ORIGINAL RESEARCH

# Exploring Danish clinical nurses' experience with personalised medicine

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## ABSTRACT

Personalised or precision medicine is expected to change healthcare significantly in the future. Growing attention is being devoted internationally as to how this development affects nursing care and demands educational initiatives for nurses. In Denmark, a lack of such educational initiatives seems evident. The aim of this study was to inquire into Danish nurses' understanding of and experience with personalised medicine (PM) in their daily practice. Furthermore, the study comprised a search for courses about personalised medicine/precision medicine that foster educational inspiration. A questionnaire was distributed among Danish nurses. The respondents represented a wide spectrum of specialties. More than half of the respondents (52%) experienced daily or weekly that PM was part of the patient's trajectory. More than a third (36%) encountered situations in which PM impacted patients' treatment daily or weekly. More than four in every ten respondents reported that they collected family history data about diseases at least monthly. About two-thirds (66%) found education in PM to be relevant for nurses, and nearly half of the respondents (47%) indicated that they would find it very or somewhat relevant themselves to receive continuing PM education and training. We found only very few published papers describing educational PM interventions for nurses. In contrast, we found numerous online descriptions of PM courses for nurses. In conclusion, this study indicated that many Danish nurses encounter PM in their daily work. However, their expressed need for further knowledge on this subject cannot be accommodated through the current education offered.

**Key Words:** Personalised medicine, Precision medicine, Nursing education, Nursing care, Questionnaire study

## 1. INTRODUCTION

The need for education in personalised medicine (PM) (also referred to as precision medicine or stratified medicine) was recognised in a European context about a decade ago. At EU level, education and training in the area of PM for professionals delivering healthcare was emphasised as a key element in a briefing paper published in 2017.[1] Attempts to bridge the 'knowledge gap' among health professionals and flesh out a long-term approach to education that may update professionals on current aspects of PM have subsequently been followed up by EU projects, vision papers and reports on PM.[2,3] In Denmark, the rapid development in

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the field is reflected in National Strategy for Personalised Medicine 2017-2020, which was developed by the National Genome Centre and updated in 2021-2022.[4,5] Both versions emphasise as a key action area that "Relevant healthcare professionals must be capable of using genetic information and informing patients and relatives about the contents and meaning of patient treatment". Education and training are important preconditions to achieving this goal. To the best of our knowledge, no attempts have been made to further this agenda in Denmark for bachelor level health professionals such as nurses, dealing with patients daily.

PM is a growing field internationally[3,6] and has gained considerable traction in Danish master level medical education.[7] While attention has been devoted internationally to the influence of PM on the nursing profession,[8–10] Danish nursing education lacks adequate consideration and inclusion of this topic.[11] For example, the Danish national guideline on nursing education fails to mention PM.[12] It may thus be assumed that the bulk of skills and knowledge needed about PM must currently be obtained through postgraduate courses (if available) or work experience. This assumption is supported by a recent small-scale empirical study,[13] inquiring into the extent and type of practical engagement with genetics among 13 nurses working in primary and secondary healthcare in Denmark. In this interview study, several of the Danish nurses described that they had obtained knowledge about genetics and genomics through work experience rather than formal education. Furthermore, most of the nurses expressed an expectation and a wish for further education in genetics and more specifically PM to be better prepared for the future. Some of the nurses described a communication gap – a lack of 'language' – when attempting to communicate with other health professionals about matters relating to PM. Although this study uncovered significant dimensions of practical engagement with genetics among professional nurses relating, e.g., to further education needs, more research is needed to substantiate these findings. Furthermore, it is important to explore whether certified courses and course descriptions are available for this group of health professionals and to which extent cultural or institutional adjustments may be required.

### Aim

The aim of the present study was to delve deeper into the findings of the previous empirical study by conducting a more extensive and nationwide survey to comprehend the understanding and practical involvement of Danish nurses in PM and to explore their perceived need for PM education. On the basis of our initial findings, we searched for relevant courses and topic areas offered both nationally and internationally in PM to uncover the extent and content of existing courses, thereby informing and inspiring the development of future PM courses targeting Danish nurses and other health professionals.

## 2. METHODS

### 2.1 Study design and participants

This study employed an exploratory, cross-sectional, descriptive design based on an online survey. The questionnaire was based on a previously conducted qualitative study[13] and inspired by Newcomb et al.[14] Besides questions collecting demographic and professional information, the survey included closed questions about experiences relating to aspects of Danish nurses' PM practice. The survey was piloted in a group of fellow researchers, improving its conceptual clarity and answer options. The survey was distributed and answered in Danish, and the questions was subsequently translated for this publication (see Tables 1-4).

Data were collected through the online questionnaire platform SurveyXact (https://rambollxact.com/surveyxact) from late January to mid-February 2023. A link to the questionnaire was distributed to a closed Danish Facebook group called "Jeg er sygeplejerske" ("I am a nurse" in Danish language), where membership requires a Danish nurse authorisation number, potentially reaching more than 29,000 group members. This targeted sampling was chosen to control who initially received the invitation to participate in the survey while ensuring access to a large representative sample of Danish nurses. As an inclusion criterion, the invitation letter stated that the survey should be answered only by nurses with patient contact in their current position. Moreover, the invitation letter described the meaning of the term personalised medicine: "Personalised medicine should be understood broadly as a comprehensive term for a development where patients and diseases are increasingly approached individually, and where treatment, rehabilitation, and prevention are "tailored" to the individual's situation and needs. We operate on the assumption that such an individualized approach involves the interplay between biological factors (including genomics) and the environment, as well as lifestyle". This was inspired by the definition adopted by the Danish Health Authority.[5]

### 2.2 Measures

The questionnaire included 18 items. Seven of these were demographic, and seven items explored how often the respondents experienced various aspects of PM in their daily practice, with answer options categorised such as "Daily", "Weekly", "Monthly", "Seldom", "Never", "Not relevant for my practice" and "Don't know". The four final items con-

cerned current knowledge about PM and future needs. At the end of the survey, the respondents had the option to provide free-text comments.

### 2.3 Data analysis

The data were exported from SurveyXact and imported into Microsoft Excel for processing and evaluation. Each question was studied independently, without regard to whether the respondent had answered the remaining questions or not. Means and standard deviations were calculated for integer-based questions such as age. Categorical questions were described using percentages for each answer based on the total number of answers received for the question.

### 2.4 Ethical considerations

The information letter explained that answering the survey in whole or part would be regarded as the participant's informed consent. Participants were ensured confidentiality with respect to any information provided and were informed that their data would be used for research purposes only. The study complied with the Ethical Guidelines for Nursing Research in the Nordic Countries (Northern Nurses Federation, 2003) and the Danish Code of Conduct for Research Integrity (Ministry of higher Education and Science, 2014). Under Danish law, ethical committee approval was not necessary for this study, and the project was therefore registered internally with VIA University College Research Centre for Health and Welfare Technology.

### 2.5 Systematic search for descriptions of courses on personalised medicine

To identify PM courses that could potentially inspire and inform the elaboration of a course for Danish healthcare bachelor students, we first performed systematic searches in PubMed, CINAHL, and Web of Science. Block searches were performed using the following words and phrases: [Personalized medicine OR Personalised medicine OR Individualized medicine OR Individualised medicine OR Precision medicine] AND [Course OR Education OR Curriculum OR diploma] AND [Nurse OR Nurses]. We included papers published as from 2010.

Since only a few peer-reviewed papers addressed our interest (see Results), we also performed a deliberate random search on Google, using the same words and phrases. All searches were finalised in December 2023.

## 3. RESULTS

### 3.1 Questionnaire study

Among the 324 nurses who responded to the questionnaire, only 161 completed all questions. Table 1 shows the respondents' general characteristics. The majority (79%) were registered nurses without a postgraduate degree and with an average of 11.81 years of working experience. In Denmark, the current basic nursing education is a 3.5-year bachelor's degree. The nurses represented a wide spectrum of specialities within Danish healthcare. The most frequently represented categories were medical units and primary healthcare. In the Danish healthcare system, primary healthcare includes home care, local healthcare centres and general practitioners. Secondary healthcare includes public hospitals.

In Table 2, aspects relating to how often the nurse encountered PM in their patient's trajectories are presented. More than half of the nurses, 52%, experienced on a daily or weekly basis that PM was part of their patients' trajectories. Furthermore, 36% encountered situations daily or weekly, in which PM influenced their patients' treatment. Approximately a third of the nurses were rarely or never consciously aware that PM played a role in patient trajectories or treatments. Around half of the nurses stated that they rarely or never experienced situations where PM affected the patient either legally, financially, psychologically, or emotionally.

Regarding the frequency of nurses collecting family history data on diseases, 43% stated that they did this on a regular basis (daily, weekly, or monthly), while 36% reported regularly helping patients and their relatives understand aspects of PM. However, more than 40% of the nurses rarely or never engaged in these practices.

Additionally, 26% of the nurses stated that they were aware that their own attitudes and values may impact their care provision in relation to PM on a daily or weekly basis.

Table 3 presents findings relating to patient information pathways and needs for further PM education and training. If nurses encountered a patient in need of further information about PM concerning their trajectory, more than half knew where to refer the patient or whom to ask. However, 28% expressed uncertainty about what steps to take in such situations. Regarding future nursing care, 66% found that PM education was relevant for nurses, and 47% of the responding nurses answered that it was very or somewhat relevant for them to receive continuing PM education and training. Only 4% of the nurses in our study found that PM was not relevant for future nursing education.

Table 4 presents findings relating to sources of PM knowledge. When asked about the source of their PM knowledge, a large share (49%) expressed that they acquired their knowledge from practical experience, while 39% had obtained knowledge from their basic education. However, 29% claimed to have no PM knowledge.

**Table 1.** Sample characteristics

| Characteristics | Number of respondents | Categories | *N* (%) or M ± SD |
|---|---|---|---|
| Age | 323 | | 40.53 (± 20.13) |
| Highest educational level | 323 | Registered nurse | 256 (79%) |
| | | Specially trained nurse | 48 (15%) |
| | | Master | 19 (6%) |
| | | PhD | 0 (0%) |
| Number of years working as a nurse since completing basic education | 323 | | 11.81 (± 9.74) |
| Place(s) of employment since completing education | 323 | Only one department in primary healthcare | 6% |
| | | Only one department in secondary healthcare | 20% |
| | | Several departments, only in primary healthcare | 8% |
| | | Several departments, only in secondary healthcare | 28% |
| | | Departments in both primary and secondary healthcare | 37% |
| | | Other | 2% |
| Current primary position | 322 | Medical unit | 85 (26) |
| | | Surgical unit | 33 (10) |
| | | Day section/clinic/ambulatory | 28 (9) |
| | | Primary healthcare | 79 (25) |
| | | Private practice | 18 (6) |
| | | Psychiatrics | 14 (4) |
| | | Intensive care unit | 8 (2) |
| | | Emergency room | 18 (6) |
| | | Other | 39 (12) |
| Have continued education within fields relating to personalised medicine (e.g., genetics) | 312 | Yes | 12 (4) |
| | | No | 296 (95) |
| | | Don't know | 4 (1) |

A minority of respondents added free-text comments. Among these, two themes emerged: 1): Being unfamiliar with or insecure about the term "Personalised medicine", 2): Believing that PM relates to prescribing, dosing and administering medication.

### 3.2 Database searches

Our systematic database searches returned 181 results in PubMed, 136 in CINAHL and 169 in Web of Science. Upon closer inspection, only very few of the search results contained descriptions of courses or educational activities for pregraduate or educated nurses: four descriptions were found in PubMed,[15–18] none in CINAHL and three in Web of Science.[17, 19, 20]

The papers identified addressed subjects such as PM in practice and nurses' knowledge about and attitudes towards PM. Several articles suggested that nurses and other healthcare professionals believe that a need exists for PM knowledge among nurses and other healthcare professionals and that it is important to integrate PM education in nursing education.

The search returned four articles describing courses for nurses, although not in detail. The context of the articles was personalised cancer genetics and community-based healthcare,[18] pharmacogenetics in oncology nursing,[17] advanced practice nursing[15] and genetics and genomics in nursing. Furthermore, one of the studies included a list of educational resources suitable for incorporating genetics and genomics in nursing education.[16]

### 3.3 Google search

The Google search returned hits on numerous courses on personalised/personalized medicine or precision medicine. These were typically offered by universities, but also by associations and private companies. The target groups of the courses were, however, typically physicians, qualified and experienced clinicians, or researchers. It is beyond the scope of the present paper to provide a comprehensive overview of the available courses on PM identified. To provide an impression of the variety of courses offered, we present a few of them in Table 5. The six courses included in the table all include a link, allowing readers to easily attain more information about each course – or even to join a PM course.

**Table 2.** Personalised medicine in nursing care

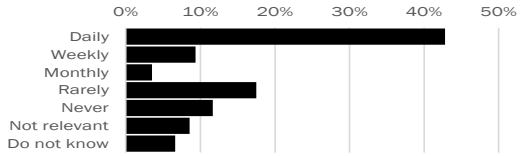
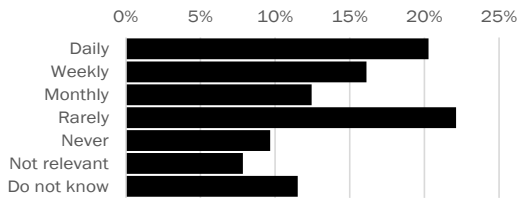
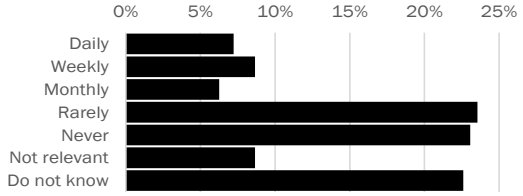
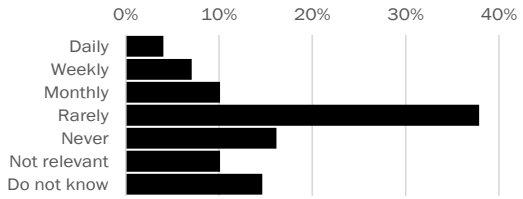
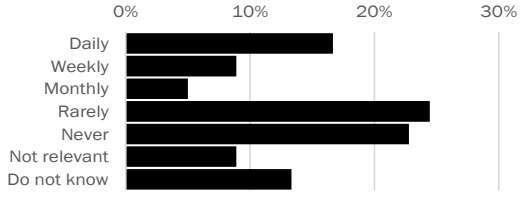
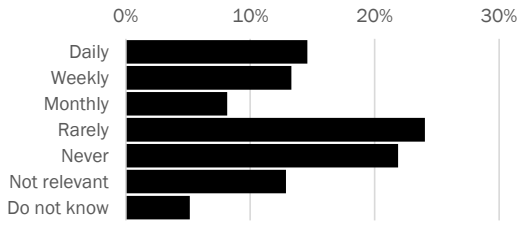
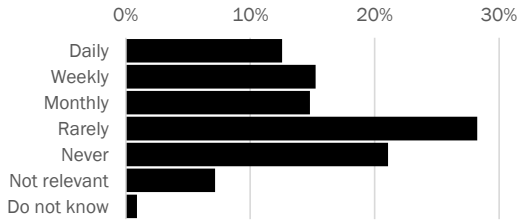
| Question | Number of respondents | Response distribution |
|---|---|---|
| How often are you aware that personal medicine is part of the patient's trajectory? | 257 |  |
| How often do you experience situations in which personalised medicine has an impact on the patient's course of treatment? | 217 |  |
| How often do you experience situations in which personalised medicine may have legal or financial consequences for patients? | 208 |  |
| How often are you aware that patients and relatives may be psychologically and emotionally affected by genetic knowledge? | 198 |  |
| How often are you aware that your own attitudes and values in relation to personalised medicine/genetics may influence the nursing care you provide? | 180 |  |
| How often do you have to help patients and relatives understand aspects of personalised medicine (e.g. the doctor's information about genetic disposition)? | 233 |  |
| How often do you collect data from patients and relatives about family history of illness? | 223 |  |

**Table 3.** Information and further education and training

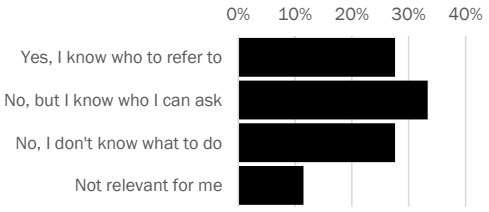
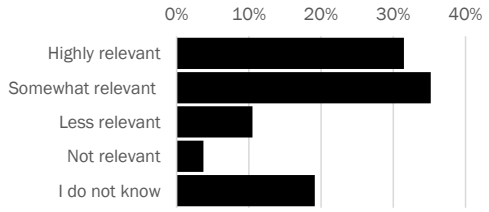
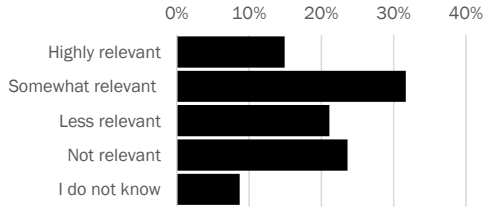
| Question | Number of respondents | Response distribution |
|---|---|---|
| Do you know what to do if you find that a patient may need additional information about personalised medicine/genetics in relation to their trajectory? | 174 |   |
| Do you consider education in personalised medicine to be relevant for the future of nursing? | 162 |   |
| If continued education about personalised medicine were offered, how relevant would it be to you? | 161 |   |

**Table 4.** Sources of knowledge

| From where did you get your knowledge of personalised medicine? (pick one or more answers) | Number of times answer was picked |
|---|---|
| Basic education | 67 |
| Postgraduate and continuing higher education | 19 |
| Practical experience | 83 |
| Peer mentoring | 20 |
| Other | 10 |
| I have no knowledge about personalised medicine | 50 |

*Note.* Number of unique respondents to one or more answers: 170

Some courses seemed very technical, and many courses required participants to have a high entry-level knowledge and understanding of, e.g., molecular biology and genetics, or even specific courses on these subjects.

We found only very few courses explicitly specifying nursing students or nurses as a target audience, and none of the available courses seemed to be well suited for Danish nursing students or nurses, either assessed by their contents or requirements for entry-level knowledge.

## 4. Discussion

The findings revealed a distinct dichotomy in Danish nurses' familiarity with PM in practice. A significant proportion of nurses reported weekly or monthly encounters with PM in their daily practice, whereas a large proportion responded that they only 'rarely or 'never' encountered PM. This variation reflects a complexity within nursing practice, suggesting the potential need for stratification on demographic variables such as educational background, work experience or place(s) of occupation. For instance, in the aforementioned small-scale qualitative study,[13] the interviews indicated that nurses with experience from more than one place of employment or from specific specialties regarded PM as more prevalent in their daily practice than did nurses with experience from only one place of employment. Unfortunately, in the present study, we were unable to make such stratifications due to the limited number of completed questionnaires.

**Table 5.** Courses on personalised medicine

| URL and title | Course contents | Target audience |
|---|---|---|
| https://www.coursera.org/learn/precision-medicine<br>Precision Medicine | Monogenic and complex diseases, cancer, health and prevention, pharmacogenomics and drug development, research. | Bachelor-level life science students, primary care physicians, first-line health care professionals, cancer specialists, public health decision makers, biomedical researchers, drug developers. |
| https://www.manchester.ac.uk/study/masters/courses/list/13018/msc-precision-medicine/course-details/<br>MSc Precision Medicine | Principles of precision and stratified medicine, clinical impact of individual molecular and lifestyle variability, multidisciplinary molecular profiling technologies, genomics, proteomics, metabolomics. | Persons holding an honours degree (minimum upper second) or overseas equivalent in, e.g., biomedical, medical, biological, chemical, biochemical and pharmacological sciences. |
| https://kursuskatalog.au.dk/da/course/116668/Genetik-og-Personlig-Medicin<br>Genetics and Personalized Medicine (in Danish) | The human genome and genetic variation, molecular pathology and inheritance patterns, epigenetics, PM and the hunt for strong and weak disease genes, new paths towards genetic treatments. | Students with a bachelor's degree in medicine. |
| https://www.coursera.org/learn/personalised-medicine-from-a-nordic-perspective<br>Personalised Medicine from a Nordic Perspective | Introduction to PM, health information used in PM: biomarkers, genetics and omics, evidence and documentation for clinical efficacy of PM, communication in PM, ethical, legal and social aspects of PM. | University students and graduates in medicine, molecular biology/biochemistry, data science/bioinformatics, psychology, law and others interested |
| https://www.futurelearn.com/courses/personalized-medicine<br>Using Personalized Medicine and Pharmacogenetics | The human genome, genome and exome sequencing, pharmacogenetics tests, PM in cancer therapy. | Qualified clinicians (general practitioners, oncologists, general physicians, pharmacists, nurse practitioners, clinical scientists) and scientists (biologists and bioinformaticians) with a role in prescribing medicines or managing patients undergoing treatments. |
| https://rochesteronline.precollegeprograms.org/medicine<br>Personalized Medicine: Customizing Care Through Genetics | How breakthroughs in PM are being used to create tests and treatments more precisely targeted than ever before, genomic sequencing, reading gene data, identify mutations that cause disease, how genomic information makes you unique. | Students aged 13+ years. |

The level of PM knowledge seemed to vary considerably among respondents. A significant number of respondents (28%) reported that they had no PM knowledge. Whether they are, in fact, practicing aspects of PM without being aware of the meaning of the term cannot be deduced from this study. We can only conclude that the term and the definition of PM presented in the survey seem unfamiliar to this group of respondents. The lack of opportunity to inquire deeper into respondents' understanding of the term is a methodological limitation of the quantitative study design. Despite all the answers affirming PM knowledge, the free-text comments revealed that some nurses seemed to be grappling with its meaning. A variety of understandings were proposed, some of which fall within the scope of well-known definitions, whereas others seem to be more intuitive, personal interpretations. For example, PM was interpreted by one respondent as the handling of medication to individual patients. Another respondent referred to the medical role and task of prescribing medication. These interpretations will count as misunderstandings if we assume that the PM definition presented in the survey is a paradigm. However, this observation also seems to indicate a lack of common

language and knowledge about PM in nursing care. This may be due to the exclusion of nurses from the development of a national educational agenda for PM within the Danish health professions.

Since the comments revealed a considerable variety of understandings, it seems reasonable to ask whether the same subjectivity and variability of understandings was at play when the respondents answered numerical questions about PM in their daily nursing practice. Other questions concerning more clearly defined tasks such as collecting a family history seem to allow less scope for individual interpretation and produce more precise answers. However, since this question does not incorporate any notion of PM as such in the questionnaire, one cannot infer directly that the respondents related this task to their understanding of PM. Even though it might be claimed that they were, in fact, enacting PM when taking a family history, we cannot infer anything about their understanding of the term from this specific question. Furthermore, we may reasonably speculate whether the conceptual vagueness of the term PM might partly explain why a considerable number of respondents failed to complete the full questionnaire. The lack of consistency among respondents in terms of their understanding of PM would not in itself pose a problem if the nurses already have sufficient insight and knowledge about the way in which they may identify and treat disease of a genetic origin and if they are able to inform patients and relatives about relevant preventive measures and measures to relieve pain and discomfort once a diagnosis has been made. If they have sufficient insight into relevant ethical and legal issues relating to diagnostic testing and the merging of various genetic and lifestyle data to protect the patients from harm and respect their autonomy and integrity, the need for further education and training might not be a pressing concern. However, in the present survey, respondents clearly stress the relevance of PM in nursing practice and their need for education to address knowledge gaps. Their request for education echoes international calls to align nursing practices with the evolving healthcare landscape, for both new nurses entering the system and for those who are already part of it.[1,21,22] Notably, a relatively large number of the responding nurses stated that they would find it relevant to enrol for further PM training if available. Hence, we suggest incorporating PM in the basic education of Danish nurses and to offer further training courses to graduated nurses.

In our searches for relevant courses and topic areas, we found no detailed descriptions of courses about PM or precision medicine in the articles identified in bibliographic databases. Such descriptions are apparently not included in published articles but need to be found elsewhere. This was confirmed by our Google searches, which identified numerous courses and detailed contents descriptions.

We acknowledge that our Google searches provide no deep insight into the number and scope of courses offered, but we do note that a paucity seems to exist of courses designed specifically for nurses with contents tailored to their specific knowledge requirements. Nonetheless, we did obtain inspiration from the course descriptions identified, which may be used to prepare a course suited for a Danish nursing context. Clearly, efforts need to be made to adjust the contents to a Danish or Nordic context since most of the courses found targeted students or health professionals in the US or UK.

In our view, however, providing tailored care to the individual is best underpinned by developing PM courses with a wide target audience furthering a cross-disciplinary understanding and cooperation between health professionals working alongside each other in practice. If such integration is not achieved, the vision of implementing a national PM strategy is unlikely to succeed.[23]

## 5. Conclusion

To ensure the successful integration of PM into Danish healthcare, prioritising its inclusion into relevant educational programmes is essential. By doing so, Denmark may empower its healthcare workforce to effectively utilise and contribute to the advancements of PM, ultimately enhancing patient care and benefitting the overall healthcare system.

The present inquiry provided ample evidence that a need exists for developing PM courses targeted specifically towards intermediate health science students and postgraduate health professionals. Furthermore, although course materials are available online, materials should be developed specifically or modified for use in a Nordic context.

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## Authors contributions

All authors were responsible for study design and survey development. KK Nissen and CB Breer were responsible for survey data collection and analysis. AT Binderup was responsible for survey data analysis, including statistical analysis. MM Jørgensen and TR Mikkelsen were responsible for literature searches and searches for courses. All authors read and approved the final manuscript.

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## DATA SHARING STATEMENT
No additional data are available.



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