

INTERNSHIP REPORT

Using Patient Journey Modelling within formal care guideline development

C. R. Hemmes

STUDENT NUMBER

2616898

COMMISSIONING PARTY

Pallas-P95

ECTS + COURSE CODE SPECIALIZATION

30 ECT – AM_471119

DATE

June 2023

VU SUPERVISOR

Dr. R. Kawous



Colophon

Title: Exploring patient journey modelling within formal care guideline development, an innovative study

Key words: Activity, Benefits, Challenges, Evidence-based, Equal participation, Formal Care, Guideline developers, Guideline Development, Improvement, Indicators, Input, Learning & Changes, Patient Journey Modelling, Theory of Change

Word count: 11.996

Author: C. R. Hemmes

Commissioning organization: Pallas-P95

On-site supervisor: Msc. J. Eeuwijk

VU supervisor: Dr. R. Kawous

June – 2023

Course code: AM_471119

This internship report was established in cooperation with the Athena Science Shop.

Athena Institute

Faculty of Science

VU University Amsterdam

De Boelelaan 1085

1081 HV Amsterdam

The Netherlands



Executive summary

Background

The demand for home care, provided by district nurses and formal care takers, has increased in recent years, as a result of the aging population, people living at home longer, and shorter hospital stays. Home care is provided by formal carers. They rely on Evidence Based (EB) guidelines to employ high quality care. However, there is a discrepancy between guidelines and their implementation into practice.

This is a result of how EB formal care guidelines are developed. EB guidelines must be developed on the basis of scientific evidence. However, there is a scarcity of literature on formal care practices making the development of EB formal care guidelines hard. Furthermore, the language and format of the guidelines is not sufficiently linked to the lower educated levels of formal carers. Lastly, during the development of formal care guidelines multi-disciplinary working groups are established, consisting of guideline developers with various backgrounds. Within these working groups hierarchical structures can make the formal carer feel hesitant to speak openly about their work in practice.

Pallas-P95 develops formal care guidelines, on behalf of V&VN, and faces these challenges, as well. They necessitate a methodology to assist them in the development of EB formal care guidelines. The method of Patient Journey Modelling (PJM) could improve guideline development by combining the expertise of health care professionals with the patients' needs and experiences.

This research aims to gain insights into the experience of using the PJM in the development of EB formal care guidelines by analyzing the perception of the guideline developers within the projects of Pallas-P95. This study will answer the research question: *How do guideline developers in the Netherlands perceive the potential benefits and challenges of using patient journey modelling in development of evidence-based formal care guidelines?*

To answer the research question a quality improvement framework was established. By combining features of the Theory of Change (ToC) and the Monitoring and Evaluation (M&E) model the Theory of Change Improvement Cycle (ToCIC) originated. The different concepts included in the ToCIC are, Inputs, Activity, Learning & Changes (L&C), and Impact. From every concept indicators are derived that illustrate the potential benefits and challenges of using PJM in EB guideline development.

From the ToCIC the following two sub-questions were formed; *What are indicators that suggest the potential benefits of using PJM within EB formal care guideline development?.* And;

What are the indicators that suggest the potential challenges of using PJM in EB formal care guideline development?.

Methods

A qualitative study design was used to answer the questions. The ToCIC was employed as a framework for the analysis of the data. Individual interviews and a focus group discussion (FGD) were used for data collection. The individual interviews and FGD were recorded and transcribed. The primary topics covered in the interviews were based on the concepts of the ToCIC (inputs, activity, L&C and impact). During the FGD a persona was created and tested to give the guideline developers an initial idea of how PJM can be used in the development of a guideline. Thematic analysis were employed to analyze the data. By first using an deductive coding approach followed by using an inductive coding approach.

Results

A total of sixteen participants were included in the study. The findings showed that the most important potential benefits of using PJM in EB guideline development included, obtaining a clear understanding of the various stakeholders' perspectives as a result of the various preparatory steps in creating a PJM, such as individual interviews and observation studies, for example. In addition, because PJM forces all guideline developers to reason from the standpoint of the formal carer and patient, it has the potential benefit to promote equal participation among all guideline developers. Another potential benefit is that formal caregivers are able to better articulate their practice. And the final potential benefit derived from the data is the adjusted parlance that results in formal carers better understanding the terminology in the guidelines, which potentially enhance the implementation.

The most important challenges of using PJM in EB formal care guideline development included; participant recruitment, investment of time allocation and budget. PJM is a time consuming method. Findings showed, in addition, that there is no systematic approach for creating a PJM resulting in guideline developers experiencing PJM as a simple method. Because PJM lacks scientific grounding it is not considered an EB method, resulting in a lower value of the guideline which is another potential challenge. The political landscape of guideline development is a challenges because changing this landscape is hard. Lastly some guidelines are already 160 pages long, a challenge of using PJM is that there are a lot of exceptions in treatments of patients, causing the length of the guideline to increase, which is unfavorable.

Discussion

The ToCIC provided clear insights into the different indicators suggesting potential benefits and challenges. The framework assisted in extracting key findings which provide insights into the potential benefits and challenges of using PJM in EB formal care guideline

development. However, improvements to the participant selection and FGD execution should be made, to enable stronger conclusions.

Conclusion

The most important deliverables that arise from the potential benefits and challenges, are; PJM will not fill the gap in scientific literature on formal care practices. PJM is lacking a systematical approach which results in PJM not considered an EB method for guideline development. However, PJM could indeed be beneficial to overcome hierarchical structures and empower equal participation within guideline development. In addition PJM assist guideline developers to write recommendations from the perspective of formal carers making the language and format of guidelines more applicable to the formal care practice.