded that the researchers shifted between diverse approaches, for example, in relation to the extent to which the researchers were ‘neutral’. On the one hand, the
researchers as ‘scientists’ aimed to formulate objective findings. On the other hand, the ‘change agent’ role demanded the researchers to subjectively nudge the project in the ‘right’ direction. The role of the ‘reflexive practitioner’ was helpful in reflecting on which roles would be most appropriate in certain situations and what the effect of having a particular role would be on the outcome of the research.

Researchers had a central role throughout the case studies: from setting up the studies, conducting the research to analysing the findings and evaluating the process. Their dominant role would have an influence on the research activities and outcomes, as well as the interpretation of the findings. Various validity strategies (see Chapter 3) were applied by the researchers to prevent researcher bias: (1) triangulation of the methods (by using different research methodologies and methods); (2) triangulation of the researchers (debriefing sessions with supervisors, and co-researchers took place); (3) member checks; (4) reflections with transdisciplinary project groups; and (5) colleagues outside the project. The transdisciplinary project groups were helpful in contextualizing interpretation of the findings from its context.

**Inclusiveness and Representativeness**

In the cases described in Chapters 5 to 8 patient representatives were involved in co-creating the research study. Although the background of these patients differed with regard to age, disease type and place of treatment, their level of education was in general high compared to the average Dutch population.

The articulated knowledge of fellow sufferers was used as input for the patient representatives. In consulting these fellow-sufferers attention was paid to their diversity and plurality. Patients differed with regard to gender (if applicable), age, disease type and place of treatment. In the second and fourth case studies (Chapters 5 and 7), there was initially an overrepresentation of patients with a high-level educational background. Therefore, purposive sampling of patients with a low or middle-level educational background was applied. A personalized strategy in the form of respectively face-to-face contact in waiting rooms and telephone contact after consent was obtained via the treating health professional was used. In addition, a targeted recruitment message to enlist patients with a low or middle-level educational background was sent via the communication channels of relevant patient organizations. These personalized strategies were found to be more effective in reaching less educated patients, because these patient groups are regularly not aware that recruitment messages are meant for them and that they could make a valuable input. Apart from the third case (Chapter 6) patients and health professionals who participated in the case studies were recruited on the basis of voluntary participation. This could have resulted in an overrepresentation of ‘enthusiasts’. Different methods were used to reduce selection bias. Yet, the most vulnerable patient groups such as low (digitally) literate patients were not reached. Moreover, patients who spoke neither Dutch nor English were involved only to a very limited extent. We expect that the patients and patients’ parents who participated were to some extent already empowered.
9.6.2 | EXTERNAL VALIDITY

The findings of this thesis – brought together in the PCCEC model depicted in Figure 9 – are based on five case studies. The case studies were conducted in different contexts and differed regarding their aims, disease types, collaborating medical disciplines and care organizations in the Netherlands. Due to these differences, the case studies offer a broader understanding of the processes of knowledge co-creation and empowerment in the context of patient-centred care. It is therefore expected that these findings also hold for other disease types and patient-centred care initiatives in the Netherlands. The fact that similar processes were found in the different case studies in relation to the main concepts, increases the likelihood of generalization beyond the Dutch health care context. However, due to differences in socio-political contexts, care systems and the power and role of the patients within this system, caution is needed in generalising these findings beyond the Dutch health care context (Hadorn et al., 2008). Yet, the shift towards patient-centred care and patient involvement and empowerment has been a worldwide phenomenon. Case studies are well-suited for naturalistic generalisations because they give an in-depth description of complex social phenomena (Stake, 1978).

9.7 | DIRECTIONS FUTURE RESEARCH

The insights of this thesis give rise to new questions that could be addressed through future research. We recommend that future studies are set up to: (1) evaluate the impact of knowledge co-creation processes; (2) test the PCCEC Model in different health care contexts; (3) study the empowerment of the most vulnerable patients; (4) obtain more insights into how health care organizations can empower health professionals to involve patients in knowledge co-creation processes; and (5) investigate the processes from a transition perspective.

As mentioned earlier, the case studies resulted in various improvement measures and empowerment tools. The tool described in Chapter 8 has been developed using a programme theory to achieve the greatest possible impact. The last step of programme theory ‘evaluation’ was not, however, included in the case study. Yet, the impact of the tool on the empowerment of patients’, patients’ parents’ and health professionals’ empowerment was assessed only at the level of expected impact. The impact of the measures and tools and their exact interrelation have also not yet been studied in the other four case studies. Evaluating the measures and tools and how these link up to desired outcomes would be valuable in order to determine the actual impact of the knowledge co-creation processes on the empowerment of patients and health professionals and the responsiveness of the care services. Vat et al. (2019) reviewed existing literature on quantitative and qualitative methods for evaluating the benefits and costs of patient involvement. The studies mostly considered a single indicator (e.g. recruitment rate) for trying to answer a single question (e.g. does patient involvement lead to better recruitment?). This may be feasible but is not useful in predicting impact for other studies, as the factors influencing impact may differ. The authors therefore stress that future studies should investigate means of coherently evaluating sets of inputs, processes, outcomes and impacts, in different contexts (Vat et al., 2019). This implies that a programme theory on empowering patients to-create knowledge might help in evaluating impact.
DISCUSSION

The PCCEC Model presented in Figure 9, is based on five case studies that focus on specific processes within the model. Future studies are needed to validate the model by addressing all the different processes. In addition, studies are needed to fully grasp the complexity of the processes, studying the different factors which influence them. Moreover, validation in different care contexts (nationally and internationally) would be worthwhile. Specifically a nation-wide and trans-disciplinary (across different medical specialties) study would be of interest.

Furthermore, future research should take account of the empowerment of the most vulnerable patients e.g. the (digitally) illiterate patients. The digital information tools developed in the fourth and fifth case (Chapter 7 and 8) exclude patients who do not have access to ICT resources and skills or do not seek additional information. Various studies show that a lower socio-economic level (through education and language barriers) prevent patients from becoming involved (Blumenthal-Barby, 2017; Fleming et al., 2017). The exclusion of (digitally) illiterate patients is expected to further exacerbate their vulnerability (Helsper and Van Deursen, 2017; Helsper and Reisdorf, 2017). In addition, previous literature highlights that vulnerable patients report less interest in becoming involved (McKinstry, 2000). This preference for a passive role may reflect their lack of self-efficacy (Légaré and Thompson-Leduc, 2014; Coulter and Collins, 2011) and thus empowerment. In line with this, Fumagalli et al. (2015) indicates that being empowered is both being skilled and motivated. Future studies should also give attention to how patients can be encouraged to play an active role in their care. By stimulating them to share their views, patients become aware of the fact that their perspectives are important (Coulter and Collins, 2011).

Enhancing patient-centred care could be seen as a transition from a paternalistic, physician-dominated, to a more patient-centred health care system. Patterns in transitions could be studied via the Pillar theory of de Haan and Rotmans (2011). Following this theory, there are three patterns: (1) empowerment (bottom-up constellation change), (2) reconstellation (top-down constellation change), and (3) adaptation (internally induced constellation). The research presented in this thesis mainly focuses on inducing a transition towards patient-centred care through the first and third pattern. By involving the health care organisation in the transition, disempowering structures could be overcome. Insights into inducing a transition through the second pattern and how to connect these patterns would be worthwhile to bring about a structural change. In the third case (Chapter 6) attention to a top-down constellation change would have been worthwhile in order to detect disempowering structures regarding the involvement of health professionals in the project at an earlier stage.

In order to stimulate this transition, future studies are needed to better understand how health care organizations could stimulate empowerment of health professionals as to involve patients in knowledge co-creation. Health care organizations should create the right conditions to empower health professionals (Knol and Van Linge, 2009; Stewart et al., 2010). As discussed in section 9.5 such organizations are advised to empower health professionals to establish co-creating relationships with patients by allocating time to reflect, develop reflection, conversational and rule-orientation skills, while also fostering an organizational culture which enhances accountability to psychosocial factors and participatory reflection. To study how these recommendations could be implemented,
insights from an organizational perspective could be of interest. These understandings could be helpful for restructuring current organizational structures and cultures in order to empower health professionals to involve patients in knowledge co-creation processes. To obtain a better understanding how these structures and cultures could be facilitated, insights into leadership or management theory could be worthwhile. Following Moore et al. (2017) leadership could be a facilitating factor for implementing patient-centred care. Various studies indicate the value of a transformational leadership (Burns, 1978) in empowering health professionals to move beyond existing technical competences which are needed in providing more patient-centred care (Delaney, 2018; Kitson, 2001; Trofino, 1995). The implementation of a transformational leadership style requires a power shift in a practice that has been dominated by top-down autocratic leaders (Murphy, 2005).

### 9.8 | CONCLUDING REMARKS

By studying the processes of knowledge co-creation and empowerment, this thesis gives more insights into how the impact of current patient-centred care initiatives could be enhanced. This thesis shows that to enhance patient-centred care, services should be more responsive to patients' needs by empowering patients and health professionals to engage in knowledge co-creation through double- and triple-loop learning. To empower health professionals to involve patients in knowledge co-creation processes, we recommend that health care organizations allocate time and accountability for participatory reflections, allocate time to discuss the psychosocial aspects of care and allocate resources to improve health professionals' communication and reflection skills and their skill to balance patients’ and organizational values'.

Through the research conducted for this thesis, I aimed to contribute to the transformation of the health care system towards patient-centred care. This contribution consisted of enhancing knowledge co-creation processes through directly empowering patients, their parents and health professionals by e.g. providing information, and indirectly by developing recommendations for improvement measures and tools based on patients' needs. I hope that the insights of this thesis will be an inspiration to anyone who wishes to support the shift towards patient-centred care.