

Scanning the Medical Terrain

An aid to quicker adoption of guidelines

Ellen A. A. Jaatun^{1,2}, Leigh-Anne Hepburn³, and Martin Gilje Jaatun⁴

¹ Department of Otorhinolaryngology Head and Neck surgery
Norwegian University of Science and Technology
Trondheim, Norway
ellen.jaatun@ntnu.no

² St. Olav University Hospital
Trondheim, Norway

³ Digital Health and Care Institute
Glasgow School of Art
Forres, UK

⁴ IDE, University of Stavanger, Norway
martin.g.jaatun@uis.no

Abstract. Guidelines exist in order to ensure efficient, effective and consistent provision of healthcare service. Unfortunately, existing guidelines are often not adopted in a timely manner, even to the point of being outdated at the time of adoption. Hence, many healthcare professionals are eschewing guidelines, sometimes leading to suboptimal outcomes. This paper will examine one way of ensuring quicker adoption of guidelines in the health sector.

1 Introduction

Implementation of guidelines and procedures is not performed at the same speed and to the same extent in all parts of the healthcare service. For complex conditions where multiple healthcare providers should work together to bring the patient through a clinical pathway, this causes reduced interoperability of the service, and may lead to delays in the clinical progression [1].

There are many barriers to the use of guidelines in healthcare, especially in primary healthcare. One practical challenge is related to multimorbidity, where different conditions affect each other, and management strategies may cause additional impact on another condition, e.g., exacerbation of Chronic Obstructive Pulmonary Disease (COPD) managed with steroids can cause increased blood sugar levels in diabetes patients. Another common barrier for implementation of guidelines is related to the time frame between development, publication and implementation. This can cause the evidence which the guidelines are built on to be outdated, and consequently make practitioners less interested in spending time and effort to change practice [2]. Within this field, different professionals may have a different attitude and comprehension of standardisation, which

may cause difficulties in navigating through the system for both patients and healthcare providers.

To remedy this challenge, more focus is given to standardisation from the healthcare authorities. This strategy may have success in some areas, but may not lead to substantial changes in others. An overall impression of the healthcare field can be interpreted as quite chaotic.

In this study we have used chronic pain as a case to explore the problem related to standardisation because chronic pain is a condition where patients will need management and service for many years. Understanding the problem and detection of changes has to be communicated and assessed in a standardized way, and pain management is an interdisciplinary approach [3]. Additionally, the clinical pathway is not a linear flow but requires continuous evaluation and new iterations during the management process. Guidelines for management are available on different websites accessible for both patients and healthcare providers. However, in older electronic health record (EHR) systems the content of the guidelines is often not directly linked to the EHR. Hence, while working with a patient, guidelines cannot give direct feedback on decisions or provide visual help.

In clinical practice, many of the EHR systems are expensive and provide limited support for work flow [4]. User involvement during implementation is limited, since these systems typically are Commercial Off-The-Shelf (COTS) systems, and user influence for adaptations and changes to the program is limited [5]. Consequently, we believe that there is a need for more flexible systems tailored to and influenced by users' targeted needs.

To illustrate this problem we have identified a clinical problem where an interdisciplinary approach is needed. Building on our previous work [6], we will try to identify how well current management strategies align with the clinical guidelines, and identify areas for improvement where scientific knowledge can be used to improve practice.

2 Background

Pain is a common reason for visiting a healthcare service. The International association for study of pain (IASP) has defined pain as *an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage* [7]. This means pain is an experience just like hunger or being tired, and is experienced with different threshold and ability to adapt from person to person. During the patient meeting, the healthcare provider should classify the patients experience as an acute or chronic pain condition. The acute pain is often more associated with the actual tissue damage and thus might be easier to comprehend; the chronic pain may have limited peripheral representation for the painful experience. In order to treat pain, we need to understand it. There are different pathomechanisms that can cause pain, and the different mechanisms may have different management strategies. However, a

vocabulary that provides common understanding of the experience does not yet exist.

Evidence shows that for many chronic pain conditions, the journey from experiencing pain to defining the cause of the pain may take many years [8]. Additionally, studies on patients living with pain show that too many patients are reporting high pain levels. The delayed diagnosis and poor management results in increased suffering for patients and implies high socio-economical costs caused by absence from or inability to work [8].

To remedy the challenges with communicating chronic pain, many different assessment tools have been developed. Healthcare organisations have also developed clinical pathways and guidelines for pain management to improve efficiency and quality of care. In Scotland a national clinical guidelines for chronic pain management was published in 2013 [9]. In addition to the guidelines a clinical pathway [10] and patient information was published [11].

In previous work we have suggested a model for pain management based on reflective learning through a patient and clinical journey[12]. The process of learning should be facilitated through a boundary object collecting and translating the key message during the interaction.

The aim of this study was to explore the current perception of the interaction between patients and healthcare providers dealing with chronic pain and compare this with our previous work. We also wanted to explore the perceived patient journey from patients and healthcare providers and compare it to the “gold standard” proposed by the national guidelines for chronic pain in Scotland. The final aim was to use the new knowledge from this study to highlight options for intervention for improvement of service.

3 Method

3.1 Object of investigation

A local chronic pain organisation was invited to participate in 5 focus group meetings. The participants were recruited through email contact with the patient organisation. Local primary healthcare providers were invited and recruited through email. Some healthcare providers were recruited through colleagues and others were mentioned by patients in the focus groups and invited to participate.

3.2 Focus groups and interviews

In order to address the aim, the study recognised a need to explore experiences of receiving and providing care for chronic pain; uncovering perceptions of interaction between patients and healthcare providers and identifying possible learning opportunities. We also wanted to explore the perceived care journey from the perspectives of patients and healthcare providers and compare it to the gold standard proposed from the national guidelines for chronic pain in Scotland [9].

3.3 Design for Complexity

Patients and healthcare providers were subject to a systematic mapping based on design methods developed by the Innovation School at Glasgow School of Art (GSA) [6].

People living with chronic pain were invited to participate in one of five small focus group design workshops that took place across three geographic locations in Moray, Scotland (see Fig. 1). These focus group workshops aimed to identify challenges and opportunities existing within current chronic pain management experiences; and to identify any knowledge gaps and potential learning opportunities for people living with chronic pain. Thirteen participants with chronic pain experience took part in the study, representing over twelve hours of discussion. The people living with chronic pain were through discussion in the group, painting, drawing or building from different materials visualising their thoughts or ideas for chronic pain management.



Fig. 1. Design workshop

Additionally, a series of semi-structured interviews were held with health professionals from community, primary and secondary care contexts. Seven participants took part, representing general practitioner care (GPs); out-of-hours GP care; chronic pain consultant-led care; pharmacy; remedial therapy; and chronic pain policy development, culminating in over fourteen hours of discussion. Data collated during focus groups and interviews were analysed thematically and findings are now discussed below, framed around the potential of an innovation learning experience that can support interaction between patients and health care providers.

3.4 Interviews

We have conducted semi-structured interviews. The participants were partly selected from the members of the chronic pain management team identified through the national guideline for chronic pain management [9], and partly identified from patient interviews. The content of the interview was based on defining the individual's perceived responsibility for pain management, perceived ideal future, and clinicians response to topics that may have come up during the patient focus group meetings such as accessibility to healthcare providers, highlighting competence in pain management and communication barriers between patients and healthcare providers.

4 Results

4.1 Patients

Five focus group meetings (design workshops) were held with patients with chronic non-cancer pain. During the workshop the conversation was recorded and later transcribed. The qualitative data was read and specific segments of text was identified. The segments were labeled and organized in thematic topics. The topics were reduced into higher order topics consisting of five higher order themes [13] as illustrated in Table 1.

Table 1. High-order themes – Patients

Chronic pain problem - high order themes	Consequence
Triage system	Low priority compared to more acute health issues and hard to access healthcare providers
GP gatekeeper for further referral	Limited access to other healthcare providers
No physical sign of disease	Disbelief and communication barrier
Medical jargon challenging and assessment methods varied	Communication barrier
Limited interdisciplinary communication	Not updated healthcare records

The participants had normal network consisting of family and friends. The patients considered the General Practitioner (GP) as one of the key personnel, but for most of them the GP was hard to access, since their problem was triaged and given low priority.

I'm battling to get a doctor's appointment, would you come with me to try and, ... because having her with me, I feel ... I'm easily shot down. If they say, We've got nothing available for four months, Ill go, Okay then, whereas she'll say, "Sorry, she needs to be seen" (Patient) [6]

The low priority was perceived as a devaluation of the condition that for many of them led to severe functional and social impairment.

The inaccessible GP was considered a problem which reduced the possible interaction with specialist healthcare professionals within the NHS who could impact their chronic pain condition. However, healthcare professionals outside the the NHS were still accessible. The network of professionals that could provide support and pain relief were presented in a fragmented way, and it was not possible to detect that patients perceived any systematic approach for management or interdisciplinary support from a chronic pain management team.

The doctors and the hospital, as much as I would like them to be my first port of call, they never are. (Patient) [6]

A clinical pathway was not mentioned, and we were not able to detect a perceived collaboration between the chronic pain healthcare providers the patient had interacted with.

What is my next step. I'm not waiting two years for another referral. They don't know, that's the problem, and I wish they would just say, "I dont know" (Patient about the GPs' knowledge of chronic pain) [6]

On the contrary, the patients perceived a lack of information exchange between the professionals. The patients' perception of their own expertise was high, i.e., they mostly considered themselves as experts; however, their field of expertise was not completely clear. Some considered their expertise to be on personal matters, impact and own patient history, but also on management strategies for chronic pain. None of the participating patients had acquired their knowledge from the national patient information web page, but considered internet searches as their main source of information.

The majority of the participants did not value their GP's knowledge on chronic pain issues as high, in spite of their dependency on their GP and high value of the GP in the network of healthcare providers.

The patients displayed a strong belief in pharmaceutical management strategies and presented barriers for physical activities and training. Psychological management strategies were not highly regarded.

4.2 Healthcare Providers

Seven interviews with primary and specialist healthcare providers responsible for chronic pain management were performed. The method was the same as described above. We ended up with a list of five higher order themes (see Fig. 2 and Table 2).

All of the participants shared an interest in chronic pain management, but all except from the pain specialist would avoid flagging their special interest to the patient.

Yes, but as I say, I dont tell anybody about it (GP with special interest in chronic pain)[6]

The reason for this was a fear of getting referrals from other GPs or getting too many patients. This was also a concern related to the resources required for management of the patient problem, which were not adequate. A frustration toward limited ability to provide efficient management and trust between patient and healthcare providers was considered a major problem.

Many of the GPs considered that their main responsibility toward the patient with chronic pain was to counsel the patient that they would have to accept that the pain would remain as way of providing relief. The other professionals seemed to be more focused on different remedies or treatment options for providing relief.

It also gives me a chance to drip feed the concept that you're always going to have pain. Stop seeking a cure going around, and round, and round this merry-go-round of drugs which almost none of them really work much. (GP)[6]

In primary care, the GP was considered to be the professional with the main responsibility to provide pain relief, although each professional considered themselves as qualified and responsible for managing the patient's problem. The GP did not present a team of service providers, and each professional in primary care considered themselves as independent contractors with a responsibility directly toward the patient.

GPs, because we're independent contractors, we are constantly looking at systems for efficiency ... (GP)[6]

In specialist healthcare the pain specialist considered the clinical guideline for chronic pain management as a tool for primary health care. The organization of management in specialist healthcare followed their own pathway, aiming to fill in the gaps or extend the service from primary healthcare. From the specialist healthcare point of view, the majority of patients should be managed in primary care. Although the primary healthcare providers had access to information about the patient from different management systems, the patient story was told by the patient themselves. In special healthcare, the specialist would depend on the patient's story to get a complete picture of the problem.

So, the people presenting to the clinic with the referrals and in the clinic, we take a step back. My typical way of approaching these people is to let them speak. Listen to them and, in fact, occasionally I do not kind of focus on the given pain. I want to know from the very beginning what exactly has happened. (Pain specialist) [6]

When asked, all healthcare providers knew of the specific national chronic pain management guideline and clinical pathway, but the participants said they were not following it in their clinical practice.

Yes. I mean, with any SIGN guidelines or NICE guidelines, you are encouraged to be looking at that regularly . . . In reality, I think the busyness of life doesn't allow us to do that in the real world. (GP) [6]

The results indicate a limited focus on a systematic approach for management of chronic pain in primary care. Patients were not informed about an existing systematic approach, and they were left to themselves to collect information about their problem.

Most of the professionals knew of existing guidelines and clinical pathway for chronic pain but did not use them for organizing their service, and they did not expand the service to include other professionals.

From the patients' point of view, an important milestone was obtaining a diagnosis. Collecting data, evaluating results and making decisions could in many cases take years in the current unsystematic way.

The different professionals working in primary care considered their service to be a supplement to the GP's service which was beneficial to the patients, but added little to the data used for decision making.

The effort of providing updated and targeted patient information was not perceived by the patients belonging to the group of patients.

5 Proposed Solution

Our results show that a service blueprint for management of a complex problem such as chronic pain has not been adapted in current practice. This adds on to the barrier for implementation of clinical guidelines related to already outdated clinical evidence, which has been flagged as a major critical issue. Hence, the current practice for implementation of new guidelines and clinical pathways provide too slow adaptation of practice and does not provide enough flexibility for navigating through the guideline and pathway.

As shown in this narratives above from patients and clinical personnel, we argue that the medical problems in primary care are not communicated unless patients are presenting and elaborating the details. Accepting that patients are proxies for their data, we propose a solution that collects the relevant information from each patient interaction. Ideally, the various types of patient record systems should have a feature for exporting the practitioners notes in a standardised format. However, this is currently not the case, and as an interim measure we propose to let the patient capture the relevant text (standardized ICD 10 [14] or ICPC2 [15]) and a medical procedure code [16] on a mobile computing device as well as identify the professional, e.g., physiotherapist, psychologist, or GP.

Most patients today own a smartphone which has more than enough computing power to serve as a data collection device. We thus need a quite simple Android/IOS app that can collect the data in a reliable and secure manner,



Fig. 3. Collecting data from various practitioners

and store it in encrypted form until it can be uploaded to a central repository (see Fig. 3). The data should be organised according to the openEHR specification [17]. Once uploaded, the data must be analysed to extract the salient details. This will then serve as an input to other centrally managed decision support tools. The patient data can be transferred to a map where the clinical pathway can be visualized with time, place, diagnose, procedure and type of professional managing the patients chronic pain problem. This map presenting the individual patient path, saving the practitioner from having to read through a never-ending patient history at each interaction.

Note that the last step is important, since the data deluge will prevent the practitioners from getting the required overview and empower the patient to provide more accurate information. The processing will start by normalising recorded standardized medical code to ensure uniform coding.

The normalized text, professional healthcare provider and the classification code for cause of visit, health related issues or diagnosis [15] and/or the procedure performed [18] can be used to identify the current "location" of the patient on the clinical pathway.

For many of the chronic medical conditions, the clinical pathway is not a linear path; patients may go through circles or loops of management strategies. Setbacks can occur, which may lead to alternative interventions. The tool we propose will follow the patient instead of the GP, and can be shared with health professionals to help identify the greater picture.

5.1 Security considerations

The app needs to be designed using current best practice regarding security for eHealth software [19, 20], the full details of which we will not cover here. However, since the idea is to use the patient’s own smartphone for data collection, this poses an extra security challenge, since we cannot in general trust this platform to fully protect information if stored in clear text on the device. We therefore propose a hybrid encryption scheme where the collected data is encrypted using a symmetric⁵ 128-bit key, and the key is encrypted by the public⁶ key of the central repository.

Once the collected data has been encrypted, the symmetric key is wiped from the phone memory, and the encrypted data is no longer accessible to anyone, not even the user, until it is uploaded to the central repository. At this time, the central repository can recover the symmetric key and decrypt the data.

6 Discussion

Healthcare organizations have not found a way for rapid implementation of care pathways and new guidelines. This leads to a vicious circle, where new guidelines for clinical practice will have limited impact on practice and provide limited evidence of efficiency, efficacy and quality. We have developed silos of practice which run independent of each other, and changes in one part of the interdisciplinary work flow does not necessarily lead to adoption of the new practices in other areas of the clinical pathway, resulting in inefficient patient pathways as shown in this study. At the same time new evidence and proposed best practice is continuously published. Hence, the gap between theoretical knowledge and clinical practice grows.

As the patient and clinician narratives above show, implementation of the SIGN 136 guidelines for chronic pain management has not successfully been performed during the 5 years they have been available [6]. Consequently, a different approach for rapid implementation is needed. The patient and healthcare providers narrative above point at patient act as proxy for their data when they visit the management team. The patients ability to present medical history play an important part for decision making for each healthcare provider when history of management is evaluated, as well as evaluating effect of previous management. Providing patients with an easy script to present to the healthcare provider may lead to more patient empowerment as shown in other studies [21]. The growing amount of information in the health record reduce the healthcare workers ability to compare the clinical notes with the history presented by the patient, and limited interoperability between different IT platforms reduce the sharing of information in the care team. Consequently, the clinicians ability to navigate

⁵ The algorithm of choice is currently AES - note that to be quantum-safe, the key length would have to be doubled

⁶ We currently recommend ECC with a modulus size of 256-383 bits – but note that this option is not quantum-safe.

in the clinical pathway and locate new and previous management approaches to the correct place in the guideline and pathway may be challenging. Additionally, implementing and updating guidelines in clinical practice is time consuming, require substantial resources and often patient involvement in the implementation process is limited. A position system based on tracking the patient movement through the individual patient pathway for individual chronic pain management represent the actual pain management practice. If an artificial Intelligent system could compare the individual patient pathway with the proposed clinical guidelines and the clinical pathway a visual representation of current individual practice can be made. This may give patients a better cue for presenting their patient history and ability to ask questions that both patients and healthcare providers can reflect on. So far, this process of navigating through the system has been the responsibility of the healthcare provider. However, the patient is the only person who have been present through the whole process and consequently could have presented the whole picture. Hence, a system that take into account the current clinical pathway and the guidelines could aid the process of management by matching the available data from the different healthcare provider with the updated guideline.

Acknowledgment

This study was funded by the Digital Health and Care Institute. The authors also wish to thank all participants of the study and in particular members of Affa Sair, the chronic pain support group based in Moray who contributed their time.

References

1. Gómez-Batiste, X., Murray, S.A., Thomas, K., Blay, C., Boyd, K., Moine, S., Gignon, M., den Eynden, B.V., Leysen, B., Wens, J., Engels, Y., Dees, M., Costantini, M.: Comprehensive and integrated palliative care for people with advanced chronic conditions: An update from several european initiatives and recommendations for policy. *Journal of Pain and Symptom Management* **53**(3) (2017) 509 – 517
2. Austad, B., Hetlevik, I., Mjølstad, B.P., Helvik, A.S.: Applying clinical guidelines in general practice: a qualitative study of potential complications. *BMC Family Practice* **17**(1) (Jul 2016) 92
3. IASP: International Association for the Study of Pain (2015)
4. Institute of Medicine (US) Committee on Quality of Health Care in America: Crossing the Quality Chasm: A New Health System for the 21st Century. National Academies Press (US) (2001)
5. Cresswell, K., Morrison, Z., Crowe, S., Robertson, A., Sheikh, A.: Anything but engaged: user involvement in the context of a national electronic health record implementation. *Inform Prim Care* **19**(4) (2011) 191–206
6. Hepburn, L.A., Jaatun, E.A.A.: Making sense of data – translating complexity for improved chronic pain management. In: *HealthCom 2018*. (2018)

7. IASP: Classification of chronic pain (2012) <http://www.iasp-pain.org/PublicationsNews/Content.aspx?ItemNumber=1673>.
8. Lynch, M.E., Campbell, F.A., Clark, A.J., Dunbar, M.J., Goldstein, D., Peng, P., Stinson, J., Tupper, H.: Waiting for treatment for chronic pain - a survey of existing benchmarks: toward establishing evidence-based benchmarks for medically acceptable waiting times. *Pain Res Manag* **12**(4) (2007) 245–248
9. Scottish Intercollegiate Guidelines Network (SIGN): Management of chronic pain. SIGN publication no. 136 (December 2013)
10. Scottish Intercollegiate Guidelines Network (SIGN): Sign 136: Chronic pain assessment, early management and care planning in non-specialist settings (2013) <http://www.ckp.scot.nhs.uk/Published/PathwayViewer.aspx?id=609>.
11. Scottish Intercollegiate Guidelines Network (SIGN): Managing chronic pain – A booklet for patients, their families and carers (2018) <https://www.sign.ac.uk/assets/pat136.pdf>.
12. Jaatun, E.A.A., Dixon, B., Brooks, E.: The language of pain – better requirements for pain tools. In: *Practical Aspects of Health Informatics*. (2014) 91–100 <http://ceur-ws.org/Vol-1251/paper9.pdf>.
13. Cruzes, D.S., Dyba, T.: Recommended steps for thematic synthesis in software engineering. In: *2011 International Symposium on Empirical Software Engineering and Measurement, IEEE* (2011) 275–284
14. WHO: International statistical classification of diseases and related health problems 10th revision (2016) <http://apps.who.int/classifications/icd10/browse/2016/en>.
15. WHO: International classification of primary care, second edition (ICPC-2) <http://www.who.int/classifications/icd/adaptations/icpc2/en/>.
16. Find-a-code: CPT Codes - medical procedure codes <https://www.findacode.com/cpt/cpt-procedure-codes-00-group.html>.
17. openEHR: openEHR – An open domain-driven platform for developing flexible e-health systems . <https://www.openehr.org>
18. WHO: International classification of health interventions (ichi) (2016)
19. Jensen, J., Tøndel, I.A., Jaatun, M.G., Meland, P.H., Andresen, H.: Reusable security requirements for healthcare applications. In: *Availability, Reliability and Security, 2009. ARES'09. International Conference on, IEEE* (2009) 380–385
20. Jaatun, M.G., Jaatun, E.A., Moser, R.: Security Considerations for Tablet-based eHealth Applications. In: *Practical Aspects of Health Informatics*. (2014) 27–36
21. Denneson, L.M., Cromer, R., Williams, H.B., Pisciotta, M., Dobscha, S.K.: A Qualitative Analysis of How Online Access to Mental Health Notes Is Changing Clinician Perceptions of Power and the Therapeutic Relationship. *J. Med. Internet Res.* **19**(6) (Jun 2017) e208