Master thesis

Active patient participation in interprofessional education of health professionals: a qualitative study on (health-related) outcomes for patients

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Abstract

Background. Through active participation of patients, medical education reacts to the increasing demand for patient-centred care, the fact that patients are becoming more empowered and the growing desire of academia to become more socially responsive to the community. However, little is known about the consequences of participation in health professions education for patients, specifically in an interprofessional setting. The presented study aims to identify the (health-related) outcomes of active participation in the education of health professionals from the perspective of the patients and their partners.

Methods. Following a social constructivist paradigm and explorative approach, data were collected through three qualitative focus group interviews, two with patients (*N*=14) and one with partners (*N*=4). The data were analysed using a directed content analysis approach, using the domains of Positive Health as a basis. Additionally, other (non-health related) outcomes were coded inductively.

Results. According to the patients and partners, active participation is believed to impact five out of six domains positively, being (1) mental functions and perceptions, (2) spiritual and existential domain, (3) quality of life, (4) social and societal participation and (5) daily activities. The participants reported negative influences on two out of four domains, namely: (1) bodily functions and (2) mental functions and perceptions. Additionally, according to the patients, participation contributed to increased assertiveness in own health trajectory, acknowledging the role partners have in illness and a high degree of involvement in the educational module for the participating patients. Partners reported feeling happy and energised to see the patients experience an increased zest for life and enthusiasm.

Discussion. The resulting outcomes might aid patients in the self-management of illness and contribute to more activated and informed patients as described in the Expanded Chronic Care Model. Further research on this topic should use larger sample size to increase the credibility and transferability of the results. To facilitate this, a quantitative survey has been developed based on the results of this thesis and other relevant aspects found in the literature. Once a broader scientific base on (health-related) outcomes is established, further research could be aimed at quantifying these (health-related) outcomes.

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NOTICE:

Throughout this thesis, the term *patient* is used. It encompasses people with health problems which could also be referred to as service users, clients or consumers, recognizing that no single word is adequate or universally acceptable.

Additionally, the term *partner* will be used for the sake of brevity. This term encompasses a person the participating patients have chosen as someone they are in close contact with. This could be a partner, informal caregiver, close relative, best friend or relative.

1. Introduction

This thesis investigated active, real patient participation in the education of health professionals. This chapter aims to define the problem in terms of background, societal and scientific relevance and ends with the formulated research objectives.

1.1 Background

Western countries are faced with ageing of the population, an increased prevalence of chronic diseases and multimorbidity (Eurostat, 2018; Marengoni et al., 2011; World Health Organisation, 2015). Besides, the health spending in Organisation for Economic Co-operation Development (OECD) countries has been rising faster than their economic growth (Organisation for Economic Co-operation Development, 2015). At the same time, expectations regarding quality of care are rising, particularly the increasing demand for patient-centred care (Chewning et al., 2012; Institute of Medicine, 2001). Demographic ageing, increasing prevalence of chronic diseases and multimorbidity, rising health care costs, and (patient) expectations regarding (their) care put additional demands on health systems and their workers.

Health systems strive to keep up with the societal challenges posed. Education of health professionals is believed to be able to strengthen health systems (Frenk et al., 2010). However, current health professional education has not kept pace with the growing and changing demand on health systems and workers, resulting in inadequately prepared health professionals (Association of Faculties of Medicine of Canada, 2015; General Medical Council, 2009). A proposed health education reform regards the promotion of interprofessional and transprofessional education, breaking down professional silos while enhancing collaborative and non-hierarchical relationships in effective teams, focussing on generic competencies such as communication (Frenk et al., 2010).

Through active participation of patients, health professions education reacts to the increasing demand for patient-centred care, the fact that patients are becoming more empowered and the growing desire of academia to become more socially responsive to the community (Towle et al., 2010). Patient as a Person (PAP) is an educational module in health professions education fostering patient-centred competencies in an interprofessional setting. In three meetings, students from different educational backgrounds and educational institutions familiarise with patients and, where applicable, their partner (Figure 1). The educational module is further elaborated on in Appendix 1. The module aims to bring students from two or more professions together so they can

learn with, from and about each other enabling effective collaboration and improving the quality of care (World Health Organisation, 2010). Additionally, the programme revolves its interprofessional education (IPE) goals around the focal point of care: patients. Students learn from each other's perspective and how to adapt a patient-centred approach in their future career as health professionals through the experiences of patients.

Figure 1. Overview of the meetings in the Patient as a Person module and their themes

1.2 Societal relevance

Patients feel that their knowledge on illness and the health systems should be included in education (Towle et al., 2010). Active participation in health professions education is believed to have beneficial effects for patients. Walters, Buszewicz, Russell, and Humphrey (2003) conducted in-depth interviews with twenty patients actively involved in undergraduate psychiatry education and identified five main elements of therapeutic benefit: (1) time to talk and be heard in a respectful way, (2) increased self-esteem, validation and empowerment, (3) development of a coherent narrative, (4) new insights into their problems and (5) depth, balance and understanding in the doctor-patient relationship. In another study conducted by Watts, Mcpherson, Robson, Rawlings, and Burge (2015), patients reported that participation in education reduced loneliness and isolation. These therapeutic outcomes due to active participation in education are a potential potent intervention to improve the well-being of patients.

To substantiate the therapeutic outcomes of active participation in education, Caron-Flinterman, Broerse, and Bunders (2005) coin the term *experiential knowledge.* This knowledge arises when lived experiences of people regarding their bodies and their illness, as well as with health care, are transformed into personal insights. It is believed that these insights, or *knowledge*, enable a patient to better cope with individual illness and disability, which in turn affects their ability to self-manage individual illness and disability (Caron-Flinterman et al., 2005).

The relevance for the ability to self-manage illness has long been described in the Chronic Care Model (CCM) by Wagner, Austin, and Von Korff (1996) and later in the Expanded Chronic Care Model (ECCM) by Barr et al. (2003), both positing self-management as an area of focus. Recently, self-management was rejuvenated as a result of a reformulation of the concept of health. Huber et al. (2011) conceptualised health as *"the ability to adapt and self-manage in the light of social, physical and emotional challenges"*. This dynamic conceptualisation of health has been tested for support among stakeholders and received considerable support from healthcare providers, patients, policymakers and insurers (Huber et al., 2016).

In The Netherlands, this approach to health has received tremendous support from policymakers. As part of the National Prevention Programme, the organisation 'Everything is Health' (Dutch: Alles is Gezondheid) reported that 63% of their network, consisting of around 3000 institutions in the Netherlands, are paying attention to this concept in 2018 (Onderzoeksbureau Sardes, 2019)**.** Combining Positive Health and the ECCM, the ability to self-manage is an increasingly important competence that patients should master.

Conclusively, one could hypothesise that active participation of patients in the education of health professionals can be used as an intervention to promote patients' well-being through the therapeutic effect of teaching and catalysing the conversion of lived, emotional experiences from patients to experiential knowledge which in turn enables patients to cope and self-manage. Due to this created experiential knowledge patients might be likely to (more) actively participate in their care with their care-team and feel more empowered to take control over their health and well-being, underscoring the societal relevance of this thesis.

1.3 Scientific relevance and research questions

Participation of patients in education has scientifically described benefits such as satisfaction in giving back to the community and having an influence on the education of future professionals (Towle et al., 2010). In addition, the described benefits are nuanced by Meehan and Glover (2007), who draw attention to patients feeling vulnerable or felt their contributions were not valued by teaching staff. Both of these findings are substantiated by recent systematic reviews on the active involvement of patients in mental health- and nursing education (Happell et al., 2014; Scammell, Heaslip, & Crowley, 2016).

The Vancouver Statement, that was published by Towle et al. (2016), aims to identify action items on the involvement of patients in the education of health and social care professionals, for the five years to come. One of the action items that this statement prioritises, is conducting and disseminating high quality, accessible research and evaluation, (…) including patient outcomes. As described under chapter *1.2 Societal relevance*, Walters et al. (2003) report five outcomes as a result of active participation of patients in undergraduate psychiatry training that impact the well-being of the participating patients. This thesis aims to assess and further explore these outcomes for patients that actively participate in education. Moreover, little is known about the (health-related) outcomes of active participation in an interprofessional setting.

To transcend the outcomes shared by patients, and simultaneously entering uncharted scientific territory, this thesis explores the views of the partners of the patients. This group has not yet been questioned in regard to their perceptions on the outcomes of active participation for patients in previous research. It is hypothesised that partners will provide a broader view on patient outcomes of participating in interprofessional education. Conclusively, this thesis aims to qualitatively and exploratively answer the following research question:

What is the impact of active participation, specifically in an interprofessional setting, from the perspective of the patients and partners?

a. What health-related positive and negative outcomes are experienced?
b. What other positive and negative outcomes are experienced?

In the following chapters of this thesis, the conceptual model upon which the research question will be answered, as well as an elaboration on the methodological principles and methods with which the research questions will be answered, have been described. Consecutively, the results found and a discussion on the significance of the results, in light of previous publications and strength and limitations of the current thesis, have been described. This thesis will be concluded with recommendations for further research.

2. Conceptual model

In this chapter the conceptual framework underpinning this thesis is described. It consists of concepts and additional relevant literature that will aid in answering the research questions regarding outcomes from the perspective of patients and their partners, after participating in an interprofessional education programme. Additionally, different theories and concepts will consecutively be discussed leading to the construction of a conceptual model.

2.1 The Expanded Chronic Care Model

The CCM, initially developed by Wagner et al. (1996), acts as a guide to higher-quality chronic illness management within primary care, aiming for system reforms in which prepared and proactive practice teams interact with informed and activated patients. The model is critiqued for its narrow focus on clinically oriented systems, overlooking communities and inter-sectoral collaboration as effective tools in the prevention of illness, and more relevant prevention of disability (Glasgow, Tracy Orleans, Wagner, Curry, & Solberg, 2001). This led to the development of the ECCM, including prevention efforts, recognition of the social determinants of health and enhanced community participation to be part of care in chronic illness (Barr et al., 2003). They redefined the areas of focus and placed them on the intersection of health systems and community, implying that activities can be integrated within and have an impact on both health systems and the community (Figure 2).

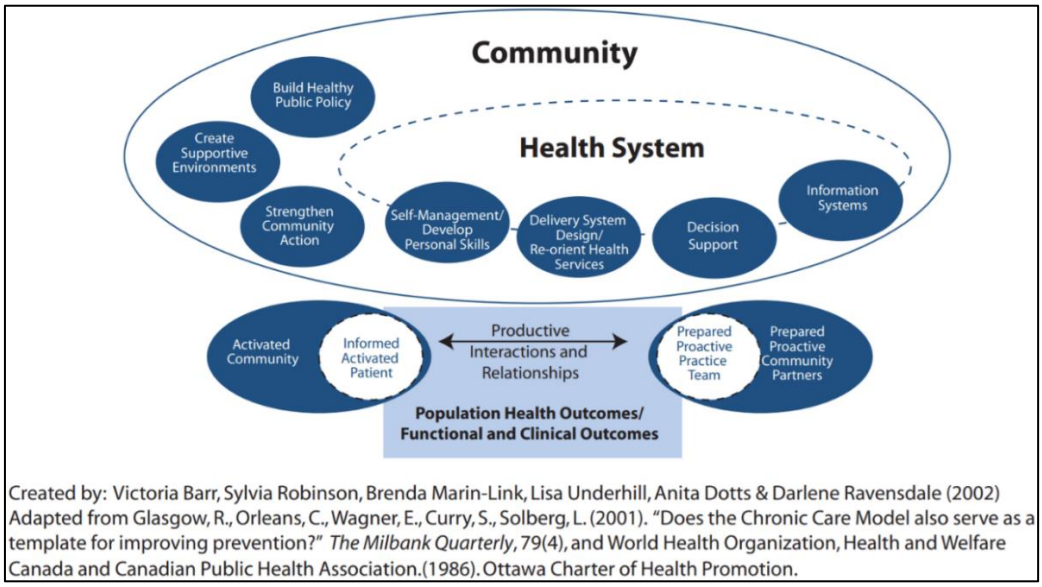

Figure 2. The Expanded Chronic Care Model (Barr et al., 2003)

Furthermore, self-management and the development of personal skills for health and wellness are explicitly described as an area of focus to attain higher-quality of (primary) care. Through the provision of information and supporting of personal and social development of individuals and groups, it aims to increase options for people to exercise increased control over health and their environments (Barr et al., 2003). Therefore, the ECCM provides a suitable theoretic setting, emphasising the need for self-management and development of personal skills, specifically in the community context leading to productive interactions and increased population health. Within this setting, further theoretic constructs will be reviewed regarding the inter-sectoral collaboration between the medical field, in which patients classically operate, and the social field of education.

2.2 Sociocultural learning theory

Active participation of patients in (interprofessional) health professions education primarily arose from social change and policy directive, and therefore the available literature is often not informed by learning theory (Towle & Godolphin, 2013). Classical educational assumptions include that learning is an individual process, resulting from teaching, that it has a beginning and an end and that it is best separated from other activities (Lave & Wenger, 1991). This individualistic approach to learning could be referred to as *acquisition*: knowledge reproduction, where learning is seen as information seeking and sedimentation of knowledge in individuals, a metaphor coined by Sfard (1998). However, according to Vygotsky's classical sociocultural theory, the group is vital in the learning process, mainly in experiential learning (Jaramillo, 1996). Vygotsky noted the zone of proximal development, which delineates the distance between the actual development level as determined by independent problem solving and the potential development possible, achievable through guidance or collaboration with peers (Vygotsky, 1978).

A more contemporary description of the sociocultural learning theory is described as collaborative knowledge production, or participation (Bleakley, 2006; Rees, Knight, & Wilkinson, 2007). This indicates an active process of legitimate engagement and situated learning in a community of practice. Communities of practice are defined as groups of people who share the same passion or concern, for example, students in health professions education and actively involved patients, and try to understand how to improve as they interact, often on a regular basis (Wenger, 2011). Within these communities of practice, learners participate in a 'hands-on' fashion

to develop a mastery of skills and knowledge, enabling them to move from peripheral to full participation within the community of practice, defined as legitimate peripheral participation (Rees et al., 2007). This is depicted in Figure 3. The described participation, as part of contemporary situated learning theory, is reckoned to be relevant to medical students within the context of medical practice. However, it should also apply to patients' participation in an educational community of practice, according to Rees et al. (2007).

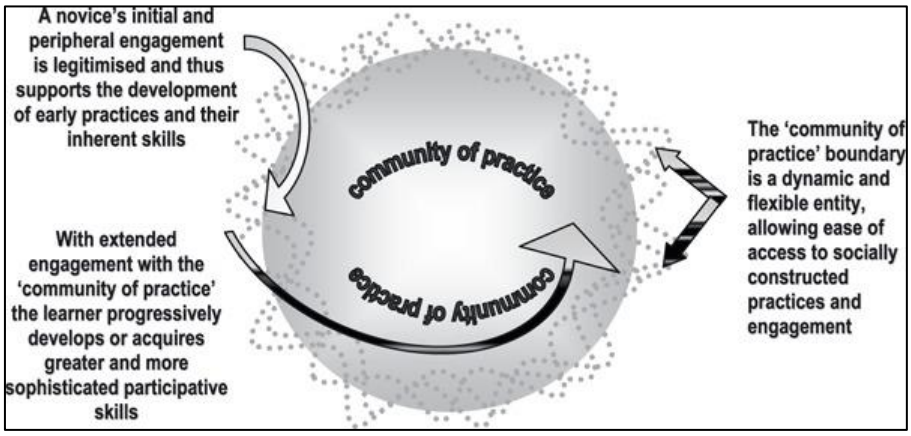

Figure 3. Legitimate peripheral participation in a community of practice (Lave & Wenger, 1991)

2.3 Experiential knowledge and expertise

Legitimate peripheral participation entails the development of learners from novices to experts. One could argue towards what kind of expertise legitimate peripheral participation of patients in health professions education would lead. Experiential knowledge refers to patient-specific knowledge such as the lived experience of individuals with their bodies and illnesses, as well as with health care. When these experiences are consciously – or unconsciously – converted into personal insights, experiential knowledge emerges. When patients share experiential knowledge, the communal body of knowledge surpasses the boundaries of individual experiences. The created body of knowledge has been described as experiential expertise (van der Schaaf & Oderwald, 1999). Research suggests that this knowledge enables a patient to better cope with individual illness and disability (Caron-Flinterman et al., 2005).

In PAP, patients and their partners are asked to share their experiences with illness and health care with students, which might aid in the emergence of experiential knowledge. This is underscored by other literature, in which the creation of knowledge is also reported as an outcome after active participation in education, as well as therapeutic effects of active participation in education of health professionals (McGarry & Thom, 2004; Walters et al., 2003).

2.4 Positive Health

In the last decade, a new concept of health was introduced by Huber et al. (2011). The World Health Organisation (WHO) definition of health is often criticised because it is alleged to contribute to the medicalisation of society. Additionally, the demography of populations and the nature of disease have changed considerably since the introduction of the WHO definition (Huber et al., 2011). Instead of describing health as a full state of physical, mental and social well-being, the new definition conceptualised health as *"the ability to adapt and to self-manage in the face of social, physical and emotional challenges"* (Huber et al, 2011, p.1). After the definition was coined, it was tested for operationalizability through the collection and verification of indicators of health in various stakeholder groups, among which patients, healthcare professionals, policymakers and insurers (Huber et al., 2016). This resulted in six dimensions of health: (1) bodily functions, (2) mental function and perception, (3) spiritual/existential dimension, (4) quality of life, (5) social and societal participation and (6) daily functioning, covering 32 aspects of health (Table 1).

Table 1. The 6 dimensions of health indicators, covering 32 aspects by Huber et al. (2016)

Bodily functions	**Mental functions**	**Spiritual/existential dimension**	**Quality of Life**	**Soci(et)al participation**	**Daily functioning**
Medical facts	Cognitive function	Meaning/meaning-fulness	Quality of life/well-being	Social and communicative skills	Basic ADL
Medical observations	Emotional state	Striving for aims	Enjoyment	Social contact	Instrumental ADL
Physical functioning	Esteem/ self-respect	Prospects	Perceived health	Meaningful relationships	Ability to work
Complaints and pain	In control/ manageability	Acceptance	Flourishing	Being accepted	Health literacy
Energy	Self-management, resilience, sense of coherence		Zest for life	Community involvement	
			Balance	Meaningful work	

The dimensions and aspects of health as posed in Table 1 could be regarded as facets of this new conceptualisation of health, as they are mainly constructed together with patients and citizens. Conjoining this with the creation of experiential knowledge could result in a suitable conceptual model by which the (learning) outcomes of patients participating in an interprofessional module in medical education could be further explored.

2.5 The conceptual model

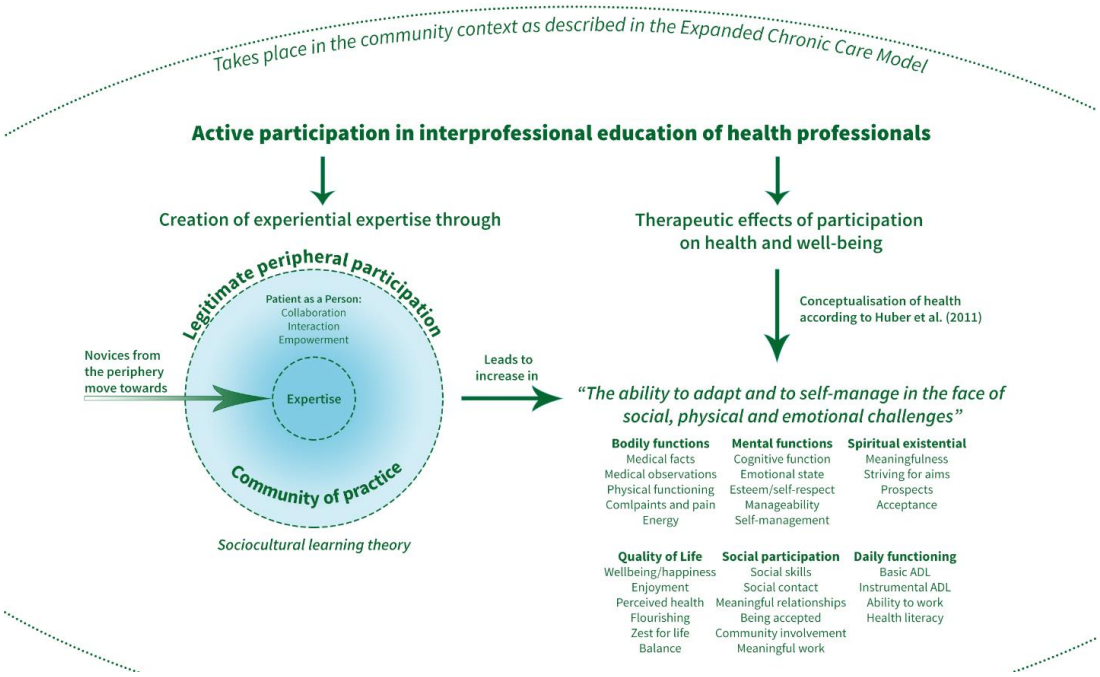

Figure 4. Conceptual model investigating the outcomes of patients' participation in medical education

The presented conceptual model contains and briefly describes the theoretic underpinnings of the research described in this thesis (Figure 4). Through the legitimate peripheral participation in a community of practice, based on contemporary socio-cultural learning theory, patients participating in education are facilitated in the creation of experiential knowledge. This is hypothesised to lead to an increased ability to cope and self-manage illness, as described in both the ECCM and new conceptualisation of health. Different components thereof, consisting of all aspects of health based on the operationalisation of Positive Health, are thought to be achieved in the community setting of the ECCM. It is hypothesised that the experienced outcomes through active participation will have the most impact on the mental functions, spiritual/existential dimension, quality of life and social participation indicators of health, based on existing literature (Walters et al., 2003; Watts et al., 2015).

3. Methods

In this chapter, the nature of the research, the design, the study population, data collection, data analysis, trustworthiness and ethical considerations of the conducted research will consecutively be reported.

3.1 Research nature, type and design

Different schools of research take different positions on the concepts objectivity and subjectivity (Guthrie, 2010). There are various research paradigms, in which a paradigm can be defined as a set of beliefs that guide action by providing a particular view of the world which, then, shapes the way that we interpret and understand our environment (Denzin & Lincoln, 2011). The philosophical paradigm that will be used throughout this study is social constructivism (Berger & Luckmann, 1991; Ross, 2012). According to social constructivism, social interaction leads to the development of new insights in which patients and partners can build on answers of other participants and develop new insights, whilst researchers can explore hidden assumptions (Holloway & Galvin, 2017).

This qualitative study using focus group interviews, can be classified as exploratory research, as little is known on this topic and this work can form the basis of conclusive research (Singh, 2007). It is considered of a (hermeneutic) phenomenological type, in which meaning of human experience is constructed through dialogue with the person who has lived the experience, and in which the experience is impacted by the individuals' senses and social context (Ross, 2012).

3.2 Setting

To facilitate the active participation of patients in the PAP-module (Appendix 1), the eponymous foundation, Patient as a Person (Dutch: Stichting Mens Achter de Patiënt), acquires patients in the community. The patients were recruited by the foundation through various channels, among which are patient organisations, nurse practitioners and medical specialists. Eligibility to participate in the module is not linked to a certain diagnosis or other inclusion criteria. Patients willing to participate are asked in a telephonic intake why they intend to participate and follow an instruction moment on the day of participation in the module, mainly on their role in, and the goals of the module. In the southern part of the Dutch province Limburg, a province that is characterised by low rate of labour participation and low health (Jansen & Kuppens, 2015), around 275 patients have registered to actively participate in education.

3.3 Data collection

Three focus group interviews were conducted to explore the impact on active participation in the educational module, for both patients and their partners separately. Focus group interviews allow the researcher to access the collective views of groups of people in a humanistic and exploratory manner (Ross, 2012). Convenience sampling per e-mail has been used to recruit patients and their partners for participation in the focus group interviews. The inclusion criterion for enrolment in the focus groups was participation in the PAP-module. The only exclusion criterion used, was prior participation in other focus group interviews related to the evaluation of the PAP-programme. The minimum of participants for a focus group was set at 4 participants, whereas 12 was the maximum number of participants, following the recommendation of Tong, Sainsbury, and Craig (2007).

Patients that have participated in the PAP-module organised in the period of February and March 2019 (N=53) in the Southern part of Limburg were approached to participate in the current study. Convenience sampling per mail was used and resulted in 18 patients (34% of the total) willing to participate in the focus group interviews, of which three had to be declined due to participation in prior evaluations of the programme and one participant declined at the last moment due to being ill. Of the fourteen participating patients, four were accompanied by a partner.

The focus group interviews were hosted at the Faculty of Health, Medicine and Life Sciences of Maastricht University in a neutral room in which confidentiality was guaranteed. Besides the moderator, the participants and a facilitator no other people were present. Two focus group interviews (F2 and F3) were moderated by MB (BSc, male), currently enrolled in the Healthcare Policy, Innovation and Management master at Maastricht University. The other focus group (F1) was moderated by SR (BSc, male), currently enrolled in the European Health Economics and Management master at Erasmus University Rotterdam. Both moderators had limited experience with focus group meetings but have been present during focus groups meetings as a facilitator on multiple occasions. Besides, the moderators were also responsible for the coordination of the PAP-module and many of the participants knew the moderators in this role.

The focus groups were audio-recorded, after informed consent had been obtained, and were transcribed verbatim. No participants opted out, no field-notes were made and in the preparation of the focus groups, no pilot or repeat focus groups were conducted. The focus groups lasted between 90 and 120 minutes and revolved around the question ‘What does participation in the

PAP-module mean to you?'. Firstly, participants were given 10-20 minutes to write down both positive and negative outcomes on post-its, to provide every participant the opportunity to deliver input for the discussion. Secondly, the post-its were collected and displayed on a white-board, after which the participants *en groupe* categorised all the displayed post-its, guided by the moderators. The constructed categories formed the agenda that the participants discussed during the focus group meeting.

3.4 Data analysis

The transcripts of the focus groups were independently coded, based on content, by two researchers (MB and HvdB), following three stages of coding as described by Corbin and Strauss (2015). The stages of coding are sequentially described as (1) open coding, (2) axial coding and (3) selective coding. NVivo 12 Pro (Version 12.2.0.443) was used to organise the data. Content analysis acted as a guide throughout coding. Content analysis aims to interpret meaning from the content of the text, identify patterns and place the responses into categories (Ross, 2012). More specifically, directed content analysis was used. This type of analysis is most often used when existing theory can provide predictions about the variables of interest and helps to determine the coding scheme (Hsieh & Shannon, 2005). This is also described as deductive category application (Mayring, 2004).

Following the conceptual model, the open coding divided parts of the transcripts in major concepts as 'Positive Health-related outcomes' and 'miscellaneous'. In the axial coding phase, the major concepts were further analysed based on patterns and – where possible – theory (e.g. the aspects of the dimensions of health according to Huber et al. (2016)). Results that did not fit the framework have been described inductively. The coders have discussed differences in their coding until consensus was reached.

3.5 Trustworthiness

Data triangulation was applied in the collection of data as both the patients and their partners were asked for perceived outcomes. With this, the researcher aimed to obtain diverse views about active participation in education for validation of perceptions (Ross, 2012). In order to increase trustworthiness, member checks were performed by sending a summary of the transcripts to the participants, resulting in one addition. Finally, two coders independently coded the transcripts and discussed them until consensus was reached. At points where the two coders would have been unable to reach consensus, a third coder would have been asked to decide deliberately. This was

not necessary. In qualitative research, the duty of assessing transferability is mostly left to the readers, as they look for resonance in the findings (Kuper, Lingard, & Levinson, 2008). To aid transferability, the results are linked to existing theoretical concepts in the discussion.

3.6 Ethical considerations and ethics approval

Patients are considered vulnerable as their physical and mental capacities may be impaired and therefore they need protection (Ross, 2012). As this master thesis is part of a bigger research project, namely *the feasibility of real patient involvement in interprofessional-, and communication skills education for educational programmes in the domain of health- and wellbeing*, the research was reviewed by the Dutch Association for Medical Education (NVMO, Nederlandse Vereniging voor Medisch Onderwijs). The ethical review board of the NVMO approved the study of which a summary has been attached (Appendix 2). Furthermore, the Medical Ethics Committee Zuyderland & Zuyd (METC-Z) reviewed the research regarding the Medical Research Involving Human Subject Acts (MRIHSA; WMO in Dutch) and concluded that the rules of the MRIHSA do not apply to this research. A summary of this decision has been attached (Appendix 3).

For the sake of brevity, ethical considerations will be discussed here shortly. For further, more in-depth information, the FHML-REC form provided in the HPI4005 Research Methods course is referred to. This form is attached as Appendix 4.

Prior to enrolment in the study, all participants received an information letter, which was constructed in cooperation with the NVMO, addressing topics as confidentiality, possible risks, data use and reimbursement. Before the start of the focus group interviews, the participants were asked whether the provided information is clear and whether questions remain. When all questions were answered, participants were asked to sign the informed consent form. Participants were made clear they can opt-out at every moment during the study, without having to provide a reason. Anonymity, which is said to exist when participant's identity cannot be linked to the responses given (Ross, 2012), was ensured during the data analysis by assigning numbers to participants. Additionally, names mentioned in transcribed text were removed. Recordings were deleted right after the data were transcribed. Transcripts are stored on Surfdrive for ten years, with consent of participants. Participants were not expected to be exposed to any risks. However, the information letter contains the contact details of a confidential advisor. Participants could consult if any inconveniences occur, which was emphasised by the moderators at the start of the focus groups.

4. Results

A total of eighteen participants contributed to the focus group interviews. These eighteen participants were divided over three different focus groups: two for patients (one with eight patients (F1), the other with six patients (F2)) and one exclusively for partners (four partners (F3)). Demographics of the patients and partners have been collected and can be found in Table 2 and Table 3 respectively. The population of patients seems heterogeneous in terms of age (mean 56), level of education, diagnosis, number of times participated in the PAP-module (range 1-5; mean 3) and whether they perceived they were still actively treated for their diagnosis. All of the patients, except one, did not have paid work. The population of partners, albeit relatively small, was heterogeneous in terms of age (mean 57), level of education and relation to the patient.

Table 2. Demographics of participating patients

N	ID	Sex	Age[1]	Level of education[2]	Diagnosis	No. of times participated	Paid labour	Active treatment
1	P1.F1	M	45-49	ISCED 5	Multiple myeloma	4	No	Yes
2	P2.F1	F	45-49	ISCED 2	Sarcoidosis	2	No	Yes
3	P3.F1	F	60-64	ISCED 2	Heart failure	4	Yes	No
4	P4.F1	M	40-45	ISCED 5	Multiple sclerosis	3	No	Yes
5	P5.F1	F	75-79	ISCED 4	Multiple sclerosis	4	No	No
6	P6.F1	F	65-69	ISCED 3	Sarcoidosis	2	No	Yes
7	P7.F1	M	65-69	ISCED 5	Cerebral infarction	5	No	No
8	P8.F1	F	50-54	ISCED 5	Polymyositis	1	No	No
9	P9.F2	F	65-69	ISCED 5	Stroke	2	No	No
10	P10.F2	F	60-64	ISCED 5	Epilepsy	1	No	Yes
11	P11.F2	M	35-39	ISCED 5	Stroke	5	No	No
12	P12.F2	F	40-44	ISCED 3	Diabetes mellitus	3	No	No
13	P13.F2	M	65-69	ISCED 5	Cardiomyopathy	1	No	No
14	P14.F2	F	55-59	ISCED 7	PAX-gene disorder	4	No	Yes

Table 3. Demographics of participating partners

N	ID[3]	Sex	Age	Level of education[1]	Relation to patient
1	R1.F3	M	65-69	ISCED 7	Husband
2	R2.F3	F	75-79	ISCED 5	Friend
3	R3.F3	F	35-39	ISCED 5	Wife
4	R4.F3	F	40-44	ISCED 4	Wife

1 To maintain anonymity, age categories are displayed. The ages are known to the researchers.
2 The Dutch educational levels have been adapted to fit the International Standard Classification of Education (ISCED-11) as formulated by UNESCO Institute for Statistics (2012) using the Dutch Classification of Education as published by Statistics Netherlands (2016).
3 To distinguish between 'patients' and 'partners', this group has been assigned the letter 'R' in their ID. This letter has been chosen because of the synonymous 'relative'.

In total, both the patient focus group meetings (F1 and F2) yielded 51 post-its, of which 31 were described positive outcomes (61%) and 20 described negative outcomes (39%). The partners described seventeen outcomes in total, of which fifteen were positive (88%) and two were negative (12%). The topic lists constructed based on these post-its, consisting of a minimum of seven and a maximum of nine topics that were covered. The moderators perceived a high degree of overlap in the topic lists with (1) the ability to contribute, (2) attitude towards professionals, (3) social contacts and (4) recognition and acknowledgement most elaborately discussed. Due to the exploratory design, data saturation was not explicitly aimed for. The topic lists for each focus group can be found in Table 4, whereas the results of the initial collection of positive and negative outcomes on post-its have been digitalised and can be found in Appendix 5.

Transcripts of these three focus group meetings have been analysed using content analysis, which resulted in nine common categories, of which six can be related to the dimensions of the new conceptualisation of health ('Positive Health'). An overview of the categories are displayed in Table 5.

Table 4. Topic lists for each focus group meeting constructed based on the post-its

ID	**Topic list**
P#.F1	(1) Enjoyable contacts, (2) recognition, (3) attitude towards professionals, (4) ability to contribute and feeling useful, (5) expressing positive health, (6) acknowledgement and recognisance, (7) participation too soon after lived experiences and (9) the perceived involvement of students of different backgrounds.
P#.F2	(1) Processing: acknowledgement and recognisance, (2) contributing to education, (3) positivity in students, (4) insight in students and current professionals, (5) defending yourself, (6) attitude of the student and (7) exhaustiveness.
R#.F3	(1) Positive energy, (2) having a goal, (3) contributing, (4) acknowledgement, (5) different contacts, (6) equivalence, (7) little effect on the participant and (8) mixed groups leads to loss.

Table 5. Categories regarding the outcomes of active participation in the PAP-module

'Positive Health' related outcomes	
1. Bodily functions	*Active participation in education contributes to…*
a. Energy	…perceiving low levels of energy after participation
2. Mental functions and perceptions	
a. Emotional state	…experiencing positive feelings …experiencing negative feelings
b. Esteem/self-respect	…dignity, being perceived as equal and being heard
3. Spiritual and existential domain	
a. Acceptance	…accepting what happened to you
b. Striving for aims	…having a goal in life (again)
c. Meaningfulness	…meaning of my existence
4. Quality of life	
a. Happiness	…positive energy, enthusiasm and strength
b. Perceived health	…a sense of perspective on my own illness
c. Zest for life	…having the feeling to get part of life back
5. Social and societal participation	
a. Being accepted	…recognition, acknowledgement by others
b. Social contacts	…contact with other patients and students
c. Meaningful work	…the ability to contribute to the development of future professionals
6. Daily functioning	
a. Health literacy	…gaining insight in the (im)possibilities of (future) healthcare professionals.
Other outcomes	
7. Increased assertiveness in own health trajectory	…being more assertive in contact with current healthcare professionals
8. Acknowledging of and effect on partners	…giving credit and acknowledging partners …positive energy and enthusiasm for the partners
9. Perceived involvement and responsibility for the module	…a feeling of responsibility for the development and execution of educational activities

4.1 'Positive Health' related outcomes

Bodily functions. Some patients told they experienced **low levels of energy** after participating in education. They said this can be attributed to several reported factors, of which one is the limitations in energy due to the illness itself. Additionally, coordinating and planning of the second meeting together with the students can lead to experiencing low levels of energy, especially when they experienced a lack of collaboration in this process from the students. This process is further complicated if students come from different educational institutions, as timetables and obligations do not match. Lastly, another factor that was mentioned by the participating patients that contributes to experiencing low levels of energy is the interprofessional aspect of the module, which leads to (the perceived need for) tailoring the story to the various professional backgrounds.

> *"You know, together with a medical student, I want to touch upon different subjects than a nursing student. Both of them are very important, but they have different needs. (…) I want to serve everyone based on their profession and [the diversity of professions] makes it tough for me."* P1.F1

On the other hand, some patients reported that the interprofessional aspect is useful in stressing the need for collaboration in practice.

> *"What we experience in our diagnosis is the [lacking] communication between healthcare professionals (…) So for me, I really like the opportunity to explain how important collaboration is"* P2.F1

Mental functions and perceptions. Despite participation in the PAP-module being bodily challenging, patients reported to experience positive effects on their **emotional state**.

> *"In terms of my body, this [participation] costs me a lot of energy but I get a lot of mental energy in return. If I have to rest and lay down later, I lay down with a smile and sense of satisfaction."* P2.F1

Patients and partners mentioned that they can turn something negative (i.e. their illness) into something positive through sharing their experiences in education. Furthermore, enthusiasm from the students was mentioned as a positive effect on the emotional state of the patients. When patients encounter students with a lot of natural empathy, they reported that this provides them with hope for future healthcare professionals.

Nonetheless, some patients reported that participation can also harm their emotional state. Disinterest and a lack of natural empathy in students have a negative effect on the emotional state. Other reported factors by the patients include participating too soon after lived experiences (i.e. having a feeling participation comes too early) and reliving negative experiences.

> *"For me, participation came too soon. I was still too invested in the process. It had a tremendous impact on me."* P1.F1

However, reliving negative experiences is not solely regarded as unfavourable by the participants, as it contributes to processing these experiences (see: Spiritual and existential domain). Another source of negative affect can be found in hearing stories from other patients, which leads to the idea that there were more possibilities in rehabilitation.

In terms of **esteem**, patients experience a feeling of being understood and acknowledgement by the students, experience genuine interest and feel equality between students and patients. These findings were mainly reported by the partners.

Spiritual and existential domain. Patients reported that reliving negative experiences, eventually contributes to the **acceptance** of what has happened to them in terms of illness and the processing thereof.

> *"It cost me a lot of effort to accept what happened to me. Talking about it [in education] helps me accepting this."* P13.F2

Furthermore, the patients reported that actively participating in interprofessional education contributed to having a purpose (again). The experiences they can share feeds the experienced **meaningfulness** by participants themselves.

> *"A part of my identity has been taken from me. In this way, one can contribute again, be it just a little."* P4.F1

The goal for the patients in participation mainly entails making sure future healthcare professionals will act more empathically, whilst many patients experience this as a contribution for others rather than for themselves, as it concerns a future generation of healthcare professionals. This altruistic motive was both described by patients and partners.

"I do not look at it as 'bullocks, I don't have it [empathy]' but I regard it more as something 'yes, that can be something beautiful for the future'." *P2.F1*

Quality of life. Actively participating in education also contributed to the **happiness** of patients. In addition to happiness, participation also provided a different perspective on how patients **perceived their health**. As different patients participated in the same group, patients heard experiences from other patients. These stories can put their own experiences into perspective in terms of the seriousness of the illness.

"If I hear all the different stories, I think, who am I to complain? Others have their complaints as well." P10.F2

The partners agreed upon the fact that they noticed an increased **zest for life** in the patients.

Social and societal participation. As part of social and societal participation, patients reported recognition and appreciation from fellow patients and students as part of **being accepted**. One of the most reported outcomes regarded the **social contacts** as a result of participating in education. In all focus groups, the participants agreed that contact with fellow patients is valuable, notably as in many cases the participants reported that their social contacts decreased because of their illness. The contact is deemed useful (e.g. tips on disease management), but most of all, joyful. As reported earlier, students' enthusiasm was regarded as contagious. Therefore, it is not only contact with fellow patients that was valued by the participating patients.

"You meet other people with similar experiences, that's positive. She's also still in contact with two medical students from the first time she participated. (…) All very positive, but also more [interaction] towards her friends. I notice that she is making progress, thanks to the Patient as a Person-module. I mean that from the heart." R2.F3

Another aspect of health that was reported was **meaningful work**, again both by the patients and their partners. The ability to contribute to future healthcare professionals has been the most reported outcome for the participants and has been described as meaningful, useful and fun.

"You feel satisfied. I mean, of course you are important in society but you definitely had to take a step back. For example, I had to give up my job after twenty years. By participating in this [module], I have the feeling I can contribute to society" P2.F1

Daily functioning. In terms of **health literacy**, patients reported having gained insight into the (im)possibilities that (future) healthcare professionals experience.

> *"When I gain more insight in the legislation, insurance and everything else, which happens in the module, I have an increased understanding of why things initially go different from what I wanted. (…) They [the future professionals] are stuck in a system, even though as a human being, they really want [to help me]."* P1.F1

The researchers concluded that both daily- and instrumental activities of daily living (ADL) can be seen as prerequisites of active participation in education and therefore have not been extensively discussed in the focus groups.

4.2 Other outcomes

Increased assertiveness in own health trajectory. The experiences of other patients, as described under 'Mental functions and perceptions', also provided the patients with insight on how others address certain topics in consultations.

This increased the assertiveness of patients in terms of participation in their own health trajectory.

> *"If you hear how others deal with similar situations, I have learnt from people who have been more assertive. Of course, you learn throughout the years, but because of the stories of others, this might go faster."* P12.F2

Acknowledging partners and the effect on them. One of the lessons that patients often convey to the students in the module, is that the impact of disease is not limited to the person with the diagnosis. Patients reported to want to acknowledge the impact on partners and relatives. Patients felt that in this way, they can acknowledge their partners. On the other hand, partners indicated to feel delighted and energised when they see the patients experience an increased zest for life and enthusiasm. When partners actively participated in the module as well, they also reported to yield social contacts from their participation.

> "*Their world gets a bit smaller, which leads to less to talk about. It is nice to be able to talk about something again. It's not that we do not have anything to discuss, but for us it's also very nice to see that they can contribute again. (…) That's something that gives me energy."* R4.F3

Perceived involvement in the educational module. Although the focus group interviews focussed on the outcomes yielded by the participating patients and their partners, the moderators had to redirect the participants repeatedly from making additions and suggestions to the educational module. At first, the researchers did not want to include this in the results but experienced the contributions made resulted from the perceived responsibility and high degree of involvement of the patients and their partners.

Familiarising with diagnosis. Two patients reported that participating in the PAP-module also provided them with the possibility to familiarise future healthcare professionals with their relatively unknown diagnosis. This is regarded a minor theme by the researchers and therefore it was not included in Table 5.

> *"Raising awareness on our diagnosis, because nobody knows about it, is important to me" P6.F1*

5. Discussion

In the last chapter of this thesis, a summary of the findings compared to existing knowledge and the conceptual model can be found. Consecutively, strength and limitations, recommendation for practice and research are presented.

5.1 Summary of the findings

This thesis aimed to explore the impact of active participation in an interprofessional module for patients, both positively and negatively, by exploring the perspectives of patients and partners. According to both patients and partners, active participation in the PAP-module had a positive impact on five out of six domains of Positive Health for the participating patients, being (1) mental functions and perceptions, (2) spiritual and existential domain, (3) quality of life, (4) social and societal participation and (5) daily functioning. Active participation negatively influenced two out of four domains, namely: (1) bodily functions and (2) mental functions. In addition to the domains of health, participation in education contributed to increased assertiveness in own health trajectory, acknowledging the role partners have in illness and perceived responsibility for the educational module in the participating patients. Partners reported feeling energised by seeing the patients experience an increased zest for life and enthusiasm.

Recent systematic reviews that incorporated patient outcomes after their active participation in education reported that patients enjoyed participation, believed their contributions were worthwhile, felt increasingly confident, could contribute to (medical) knowledge of students, felt anxious about revisiting negative experiences and that participation had therapeutic benefits for them (Happell et al., 2014; Scammell et al., 2016; Towle et al., 2010). The results of this thesis are in line with the mentioned results. In addition to existing knowledge, this thesis adds valuable insights on the active participation of patients in an interprofessional setting. Although patients deem it valuable to stress the importance of interprofessional collaboration to students, the tailoring of the story to the different students present does cost more energy.

The finding of increased knowledge, depth and understanding of the professional-patient relationship as described by Walters et al. (2003) is confirmed by the findings of this thesis, as patients report gaining insight in the (im)possibilities of (future) healthcare professionals through the interaction with students. Additionally, patients explicitly reported increased assertiveness in their health trajectory. This outcome can be attributed to patients gaining insight in the way other

patients address certain topics during consultations. Furthermore, this increased assertiveness is especially relevant in the productive partnership between the informed and activated patient and the prepared and proactive practice team, as described in the ECCM by Barr et al. (2003). Active participation in education might be regarded as an intervention to foster self-management competencies in patients, fitting the self-management area of focus combined with a strong link to the community, as education classically operates in the social sector.

Lastly, this thesis provides insight into the views of partners on active participation in interprofessional education. In light of the undisputed fact that having a role as informal caregiver puts someone at risk of poorer physical and mental health (Adelman, Tmanova, Delgado, Dion, & Lachs, 2014; Gérain & Zech, 2019), the fact that active participation in education by the patient alone had a positive influence on the partners in terms of enthusiasm and positive energy seems highly relevant in the societal challenge of tackling the burden on informal caregivers.

5.2 Strengths and limitation

This thesis explicitly used triangulation in data collection by incorporating the views of the partners on the outcomes of active participation in education. The views of the partners not only yielded a broader view on the (health-related) outcomes for patients, but also showed that active participation in health professions education impacts the partners themselves. This can be regarded as a strength of this thesis.

This thesis used the operationalisation of positive health by Huber et al. (2016) as a framework in the data analysis and reporting of the results. However, as clear definitions of the 32 aspects lack, most of the aspects are left to the interpretation of the researchers. Closely related aspects, such as ‘Happiness’ (Quality of Life) and ‘Emotional state’ (Mental functions and perceptions) or ‘Meaningfulness’ (Spiritual and existential domain), ‘Meaningful work’ (Social and societal participation) and ‘Work’ (Daily functioning), made coding based on this framework ambiguous at times. An alternative that could be suggested is the *four-domain model*, developed by Maastricht University and Zuyd University of Applied Sciences (Zuyd Hogeschool, 2017). This model is derived from the domains of the International Classification of Functioning, Disability and Health (ICF) developed by the WHO and the latter is methodologically validated.

Another limitation is the double role fulfilled by MB and SR, both of the moderators of the focus groups. They initiated, developed and coordinated the execution of the educational module

and MB analysed the focus group interviews as a researcher. Therefore, they were at risk of having an overly positive view of the results. Additionally, the participating patients knew them in this role. This could have influenced their answers to be more socially desirable. Lastly, in terms of transferability, the focus group with partners included only four participants which could be regarded as a limitation of this thesis.

5.3 Conclusion and suggestions for further research

This qualitative study on the (health-related) outcomes of participation in interprofessional/health professions education for patients suggests several 'Positive health'-related outcomes, both positive and negative, an increased assertiveness in own health trajectory and a positive effect on patients' partners. These outcomes might aid in the self-management of disease and contribute to the activated and informed patients as described in the ECCM.

Further research on this topic should use larger sample size to increase the transferability of the results, by including patients and partners with experience in other educational activities that actively involve patients in other (international) contexts. To this end, a quantitative survey has been developed based on the results of this thesis and other relevant aspects found in the literature. The survey has been piloted and tested for face-validity using 'thinking-out-loud'-sessions with two patients, two partners and the supervisor of this thesis, but still should be tested for construct- and content validity. The survey can be found in Appendix 6. Once a broader scientific base on health-related outcomes is established, another direction for further research could be aimed at quantifying these health-related outcomes.

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Appendices

Appendix 1 - Description Patient as a Person-module

The module aims to increase (1) students' insight into the impact of illness on mental and social dimensions of health, (2) awareness of the importance of a holistic approach to patients and (3) insight into other disciplines and how they can complement each other. The role of patients was to share their experiences and discuss potential improvements in healthcare delivery with students. Teachers acted as moderators of the discussion and facilitators of the group process and thereby had no traditional role as a teacher in terms of sharing knowledge

Meeting 1

In the first meeting twelve students of different health professions (medicine, health sciences, physiotherapy, occupational therapy, nursing, biometry, speech therapy, creative therapy and home care provision) and four people with a diverse range of experience with illness have a plenary meeting in which the person centeredness of medical and paramedical care is discussed. More specifically the needed competencies from the point of view of the students and patients.

Meeting 2

Two students with different educational backgrounds visit one patient. In these groups of three, the patient shares how disease has impacted the mental and social dimension of health. Moreover, the patient reflects on the extent to which healthcare professionals have addressed these dimensions adequately and provides suggestions for future improvements in professional-patient communication. After this meeting, students write a reflective essay in which they elaborate on (1) how they will cater to patients' needs concerning the mental and social impact of health in their future work and (2) whether (and if so, what) they learned from the perspective of the student of another profession. Additionally, students are asked to highlight similarities and differences between their perspectives and those of their fellow student.

Meeting 3

In this plenary session, the group of ten students formulate how they will translate the lessons learned into their future practice. Students share the lessons they learned and discuss these with fellow students and the patients. Commonalities and differences between the five stories are discussed, thereby broadening the learning experience

Appendix 2 - Ethical approval by the NVMO ethical review board

NVMO-ERB
Ethical Review Report

Applicant:	Primary researcher:	Supervising researcher:
van den Eertwegh V Trappendaal 67 6228GA Maastricht Nederland	Bosveld/Romme Maastricht University, Maastricht	Van den Eertwegh

NERB dossier number:	Date of application:	Date of decision:
992	09-01-2018	20-02-2018

Title of the study:
Procesevaluatie naar de haalbaarheid van de inzet van echte patiënten in interprofessioneel empathie- en communicatieonderwijs in opleidingen in het gezondheids- en welzijnsdomein.

The above mentioned applicant has asked the NVMO Ethical Review Board for ethical review of a research proposal.

Nature of the data to be collected and nature of the study.
The researcher has provided the NVMO Ethical Review Board with information leading the board to conclude that this research project poses no realistic risk for any subject involved in the study and there is no risk of them being misled or deceived.
The researcher has declared that participants will be fully informed prior to the study and that the specimen consent form uploaded is identical to the version that will be provided to subjects. The Review Board is satisfied with the information it has received on how consent will be collected.
The researcher has declared that participants in the study will be informed that participation is completely voluntary and that they can withdraw from the study at any time without giving a reason.
The researcher has declared that the data collected in this study will be stored anonymously or encrypted. Information included in any publication arising from this study will be anonymised and not attributable to an identifiable person in any way.

Recommendation
Based on the information provided by the researcher, the NVMO Ethical Review Board concludes that it is competent to review this project. Based on responses given to the questions and review of the supporting documents, no further ethical review is necessary. The board therefore approves the study.

Disclaimer
The NVMO Ethical Review Board operates commissioned by the Dutch Association for Medical Education (NVMO) and its scope is limited to research projects which are conducted in the Netherlands.
The NVMO Ethical Review Board stipulates that the researcher is responsible for the correctness of the information provided to the review board and that any decision about this study can therefore only apply under the condition that the researcher will execute the study as indicated.
If any changes to the study are made that would affect the responses given to the questions asked in this process and on which this report is based, a new NVMO Ethical Review Board procedure is indicated.

The NVMO Ethical Review Board
Current members of the NVMO Ethical Review Board are: Dr. S.J. (Scheltus) van Luijk (chair) - Drs. W.E.S. (Sjoukje) van den Broek (secretary) - Drs. L.M.L. (Lieselotte) Postmes (secretary) - Dr. E. (Esther) de Groot - Dr. K.D. (Karen) Könings - Mr. M. (Mieke) Peels-Nooter - R. (Ragna) Rood - Dr. A.N. (Janet) Raat – Dr. A. (Anouk) Wouters - R.H.P. (Roel) Wouters MD

Appendix 3 - MRIHSA exemption (Niet-WMO plichtig verklaring) by the METC-Z

METC Z
Zuyderland - Zuyd

Correspondentieadres:
METC Z
Secretariaat, T3 Heerlen
Postbus 5500
6130 MB Sittard

metc@zuyderland.nl

Bezoekadres:
Zuyderland Heerlen
K & E
Hoofdgebouw etage 3
H. Dunantstraat 5
T 088 – 4590129

www.zuyderland.nl/METC

Beoordeling Niet WMO onderzoek

METC nummer:	METCZ20180002
Titel onderzoek	Impactanalyse onderwijsmodule Mens Achter de Patiënt
Datum besluit	22 januari 2019
Onderzoekers	Sjim Romme en Matthijs Bosveld

Op uw verzoek van 9 januari 2018 heeft de Medisch Ethisch Toetsingscommissie in het overleg van voorzitter en secretaris kennis genomen van bovengenoemd onderzoeksprotocol. De Commissie heeft de in bijlage 1 genoemde documenten beoordeeld en is tot de conclusie gekomen dat:

- er wel sprake is van een medisch wetenschappelijke vraag;
- de proefpersonen niet aan een handeling worden onderworpen en er wordt hen geen gedragswijze opgelegd, beide zoals bedoeld in de WMO.

Omdat aan één van beide voorwaarden voor WMO-plichtigheid niet is voldaan, heeft de Commissie besloten dat bovenvermeld onderzoek niet WMO plichtig is.

De Commissie maakt u attent op het volgende:

- Dit onderzoek – voor zover u het uitvoert binnen Zuyderland – moet worden aangemeld bij BWO voor goedkeuring van de Raad van Bestuur, alvorens u mag beginnen met de uitvoering (www.zuyderland/onderzoek, Toetsing, Raad van Bestuur).
- U en uw afdeling zijn verantwoordelijk voor de correcte uitvoering van het onderzoek volgens de geldende wet- en regelgeving. Hierbij vestigen wij u aandacht op het volgende:
  - U dient correct om te gaan met de in uw onderzoek verzamelde gegevens zoals bepaald in de Gedragscode Gezondheidsonderzoek (Code Goed Gedrag), het privacy reglement van Zuyderland en de Wet bescherming persoonsgegevens (zie ook www.federa.org).
  - Alle wijzigingen aan dit onderzoek dienen als amendement aan de Commissie ter beoordeling te worden voorgelegd, zodat eveneens kan worden beoordeeld of het onderzoek nog steeds buiten de reikwijdte van de WMO blijft.
  - Verder wil de Commissie u erop attenderen dat het onderzoek VOOR de start, bij een openbaar trialregister aangemeld dient te worden. U kunt dit doen bij: http://www.trialregister.nl of bij ClinicalTrials.gov. Zonder aanmelding kunt u in bepaalde *journals* niet publiceren.

METC Zuyderland - Zuyd

U dient de Commissie via METC Management op de hoogte te stellen van:

- de startdatum van het onderzoek.
- Tevens dient u alle wijzigingen die u aanbrengt in het onderzoek voor te leggen aan de Commissie.
- De einddatum van het onderzoek.
- Bij beëindiging van de studie ontvangt de Commissie het eindverslag en publicaties.

Met vriendelijke groet,
METC Z
dr. J.W. Greve, voorzitter
namens deze,

mr. Van den Besselaar (Hélène)
secretaris METC Z

To whom it may concern,

METC Z, (Heerlen, The Netherlands), the Medical Ethics Committee Zuyderland & Zuyd (hereafter the Committee) has reviewed the above mentioned research proposal. As a result of this review the Committee informs that the rules of the Medical Research Involving Human Subjects Act (WMO in Dutch), do not apply to this research proposal.

Sincerely yours,
METC Z
dr. J.W. Greve, chairman
on his behalf,

mr. Van den Besselaar (Hélène)
secretary METC Z

METC Zuyderland - Zuyd

Bijlage 1

Beoordeelde documenten

- CV Sjim Romme - Versie 1.0, 08JAN2018
- CV Matthijs Hugo Bosveld - Versie 1.0, 08JAN2018
- Deelnemersbrief Medisch-ethische commissie NVMO (patiënt) – Versie 1.0, 08JAN2018
- Deelnemersbrief Medisch-ethische commissie NVMO (student) – Versie 1.0, 08JAN2018
- Informed Consent formulier MAP - Versie 1.0, 08JAN2018
- Onderzoeksprotocol MAP - Versie 1.0, 09JAN2018
- CV Sjim Romme - Versie 1.0, 08JAN2018
- CV Matthijs Hugo Bosveld - Versie 1.0, 08JAN2018
- Samenvatting onderzoeksprocotol Mens Achter de Patiënt

Appendix 4 - FHML REC-form

This appendix was written during the course 'HPI4005 – Research Methods'. As research is subject to change, some descriptions of methodological approaches under Chapter 1 in this appendix could differ from the approaches in the thesis. However, the ethical considerations regarding the data collection among patients remained the same throughout the development of this thesis and therefore this appendix has not been fully updated.

Programme: Master Healthcare Policy, Innovation and Management
Student Name: Matthijs Bosveld, BSc
Email: mh.bosveld@student.maastrichtuniversity.nl

Supervisor Name: Mariëlle Kroese, PhD
email: marielle.kroese@maastrichtuniversity.nl

Project Title: Active patient participation in interprofessional education of health professionals: a qualitative study on (health related) outcomes for patients and their partners

The following list presents the key characteristics of a high-risk study. Please indicate which of these characteristics (if any) apply to the study that you will conduct for your master thesis project.

- ○ own data collection among population below 18 years of age
- ✓ **own data collection among patients or persons placed in long-term care institutions**
- ○ own data collection among persons with limited decision-making capacities or disabilities
- ○ own data collection among persons with a specific disease, e.g. diabetes, HIV, dementia, etc.
- ○ own data collection among other vulnerable groups, e.g. migrants, minorities, etc.
- ○ own data collection on a sensitive topic, e.g. deviance, informality, taboo subject, etc.
- ○ own data collection using invasive research instrument(s), e.g. medical intervention, etc.

Please complete the following in a free style with a high level of detail. FHML*REC* is looking to see that you have identified ethical issues and addressed them satisfactorily; and, that you are thinking about undertaking your research in an ethical manner, and can communicate this to your research participants and other people in society generally.

1. The Study

1.1 What is the nature of the study? What are the key questions that you are seeking to address?

The research proposed aims to identify outcomes of patients after participating in an educational module organised by Maastricht University, Zuyd University of Applied Sciences, ROC Leeuwenborgh (vocational level) and Gilde Opleidingen (vocational level). As there is limited evidence on patient related outcomes in interprofessional education, explorative mixed-method research is proposed. Further methodological explanation is elaborated on below.

1.2 What are the methodologies that you will employ in the study?

Firstly, qualitative focus groups will be conducted with patients who have participated in the programme, as well as with their partners/informal care givers/close relatives. The outcomes of these focus groups

will lead to the compilation of list of outcomes, which in turn will be send to all other patients and their partners (except the ones who participated in the focus groups) for verification purposes. Besides the exploratory questions, demographic information such as age, gender, disease number of times participated in the programme will (anonymously) be collected. This allows stratification for certain subgroups. The main question for the quantitative part is: *To what extent do you agree that the following outcomes are a result of active participation in the module?*

1.3 How will humans be participants in the study (either directly or indirectly, for example, through the use of their personal data)?
Human will be direct participants in the study, in the sense that they will be the main subjects of the focus groups. Each member of the focus group will be asked to fill out a form regarding demographic information (as described). This will not include a participant's name and therefore the personal data will not be able to be linked back to the participant.

For the quantitative part of the study, the patients will be reached via e-mail and will fill out an online survey using Qualtrics Online Survey Software.

1.4 Does your study re-use data that has already been gathered for another project or purpose? If so, do you have permission to re-use that data, and was there the relevant consent for this re-use in the first study? (Please explain, with reference to, for example, previous ethics committee decisions and informed consent protocols.)
No, the proposed research does not re-use data that has already been gathered for another research project.

1.5 What sort of people will be involved? (For example, professionals in the course of their profession, members of the general public.)
Members of the general public, and more specifically, people who have experience regarding disease and health care (referred to as *patients* but could also include e.g. parents of diseased children) and their partners/close relatives/informal care givers (i.e. someone who is in close contact with the patient).

1.6 On what grounds did you determine the number of participants needed for the study?
The number of participants is to be defined. We do not know to what extent saturation will be reach during the focus groups, but the aim is to include a maximum of 24 patients and 24 partners in the focus groups. Patients are identified after their participation in the educational module, for which they have voluntarily subscribed.

1.7 On what grounds did you determine that this is a useful study?
Medical educations are believed to strengthen health systems. To tackle the current challenges posed, reforms are called for. Interprofessional education is emerging as a solution and combined with the increasing demand for patient-centred care, the fact that patients are becoming more empowered and the desire to make health services more responsive to the needs of the public, drive active patient involvement in (interprofessional) health professions education (Towle et al., 2010). However, little is known about the expected and unexpected consequences from the perspective of patient-educators. As published by Towle et al. (2016), the Vancouver Statement prioritises conducting and disseminating high

quality, inclusive accessible research and evaluation, (…) including patient outcomes, underscoring the scientific importance of this research paper.

1.8 Is this a 'one-off'/ 'stand-alone' project, or do you foresee that you will want to re-use the data in future (different) research, or to share the data with other researchers for their future research? How have you ensured consent for this from your participants?

If the data is to be re-used for further research, informed consent is to be obtained again. This has been discussed with the Dutch Society for Medical Education (Nederlandse Vereniging voor Medisch Onderwijs), which have also ethically approved the proposed research (see point 4).

1.9 If relevant, what is your publication strategy?

The aim is to publish the proposed research (eventually) in a scientific journal. However, no publication strategy has been determined yet.

1.10 If the work is not going to be undertaken (solely) in The Netherlands, is local Ethics Review required in the country/countries where the research is to be undertaken? How will this be achieved?

Not applicable.

2. Identifying Harms

2.1 What are the possible harms that participation in your study could bring for the human participants? (These could be, for example, physical, psychological, economic, harms, harms relating to privacy, etc.)

There are no physical or economic harms to be expected. Preliminary research suggests that one of the outcomes of patient participation in medical education includes reliving negative experiences (i.e. psychological harm). For this reason, a confidential advisor (a retired professional with a background as social worker and currently finalising her dissertation) has been appointed to the research. In the information letter provided, the confidential advisor is mentioned and the possibility to contact this advisor will be emphasised during the focus groups.

2.2 How will you ensure integrity in the use of other researchers' data and published work?

The proposed research will not use other researchers' data. Only work that has been published in (renowned) scientific journals will be used to substantiate statements throughout this research. When doing this, appropriate referencing in APA-style will be used to avoid plagiarism and maintain integrity.

2.3 How will you ensure within your team that the highest standards of academic integrity are maintained, and that there are mechanisms to raise and discuss concerns within the team (and to the University Integrity Officer)?

Firstly, the researchers take note and comply to the Netherlands Code of Conduct for Scientific Practice, as well as the Regulation for Scientific Integrity at Maastricht University. The research is bound to follow the principles of honesty, scrupulousness, transparency, independence and responsibility. This statement is substantiated through the signing of the informed consent form at the start of the research. Regular check-ins with the supervisor of this master thesis project will ensure that concerns can be raised and iscussed, after which appropriate action can be taken if necessary.

3. Safeguards

3.1 How will you inform participants about their participation in your study? (Please also comment on any re-use of data issues.)

The ethical review done by the ethical review board of the Dutch Society of Medical Association (NVMO), included the review of information letters for participants. Together with the NVMO, the researchers constructed (Dutch) information letters which have been attached to this FHML-REC form (Appendix B). Before commencing qualitative data collection, the participants will have been able to read the information letter and will be asked if any questions remain. If questions remain, they will be answered by the facilitator present. Afterwards, the participants are asked to sign an informed consent form which will be provided in two-fold. At any point in the study participants can opt out without providing a reason. For the quantitative part, the participants are provided with a digital version of the informed consent form. Conclusively, no data will be re-used during the research. If the data is to be reused for different scientific research, informed consent is to be obtained again.

3.2 Will individuals be invited to participate in your study through informed consent, or are you appealing to, for example, the public interest in undertaking the work (for example, you might be undertaking a participant observation)?

Please supply details (and, where appropriate, drafts of any forms) of your informed consent process (i.e. both how you will gain informed consent from your participants and how you will evidence that consent), and the information sheets that you will use.

Participants will be invited in the proposed research through informed consent. Besides the (Dutch) information letters, the informed consent for patients is attached (Appendix A), which have been compiled and reviewed by the ethical review board of the NVMO. As previously described, informed consent forms will be provided before the commencing of the data collection. The participants of the focus groups will sign the informed consent forms, after which they will be digitally stored in the shared space to which only the researchers have access, separated from the obtained data. The digital informed consent forms of the quantitative survey will be stored online in the Qualtrics Online Survey Software.

3.3 How will you process any personal data in the project? (You should explain the safeguards in place throughout the processing of the data from gathering the data, analysing the data, storing the data, and destroying the data at the end of the period.)

The participants will be approached for participation directly after their participation in the educational module by the teacher that is present. Patients are asked to subscribe to a list stating their name(s) and e-mail if interested in participating. These lists will be conveyed to the lead researcher of this project (MB) and he in turn will send the information letters, date and times to the interested participants. Afterwards, the list will be shredded and disposed.

During the focus group meetings informed consent will be obtained and signed, which in turn will be scanned and stored digitally in the password protected OneDrive folder. The paper version will be shredded and disposed. Direct access to the OneDrive folder is granted only to the two firstly mentioned researchers (Appendix B, MB and SR). No USB-sticks will be used to transfer data. The audio files will be stored similarly, as well as the transcripts. The transcripts will not contain any personal information and coding of participants will be used during the transcription process. The files will be destroyed after 10 years, and will not be reused without informed consent for further research purposes.

3.4 Who will have access to the personal data? In particular, will you use de-identification methods (coding, anonymising, etc.) as a protection? Will you engage in "open data" methods of data sharing for integrity issues? Under what conditions will they have access?
The research team as mentioned in the information letter will have access to the signed informed consent forms, audio files, demographic information (de-identified). Direct access is granted only to the two firstly mentioned researchers (Appendix B, MB and SR). The audio files will be deleted after transcription. De-identification methods will be used in data-analysis (numbers will be assigned to focus groups and participants to refer to them).

3.5 Will there be any reimbursement, remuneration or reward for participation? If so, what is your reasoning for this and is it proportionate and appropriate?
No reimbursement will be available for participation in this research.

3.6 Are there any further safeguards that you have put in place?
Not applicable.

3.7 In what circumstances and to what extent will your participants have the opportunity to withdraw their participation? How will this be communicated to them?
Participants can opt-out at any point in the research, without providing a reason. This is explicitly addressed in the information letter, as well as the fact that if they opt-out during the audio recorded focus groups, their contributions up to that point can not be deleted. Finally, it is communicated in the informed consent form provided and signed by all participants.

3.8 Is participation in the study confidential? In particular, will participants be identifiable in any publications or other dissemination of research results? If so, will you have a specific consent for this use of the data? If participants will be unidentifiable, how will you ensure this in your publications?
Participation in the study is confidential. Participants will not be identifiable in any publication or other dissemination of research results, a matter which is explicitly mentioned in the information letter. Certain excerpts or quotes may be used to illustrate a topic but will in no way be traceable to the participant. In transcribing, the participants will be coded. Separating the personal information from the quotations will ensure unidentifiability, leaving only the possibility to report quotations by "Participant X".

3.9 How will the data be stored, and for how long will it be stored? Please indicate which data storage plan you will use (please copy here one of the data storage plans describe below). If you are not proposing to use this, why not?
Data will be stored using Surfdrive provided by Maastricht University for the length of 10 years, which is communicated with the participants in the information letter and informed consent form.

Situation 2: Student collects new data under the guidance of a researcher who works at the FHML
- Property: original data and modified data files are the joint property of the student and FHML.
- Specific agreement has to be made between the student and the researcher who guides the data collection about safe handling of the data, i.e. that:

- Data, once collected, are anonymised. Data that cannot be anonymised (e.g., tapes) are handled by the student with extreme precautions, and deleted after data processing (e.g. once anonymous transcripts are made).
- Precautions are taken by the student to prevent the loss of the data (e.g., not travelling around with the data unnecessarily, being careful not losing an USB stick or laptop with the data during travel)
- Precautions are taken by the student to prevent that the data can be viewed or used by others (e.g., prevent access to laptop with data or completed paper questionnaires by housemates, remove data from laptop immediately after finishing the research).
- Storage: At the end of the thesis period, the student has to give the original data and all copies of (modified) data file(s) to the researcher who guides the data collection, as well as all documents from which the data can be retrieved. After that, the student has to delete the original data and all copies of the (modified) data file(s), and all documents from which the data can be retrieved. The data are stored by the researcher who guides the data collection.

4. Any other ethics observations that you wish to make.

Here you might, for example, indicate how you will communicate your ethics strategy to third parties - to the broader society.

As this master thesis is part of a bigger research project, namely *the feasibility of real patient involvement in interprofessional-, and communication skills education for educational programmes in the domain of health- and wellbeing*, the research was reviewed by the Dutch Association for Medical Education (NVMO, Nederlandse Vereniging voor Medisch Onderwijs). The ethical review board of the NVMO approved the study of which a summary has been attached (Appendix 2 of the original proposal). Furthermore, the Medical Ethics Committee Zuyderland & Zuyd (METC-Z) reviewed the research regarding the Medical Research Involving Human Subject Acts (MRIHSA, WMO in Dutch) and concluded that the rules of the MRIHSA do not apply to this research. A summary of this decision has been attached (Appendix 3 of the original proposal).

Appendix A: Informed consent participants;
Appendix B: Information letter participants

Appendix A – Informed consent (Dutch)

Met het ondertekenen van dit Informed Consent verklaar ik het volgende:

- Ik heb de informatie voor de deelnemer gelezen. Ik kon aanvullende vragen stellen. Mijn vragen zijn genoeg beantwoord. Ik had genoeg tijd om te beslissen of ik meedoe;
- Ik weet dat meedoen helemaal vrijwillig is. Ik ben me ervan bewust dat ik op ieder moment kan beslissen om toch niet mee te doen. Daarvoor hoef ik geen reden te geven;
- Ik weet dat sommige mensen mijn gegevens kunnen zien. Die mensen staan vermeld in de informatie(brief). Zelf heb ik het recht om de wijze waarop mijn gegevens zijn opgeslagen in te zien;
- Ik weet dat ik niet hoef te reageren op vragen of stellingen als ik dat niet wil;
- Ik weet dat door mij gedane uitspraken geen invloed hebben op mijn volgende deelnames aan onderwijsprogramma Mens Achter de Patiënt;
- Ik geef toestemming om mijn gegevens te gebruiken, voor de doelen die in de informatie(brief) staan. Mocht er aanleiding zijn om de gegevens te gebruiken voor een ander onderzoeksdoel dan zal opnieuw toestemming aan mij worden gevraagd;
- Ik geef toestemming om gegevens nog 10 jaar na afloop van dit onderzoek te bewaren voor nadere analyse in het kader van dit onderzoek (indien van toepassing);
- Ik ga ermee akkoord dat alles wat besproken wordt tijdens de focusgroepen vertrouwelijk is en ik zal deze informatie niet buiten de focusgroep om bespreken met anderen;
- Ik heb een kopie van dit Informed Consent ontvangen.

Voornaam + Achternaam:_____

Datum: ____ - ____ - 2019

Handtekening:

Ik verklaar hierbij dat ik deze deelnemer voldoende heb geïnformeerd over het genoemde onderzoek.
Als er tijdens het onderzoek informatie bekend wordt die de toestemming van de deelnemer zou kunnen beïnvloeden, dan breng ik hem/haar daarvan tijdig op de hoogte op een wijze waardoor ik er zeker van ben dat de informatie de deelnemer bereikt heeft.

Voornaam + Achternaam:_____

Datum: ____ - ____ - 2019

Handtekening:

Appendix B – Information letter (Dutch)

Inleiding

Naar aanleiding van uw zojuist voltooide deelname aan onderwijsmodule Mens Achter de Patiënt, zouden wij graag u graag willen vragen om uw ervaringen te delen in een focusgroep. Een focusgroep is een kleine groep mensen die onder leiding van een interviewer en moderator antwoorden geeft op vragen en meningen en/of discussiëren over stellingen.

Om inzichtelijk te maken of invoering van de onderwijsmodule Mens Achter de Patiënt (MAP haalbaar is, wordt o.a. de ervaring van mensen in de chronische fase van hun ziekte meegenomen. Hierin wordt gekeken wat de positieve/negatieve ervaringen met de onderwijsmodule waren, wat zij meenemen uit deelname en of ze nogmaals deel willen nemen.

Het onderzoek wordt uitgevoerd door dhr. Sjim Romme (BSc.) en dhr. Matthijs Bosveld (BSc), in samenwerking met Valerie van den Eertwegh (PhD), Jascha de Nooijer (PhD), Jerôme van Dongen (PhD) en Hester Smeets (MSc.).

Doel van het onderzoek

Het doel van het onderzoek is om de haalbaarheid van de implementatie van de onderwijsmodule Mens Achter de Patiënt inzichtelijk te maken voor de curricula van de bacheloropleidingen Gezondheidswetenschappen en Geneeskunde te Maastricht University, de opleidingen Fysiotherapie, Ergotherapie, Creatieve Therapie, Logopedie en Verpleegkunde te Zuyd Hogeschool en de opleidingen verpleegkunde en verzorgende IG op de diverse MBO-instellingen voor alle betrokken partijen.

Procedure

Na de laatste bijeenkomst van de onderwijsmodule wordt u gevraagd of u geïnteresseerd bent om op vrijwillige basis deel te nemen aan een focusgroep. Een focusgroep is een kleine groep mensen die onder leiding van een moderator antwoorden geven op vragen en meningen geven en/of discussiëren over stellingen.

De focusgroep duurt ongeveer 1,5 uur. Er zullen geluidsopnamen van de focusgroepen gemaakt worden, die daarna letterlijk uitgetypt worden. De onderzoeker zal tijdens de focusgroepen ook notities maken van dat wat er gezegd wordt. Op deze manier proberen wij ervoor te zorgen dat datgene wat jij zegt zo nauwkeurig mogelijk wordt vastgelegd. Met deze informatie zal vertrouwelijk worden omgegaan.

Na afloop van de derde bijeenkomst wordt gevraagd wie er geïnteresseerd zijn om deel te nemen aan een focusgroep. Deze geïnteresseerden worden uitgenodigd om 1-2 weken later deel te nemen aan het groepje om te discussiëren op de hierboven beschreven manier, ter verbetering van het onderwijsprogramma.

Verwachtingen

In een focusgroep worden uw ervaringen met de onderwijsmodule uitgevraagd in een groep met circa zes tot acht deelnemers die geleid zal worden door de supervisors van de onderzoekers.

Vertrouwelijkheid
Alle informatie die tijdens de focusgroepen verzameld wordt, is vertrouwelijk. Alleen de onderzoekers, hun leidinggevenden en assistenten hebben toegang tot deze informatie. Al het onderzoeksmateriaal krijgt een code en wordt apart bewaard, gescheiden van uw naam of andere directe informatie over u. Alle verwijzingen naar uw identiteit zullen worden verwijderd voordat de informatie wordt gepubliceerd. Het is mogelijk dat (een) specifieke opmerking(en) van u wordt gebruikt om een algemeen thema te illustreren. Uw echte naam zal nooit aan deze opmerkingen verbonden worden. De geluidsopnamen zullen na 10 jaar worden vernietigd.

Risico's
U zult geen fysiek of psychologisch risico lopen tijdens dit onderzoek. Ook is geenszins de bedoeling dat u zich oncomfortabel voelt tijdens het onderzoek. Mocht dit onverhoopt toch het geval zijn, is er vanuit het onderwijsprogramma een vertrouwenspersoon beschikbaar. Mocht er naar aanleiding van de ervaringen opgedaan in het onderwijsprogramma of in de focusgroep nog verdere vragen zijn, dan kunt contact opnemen met de vertrouwenspersoon gekoppeld aan dit onderzoek. Dit is Hélène van den Besselaar en zij is te bereiken via vertrouwenspersoon@mensachterdepatient.nl. Zij zal verder contact met u opnemen voor vragen. Voor vragen over het onderzoek kunt u de onderzoekers contacteren. De benodigde contactgegevens staat onderaan deze brief.

Voor- en nadelen
Nadelen van deelname aan het onderzoek is de tijd deelname aan de focusgroepen kost. De focusgroepen zijn voor zover bekend niet confronterend of emotioneel belastend. U heeft zelf geen voordeel van deelname aan dit onderzoek: voor het onderwijs en de zorg in de toekomst kan het onderzoek wel nuttige gegevens opleveren.

Consequenties van niet deelnemen/voortijdig stoppen met deelname
U beslist zelf of u meedoet aan het onderzoek. Als u besluit niet mee te doen, hoeft u verder niets te doen en hoeft u hiervoor geen reden te geven. Als u wel meedoet, kunt u zich altijd bedenken en toch stoppen, ook tijdens het onderzoek.

Tijdens een focusgroep, is het niet mogelijk om de gegevens die reeds verzameld zijn achteraf nog te wissen. Terugtrekken van deelname zal betekenen dat de tot dan toe verzamelde gegevens wel worden meegenomen in het onderzoek.

Gegevensgebruik
De onderzoeksgegevens worden tien jaar bewaard. Daarvoor geeft u toestemming als u meedoet aan dit onderzoek. Als u dat niet wilt, kunt u niet meedoen. 10 jaar na afronding van de dataverzameling zullen wij de gegevens vernietigen. Indien er aanleiding is om op basis van dezelfde onderzoeksresultaten ander onderzoek te doen dan zal u opnieuw vooraf toestemming worden gevraagd. Er worden geen persoonsgegevens van deelnemers verzameld. De gegevens die we opslaan en bewaren zijn op geen enkele manier naar u herleidbaar.

Vergoeding
Er zullen tijdens de focusgroep versnaperingen aanwezig zijn. Verder ontvangt u geen vergoeding voor deelname aan dit onderzoek.
Vragen
Voor verdere vragen over het onderzoek, neem contact op met:
Matthijs Bosveld, tel 06 XX XX XX XX of email: XXX@maastrichtuniversity.nl

Voor dit onderzoek is goedkeuring verkregen van de Ethische toetsingscommissie van de Nederlandse Vereniging voor Medisch Onderwijs (NVMO).

Met hartelijke groet,
Sjim Romme (onderzoeker)
Matthijs Bosveld (onderzoeker)

Valerie van den Eertwegh (supervisor)
Jascha de Nooijer (supervisor)
Hesther Smeets (supervisor)
Jerôme van Dongen (supervisor)

Appendix 5 – Overview initial collected outcomes

In this attachment you can find the transcribed post-its used in the focus group meetings to construct the topic list, as described in the method section. The outcomes are displayed in a random order, separately for patients (Table 1) and partners (Table 2).

Table 1. Initial collected outcomes of participation in education in two focus groups with patients

Positive outcomes	**Negative outcomes**
Recognisance	I have to defend myself because through my handicap, I do not belong anywhere
To meet people that also have problems	Outside world only looks at visible handicaps
Inspiration from the stories from others. How do they cope with difficulties?	Little insight in the importance of empathy by (future) professionals
Genuine interest from students	Tiring
Appreciation	At one occasion: uninterested students who wanted to go home quickly
Contributing to education	Negative attitude of students; irritation
Supporting students through my practical experiences	Sometimes a feeling of 'us'/'them' in relation to professional and patients
Students always take something from what I tell, something I heard in the post-discussion.	Confronting for the patient
Coping through talking	Little to no attention for empathy in education
The PAP-module makes relation between patients and professionals more humane	The first and third meeting are static, which does not invite to active participation
Nice to do	Be aware of too much negativity
The PAP-module brings empathy in education	Participants are not always present
Exchanging experiences	Select good professionals
Exceptions [referring to people] have a lot of insight!	I have no clue how other patients execute their story, although there is a wrap up in the third meeting
Nice contacts	Different level of participants
Being able to share experiences from two sides	Different level of teachers
The initiation of this programme	Too quickly after disease trajectory
Carrying out 'positive health'	None

Table 1. Initial collected outcomes of participation in education in two focus groups with patients (cont.)

Being meaningful through the sharing of pure, vulnerable stories with the aim to humanize health care	Nothing
There are a lot of people that are way worse off compared to my situation	Differences in practical experiences of students
The ability to contribute to better, more empathic care	
Aiding in new insights	
Empathy	
Meaningfulness	
Meaningful spending of my leisure time: I can be meaningful	
Questions for students	
Using my participation [in education] in my contact with professionals	
I have grown to speak up more towards professionals, but also in general	
Returning to education, for me feels like going back to work	
Mental energy	
Nice having the different levels together	

Table 2. Initial collected outcomes of participation in education in on focus group with partners

Positive outcomes	**Negative outcomes**
Different contacts	She does not get to benefit from the effect herself
Being heard	Mixed groups
She feels heard, more than in hospital or GP-visits	
Recognition	
Appreciation	
Sharing experiences	
It is nice to convert negative experiences into something positive: convey the message to young people in education	
Positive contribution to the development of professionals in health care	
Equivalence of doctor and patient	
Meaningful activity	
Having a goal: positive feeling when groups are approaching	
Strength	
Positivity	
Energy	
Enthusiasm: comes home with a lot of stories	

Appendix 6 – Quantitative survey

Start of Block: Informed Consent

Hartelijk dank voor uw bereidheid om bij te dragen aan het onderzoek naar de uitkomsten voor patiënten en hun naasten na actieve deelname in onderwijs. In de bijlage van de begeleidende mail is een informatiebrief bijgevoegd waarin onder andere het doel van het onderzoek, anonimiteit en datagebruik uitgebreider toegelicht worden. Ook kunt u de informatiebrief hier downloaden. Het wordt aangeraden om deze brief voor deelname aan deze vragenlijst door te nemen en indien nodig vragen te stellen aan Matthijs Bosveld. Dit kan via het volgende e-mailadres: mh.bosveld@student.maastrichtuniversity.nl

Deze vragenlijst kan het best ingevuld worden op een laptop of computer. Het invullen van de vragenlijst zal ongeveer 10-20 minuten duren. Voor deelname aan het onderzoek vragen we u onderstaande toestemmingsverklaring te lezen. Als u het hier mee eens bent, kunt u hiermee akkoord gaan. Mocht u voor akkoord nog aanvullende vragen willen stellen, kunt u deze stellen via bovenstaand e-mailadres. Door hiermee akkoord te gaan, verklaart u het volgende:

- Ik heb de informatie voor de deelnemer gelezen. Ik kon aanvullende vragen stellen. Mijn vragen zijn voldoende beantwoord. Ik had genoeg tijd om te beslissen of ik meedoe;
- Ik geef toestemming voor het anoniem verzamelen, bewaren en gebruiken van mijn gegevens voor de beantwoording van de onderzoeksvraag in dit onderzoek, zoals beschreven in de informatiebrief;
- Ik weet dat meedoen helemaal vrijwillig is. Ik ben me ervan bewust dat ik op ieder moment kan beslissen om toch niet (meer) mee te doen. Daarvoor hoef ik geen reden te geven. Ik weet dat reeds verzamelde gegevens tot op dat punt zullen worden verwijderd;
- Ik weet dat sommige mensen mijn gegevens kunnen zien ter controle van de wetenschappelijke integriteit van dit onderzoek. Die mensen staan vermeld in de informatie(brief). Zelf heb ik het recht om de wijze waarop mijn gegevens zijn opgeslagen in te zien;
- Ik weet dat door mij gegeven antwoorden geen invloed hebben op mijn volgende deelnames aan Mens Achter de Patiënt, of die van mijn naaste;
- Ik geef toestemming om mijn gegevens te gebruiken, voor de doelen die in de informatiebrief staan. Mocht er aanleiding zijn om de gegevens te gebruiken voor een ander onderzoeksdoel dan zal opnieuw toestemming aan mij worden gevraagd;
- Ik geef toestemming om gegevens nog 10 jaar na afloop van dit onderzoek te bewaren voor nadere analyse in het kader van dit onderzoek (indien van toepassing);
- Ik wil meedoen aan dit onderzoek en weet dat mijn gegevens geheel anoniem verwerkt worden;
- Ik heb een digitaal kopie van deze toestemmingsverklaring ontvangen, deze kan ik vinden in de bijlage van de mail.

○ Ja, ik wil deelnemen aan dit onderzoek en geef toestemming. Begin de vragenlijst (1)

○ Nee, ik wil NIET deelnemen aan dit onderzoek en geef GEEN toestemming (2)

Skip To: End of Survey If Welkom! Hartelijk dank voor uw bereidheid om bij te dragen aan het onderzoek naar de uitkomst... = Ik stem hier niet mee in, ik wens niet deel te nemen

Start of Block: Rol

Ik vul deze vragenlijst in, in mijn rol als:

- ○ Patiënt (directe deelnemer aan het onderwijsprogramma) (1)
- ○ Naaste (partner, mantelzorger, familielid of vriend(in) van de directe deelnemer) (2)

End of Block: Rol

Start of Block: Demografische gegevens

Geslacht:

▼ Man (1) ... Anders (3)

Leeftijd: _____

Het door mij hoogst voltooide opleidingsniveau is:

▼ Geen opleiding (1) ... Universitair gespecialiseerd (doctoraal/PhD) (8)

Display This Question:

If Ik vul deze vragenlijst in, in mijn rol als: = Patiënt (directe deelnemer aan het onderwijsprogramma)

Mijn voornaamste ziektebeeld is: _____

Display This Question:

If Ik vul deze vragenlijst in, in mijn rol als: = Patiënt (directe deelnemer aan het onderwijsprogramma)

Het aantal keren dat ik deelgenomen heb aan Mens Achter de Patiënt, is: _____

Display This Question:

If Ik vul deze vragenlijst in, in mijn rol als: = Patiënt (directe deelnemer aan het onderwijsprogramma)

Momenteel ben ik ergens werkzaam waarvoor ik loon ontvang

▼ Ja (1) ... Nee (2)

Display This Question:

If Ik vul deze vragenlijst in, in mijn rol als: = Patiënt (directe deelnemer aan het onderwijsprogramma)

And Momenteel ben ik ergens werkzaam waarvoor ik loon ontvang = Ja

Zo ja, hoeveel uur per week? _____

Display This Question:

If Ik vul deze vragenlijst in, in mijn rol als: = Patiënt (directe deelnemer aan het onderwijsprogramma)

Ik ben momenteel **actief** onder behandeling van zorgprofessionals

▼ Ja (8) ... Nee (9)

Display This Question:

If Ik ben momenteel actief onder behandeling van zorgprofessionals = Ja

And Ik vul deze vragenlijst in, in mijn rol als: = Patiënt (directe deelnemer aan het onderwijsprogramma)

Beschrijf hieronder beknopt en puntsgewijs hoe uw contact met zorgprofessionals eruit ziet.
Bijvoorbeeld: 2x per maand fysiotherapeut, 1x per maand ergotherapeut en 1x per half jaar controle medisch specialist

_____

_____

_____

_____

_____

Display This Question:

If Ik vul deze vragenlijst in, in mijn rol als: = Naaste (partner, mantelzorger, familielid of vriend(in) van de directe deelnemer)

Mijn relatie tot de directe deelnemer (lees: 'patiënt') aan de onderwijsmodule is:_____

End of Block: Demografische gegevens

Start of Block: Stellingen m.b.t. naasten

Display This Question:

If Ik vul deze vragenlijst in, in mijn rol als: = Naaste (partner, mantelzorger, familielid of vriend(in) van de directe deelnemer)

We vragen uw volledige aandacht bij het invullen van de antwoorden van deze vragenlijst, omdat de volgorde van de antwoordmogelijkheden onregelmatig verandert.

U neemt deel aan deze vragenlijst in uw rol als 'Naaste'. Allereerst volgen een drietal stellingen die betrekking hebben op uw eigen situatie. Beoordeel de volgende stellingen in hoeverre deze **op uzelf van toepassing zijn**.

Display This Question:

If Ik vul deze vragenlijst in, in mijn rol als: = Naaste (partner, mantelzorger, familielid of vriend(in) van de directe deelnemer)

Deelname van mijn naaste aan Mens Achter de Patiënt zorgt ervoor dat ik mij **erkend voel in mijn rol als naaste**

- Helemaal oneens (1)
- Oneens (2)
- Neutraal (3)
- Eens (4)
- Helemaal eens (5)

Display This Question:

If Ik vul deze vragenlijst in, in mijn rol als: = Naaste (partner, mantelzorger, familielid of vriend(in) van de directe deelnemer)

Deelname van mijn naaste aan Mens Achter de Patiënt zorgt ervoor dat ik **positieve energie** ervaar

- Helemaal oneens (1)
- Oneens (2)
- Neutraal (3)
- Eens (4)
- Helemaal eens (5)

Display This Question:

If Ik vul deze vragenlijst in, in mijn rol als: = Naaste (partner, mantelzorger, familielid of vriend(in) van de directe deelnemer)

Deelname van mijn naaste aan Mens Achter de Patiënt zorgt voor een **enthousiast** gevoel bij mijzelf

- Helemaal eens (1)
- Eens (2)
- Neutraal (3)
- Oneens (4)
- Helemaal oneens (5)

End of Block: Stellingen m.b.t. naasten

Start of Block: Overgang naasten

Display This Question:

If Ik vul deze vragenlijst in, in mijn rol als: = Naaste (partner, mantelzorger, familielid of vriend(in) van de directe deelnemer)

Hartelijk dank voor het invullen van de stellingen die betrekking op uzelf hebben.

Hierna volgen een aantal stellingen waarin we u vragen in hoeverre u denkt dat deze **op de directe deelnemer van het onderwijsprogramma (lees: 'patiënt') van toepassing zijn,** dus **niet** op uzelf.

End of Block: Overgang naasten

Start of Block: Overgang patiënten

Display This Question:

If Ik vul deze vragenlijst in, in mijn rol als: = Patiënt (directe deelnemer aan het onderwijsprogramma)

Hierna volgen een aantal stellingen met betrekking tot de uitkomsten van actieve deelname aan onderwijs. Beoordeel de volgende stellingen in hoeverre deze op uzelf van toepassing zijn.

We vragen uw volledige aandacht bij het invullen van de antwoorden van deze vragenlijst, omdat de volgorde van de antwoordmogelijkheden onregelmatig verandert.

End of Block: Overgang patiënten

Start of Block: Dataverzameling deel 1

Q1a Deelname aan Mens Achter de Patiënt zorgt dat ik na deelname **een verminderd (lichamelijk) energieniveau** ervaar

- ○ Helemaal mee eens (1)
- ○ Eens (2)
- ○ Neutraal (3)
- ○ Oneens (4)
- ○ Helemaal mee oneens (5)

Q2b Deelname aan Mens Achter de Patiënt zorgt dat ik **positieve gevoelens** ervaar

- ○ Helemaal mee oneens (1)
- ○ Oneens (2)
- ○ Neutraal (3)
- ○ Eens (4)
- ○ Helemaal mee eens (5)

Q3b Deelname aan Mens Achter de Patiënt zorgt dat ik **negatieve gevoelens** ervaar

- ○ Helemaal mee oneens (1)
- ○ Oneens (2)
- ○ Neutraal (3)
- ○ Eens (4)
- ○ Helemaal mee eens (5)

Q4a Deelname aan Mens Achter de Patiënt zorgt ervoor dat ik een gevoel van **waardigheid** ervaar

- ○ Helemaal mee eens (1)
- ○ Eens (2)
- ○ Neutraal (3)
- ○ Oneens (4)
- ○ Helemaal mee oneens (5)

Q5a Deelname aan Mens Achter de Patiënt zorgt ervoor dat ik **mij gehoord voel**

- ○ Helemaal mee eens (1)
- ○ Eens (2)
- ○ Neutraal (3)
- ○ Oneens (4)
- ○ Helemaal mee oneens (5)

Q6b Deelname aan Mens Achter de Patiënt zorgt ervoor dat ik mijn leven **betekenisvol** ervaar

- Helemaal mee oneens (1)
- Oneens (2)
- Neutraal (3)
- Eens (4)
- Helemaal mee eens (5)

End of Block: Dataverzameling deel 1

Start of Block: Dataverzameling deel 2

Q7a Deelname aan Mens Achter de Patiënt zorgt ervoor dat ik **(weer) een doel heb in het leven**

- Helemaal mee eens (1)
- Eens (2)
- Neutraal (3)
- Oneens (4)
- Helemaal mee oneens (5)

Q8b Deelname aan Mens Achter de Patiënt zorgt ervoor dat ik in **contact kom met andere patiënten**

- Helemaal mee oneens (1)
- Oneens (2)
- Neutraal (3)
- Eens (4)
- Helemaal mee eens (5)

Q9b Deelname aan Mens Achter de Patiënt zorgt ervoor dat ik in **contact blijf met studenten**

- ○ Helemaal mee oneens (1)
- ○ Oneens (2)
- ○ Neutraal (3)
- ○ Eens (4)
- ○ Helemaal mee eens (5)

Q10a Deelname aan Mens Achter de Patiënt zorgt ervoor dat ik **inzicht krijg in de mogelijkheden en beperkingen van zorgprofessionals**

- ○ Helemaal mee eens (1)
- ○ Eens (2)
- ○ Neutraal (3)
- ○ Oneens (4)
- ○ Helemaal mee oneens (5)

Q11a Deelname aan Mens Achter de Patiënt zorgt ervoor dat ik **me soms zorgen maak over hoe studenten mijn verhaal opschrijven**

- ○ Helemaal mee eens (1)
- ○ Eens (2)
- ○ Neutraal (3)
- ○ Oneens (4)
- ○ Helemaal mee oneens (5)

Q12a Deelname aan Mens Achter de Patiënt zorgt ervoor dat ik **overzichtelijk kan vertellen over mijn ziektegeschiedenis**

- ○ Helemaal mee eens (1)
- ○ Eens (2)
- ○ Neutraal (3)
- ○ Oneens (4)
- ○ Helemaal mee oneens (5)

End of Block: Dataverzameling deel 2

Start of Block: Dataverzameling deel 3

Q13a Deelname aan Mens Achter de Patiënt voelde **verplicht** omdat ik doorverwezen werd door mijn behandelaar

- Helemaal mee eens (1)
- Eens (2)
- Neutraal (3)
- Oneens (4)
- Helemaal mee oneens (5)
- Niet van toepassing (6)

Q14b Deelname aan Mens Achter de Patiënt zorgt ervoor dat ik **positiviteit** ervaar

- Helemaal mee oneens (1)
- Oneens (2)
- Neutraal (3)
- Eens (4)
- Helemaal mee eens (5)

Q15b Deelname aan Mens Achter de Patiënt zorgt voor **herkenning**

- Helemaal mee oneens (1)
- Oneens (2)
- Neutraal (3)
- Eens (4)
- Helemaal mee eens (5)

Q16a Deelname aan Mens Achter de Patiënt zorgt ervoor dat ik me **erkend voel**

- Helemaal mee eens (1)
- Eens (2)
- Neutraal (3)
- Oneens (4)
- Helemaal mee oneens (5)

Q17a Deelname aan Mens Achter de Patiënt zorgt ervoor dat ik **kracht** ervaar

- Helemaal mee eens (1)
- Eens (2)
- Neutraal (3)
- Oneens (4)
- Helemaal mee oneens (5)

End of Block: Dataverzameling deel 3

Start of Block: Herhaling naasten

Display This Question:

If Ik vul deze vragenlijst in, in mijn rol als: = Naaste (partner, mantelzorger, familielid of vriend(in) van de directe deelnemer)

T4
Ter herinnering:

Hierna volgen een aantal stellingen waarin we u vragen in hoeverre u denkt dat deze **op de directe deelnemer van het onderwijsprogramma (lees: 'patiënt') van toepassing zijn,** dus **niet** op uzelf.

End of Block: Herhaling naasten

Start of Block: Dataverzameling deel 4

Q18a Deelname aan Mens Achter de Patiënt zorgt ervoor dat ik me **medeverantwoordelijk voel voor de ontwikkeling en uitvoer van de onderwijsmodule**

- ◯ Helemaal mee eens (1)
- ◯ Eens (2)
- ◯ Neutraal (3)
- ◯ Oneens (4)
- ◯ Helemaal mee oneens (5)

Q19b Deelname aan Mens Achter de Patiënt geeft mij het **gevoel bij te dragen aan de volgende generatie zorgprofessionals**

- ◯ Helemaal mee oneens (1)
- ◯ Oneens (2)
- ◯ Neutraal (3)
- ◯ Eens (4)
- ◯ Helemaal mee eens (5)

Q20a Deelname aan Mens Achter de Patiënt zorgt ervoor dat ik mij **enthousiast** voel

- ◯ Helemaal mee eens (1)
- ◯ Eens (2)
- ◯ Neutraal (3)
- ◯ Oneens (4)
- ◯ Helemaal mee oneens (5)

Q21b Deelname aan Mens Achter de Patiënt zorgt ervoor dat ik mijn **ziekte(last) kan relativeren**

- ◯ Helemaal mee oneens (1)
- ◯ Oneens (2)
- ◯ Neutraal (3)
- ◯ Eens (4)
- ◯ Helemaal mee eens (5)

Q22b Deelname aan Mens Achter de Patiënt zorgt ervoor dat ik **me soms zorgen maak over hoe studenten mij beoordelen op basis van mijn verhaal**

- ○ Helemaal mee oneens (1)
- ○ Oneens (2)
- ○ Neutraal (3)
- ○ Eens (4)
- ○ Helemaal mee eens (5)

End of Block: Dataverzameling deel 4

Start of Block: Dataverzameling deel 5

Q23a Deelname aan Mens Achter de Patiënt zorgt ervoor dat mijn **kennis over het verloop van mijn ziektegeschiedenis** toeneemt

- ○ Helemaal mee eens (1)
- ○ Eens (2)
- ○ Neutraal (3)
- ○ Oneens (4)
- ○ Helemaal mee oneens (5)

Q24b Deelname aan Mens Achter de Patiënt zorgt voor een **altruïstisch gevoel**
al·tru·ïs·me: onbaatzuchtigheid (tegenstelling: egoïsme)

- ○ Helemaal mee oneens (1)
- ○ Oneens (2)
- ○ Neutraal (3)
- ○ Eens (4)
- ○ Helemaal mee eens (5)

Q25b Deelname aan Mens Achter de Patiënt zorgt ervoor dat ik **bekendheid kan geven aan mijn ziektebeeld**

- Helemaal mee oneens (1)
- Oneens (2)
- Neutraal (3)
- Eens (4)
- Helemaal mee eens (5)

Q26b Deelname aan Mens Achter de Patiënt zorgt ervoor dat ik **accepteer wat mij is overkomen**

- Helemaal mee oneens (1)
- Oneens (2)
- Neutraal (3)
- Eens (4)
- Helemaal mee eens (5)

Q27b Deelname aan Mens Achter de Patiënt zorgt ervoor dat ik **een stuk leven terug krijg**

- Helemaal mee oneens (1)
- Oneens (2)
- Neutraal (3)
- Eens (4)
- Helemaal mee eens (5)

End of Block: Dataverzameling deel 5

Start of Block: Dataverzameling deel 6

Display This Question:

If Ik vul deze vragenlijst in, in mijn rol als: = Patiënt (directe deelnemer aan het onderwijsprogramma)

Q28a Deelname aan Mens Achter de Patiënt zorgt ervoor dat ik mijn naaste **erken bij toekomstig zorgprofessionals**

- Helemaal mee eens (1)
- Eens (2)
- Neutraal (3)
- Oneens (4)
- Helemaal mee oneens (5)
- Niet van toepassing (6)

Display This Question:

If Ik vul deze vragenlijst in, in mijn rol als: = Patiënt (directe deelnemer aan het onderwijsprogramma)

Q29b Deelname aan Mens Achter de Patiënt zorgt voor **positieve energie van mijn naaste**

- Helemaal mee oneens (1)
- Oneens (2)
- Neutraal (3)
- Eens (4)
- Helemaal mee eens (5)
- Niet van toepassing (6)

Display This Question:

If Ik vul deze vragenlijst in, in mijn rol als: = Patiënt (directe deelnemer aan het onderwijsprogramma)

Q30a Deelname aan Mens Achter de Patiënt zorgt voor **enthousiasme bij mijn naaste**

- Helemaal mee eens (1)
- Eens (2)
- Neutraal (3)
- Oneens (4)
- Helemaal mee oneens (5)
- Niet van toepassing (6)

Display This Question:

If Ik ben momenteel actief onder behandeling van zorgprofessionals = Ja

Or Ik vul deze vragenlijst in, in mijn rol als: = Naaste (partner, mantelzorger, familielid of vriend(in) van de directe deelnemer)

Q31a Deelname aan Mens Achter de Patiënt zorgt ervoor dat ik **mondiger ben in het contact met mijn huidige zorgprofessionals**

- Helemaal mee eens (1)
- Eens (2)
- Neutraal (3)
- Oneens (4)
- Helemaal mee oneens (5)

Display This Question:

If Ik ben momenteel actief onder behandeling van zorgprofessionals = Ja

Or Ik vul deze vragenlijst in, in mijn rol als: = Naaste (partner, mantelzorger, familielid of vriend(in) van de directe deelnemer)

Q32a Deelname aan Mens Achter de Patiënt zorgt ervoor dat ik **gelijkwaardigheid ervaar in het contact met mijn huidige zorgprofessionals**

- Helemaal mee eens (1)
- Eens (2)
- Neutraal (3)
- Oneens (4)
- Helemaal mee oneens (5)

End of Block: Dataverzameling deel 6

Start of Block: Open vraag

In deze vragenlijst zijn mogelijke uitkomsten van actieve deelname aan onderwijs, in de vorm van Mens Achter de Patiënt, genoemd. Hieronder vindt u een overzicht van de genoemde uitkomsten.

Missen er nog uitkomsten in onderstaand overzicht vanuit uw ervaring? Zo ja, kunt u deze hieronder beschrijven. Zo nee, kunt u onderstaand tekstvak leeg laten.

1. Verminderde (lichamelijke) energieniveaus na deelname
2. Het ervaren van positieve gevoelens

3. Het ervaren van negatieve gevoelens
4. Een gevoel van (gelijk)waardigheid en het gevoel gehoord te worden
5. Acceptatie
6. (Weer) een doel hebben in het leven
7. Betekenisvol leven
8. Positiviteit, enthousiasme en kracht
9. Relativeringsvermogen wat betreft mijn ziekte(last)
10. Gevoel een stuk leven terug te krijgen
11. Erkenning voor mantelzorgers
12. Positieve energie en enthousiasme mantelzorgers
13. Gevoel van medeverantwoordelijkheid voor de ontwikkeling en uitvoer van onderwijs
14. Herkenning en erkenning
15. Contact met andere patiënten en studenten
16. Gevoel bij te dragen aan de volgende generatie zorgprofessionals
17. Inzicht in de (on)mogelijkheden van (toekomstig) zorgprofessionals
18. Mondiger zijn in het contact met huidige zorgprofessionals
19. Toegenomen kennis over ziektegeschiedenis
20. Overzichtelijk kunnen vertellen over ziektegeschiedenis
21. Gelijkwaardigheid in contact met huidige zorgprofessionals
22. Verplicht gevoel om deel te nemen
23. Altruïstisch gevoel van bijdragen (al·tru·ïs·me: onbaatzuchtigheid (tegenstelling: egoïsme))
24. Bekendheid geven aan ziekte
25. Angst om beoordeeld te worden door studenten op basis van je verhaal
26. Angst over hoe studenten het verhaal opschrijven voor hun opdracht

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End of Block: Open vraag