Introduction

Even though chronic diseases are on the rise, worldwide deficits exist regarding their long-term monitoring and structured follow up. To efficiently monitor patients with chronic diseases, a well-structured and organized electronic medical record (EMR) is crucial to ensure that all necessary information can be easily entered and retrieved and no essential information is missed. Surprisingly no standards exist regarding the monitoring of patients with chronic diseases by means of EMR. Too often even the electronic basis is lacking, since many general practitioners still use paper based medical records. In 2012 31 European countries were ranked concerning their EMR usage in primary care; Switzerland was ranked 24th[1]. A Swiss study showed similar results, with 44.8% EMR usage in Swiss primary care [2]. To introduce a useful tool for monitoring patients with chronic conditions by means of EMR, it is essential to know the needs of potential users and to develop the tool accordingly. A survey among physicians not using EMR showed that most concerns relate to improvement of quality of care, workflow processes and physician-patient relationship [2]. Therefore, to increase EMR usage it is crucial to enhance benefit of EMR usage compared to paper based medical records. This can be achieved for example by means of time saving features, such as improved monitoring elements with ergonomic navigation and clear design, generating a fast overview enabling to retrieve all relevant information by the glimpse of an eye. EMR use is not only a practical bookkeeping feature it can improve management of chronic diseases by more thorough record keeping, treatment intensification and better monitoring [3-5]. In addition, documentation errors, which are common in paper-based medical records, such as prescribing and transcription errors and problems of legibility can be reduced by means of EMR use [6, 7]. Since on the one hand, currently no international standards are available on the monitoring of patients with chronic diseases by means of EMR and on the other hand, deficits exist regarding monitoring and structured follow up, we aimed to develop an evidence based standardized EMR monitoring tool for chronic conditions in general practice.

Methods

Figure 1 shows an overview of the methodology that we followed in this study. As a first step the systematic literature review was performed, as a second step we developed the monitoring tool.

Figure 1. The study flow.
**Systematic identification and assessment of supporting evidence**

We followed the principles of systematic reviews [8] and developed a protocol a-priori in order to identify and assess the monitoring indicators.

**Inclusion criteria**

We included primary peer-reviewed studies of any design carried-out mainly in primary general practice (family healthcare) for adult patients 18 years and older diagnosed with either of five chronic conditions including diabetes mellitus type 2/non-insulin dependent diabetes mellitus, arterial hypertension, asthma, chronic heart failure or osteoarthritis. In order to be included, studies must have also reported on any indicators that allow the assessment of care and help monitoring the status and process of disease for these five chronic conditions. Therefore, we considered disease indicators that help reducing the risk of exacerbation such as intermediate outcome indicators (e.g. HbA1c for diabetics or blood pressure measurements for hypertensive patients) and process indicators (e.g. regular foot care or nutrition counselling). We included studies regardless of whether specific interventions were evaluated. In addition, all studies and clinical guidelines should have been published in English or German.
Search methods and study identification

We developed a comprehensive search strategy in collaboration with an expert librarian. The librarian conducted the search and produced a list of all studies that match the predefined search terms. We identified studies published between 2000 and 2015 by applying this strategy to the databases in MEDLINE (Ovid), EMBASE (Elsevier) and The Cochrane Library (Wiley). No restrictions were made regarding the country of origin of the studies. The concepts and terminology for the search strategy included “monitoring” and “electronic patient record/electronic health record” as well as “primary or family healthcare/general practitioner” in combination with the five selected diseases. Further terms might include “indicators” and “management”. An example of the full search strategy in MEDLINE is available in Appendix 1.

We identified additional publications by manually searching the reference lists of included studies, relevant reviews and clinical guidelines. Given that most guidelines are not indexed in the former medical literature databases, and to identify the clinical guidelines related to any of the five chronic diseases, we searched World Wide Web-based databases including the National Guideline Clearinghouse (NGC) for USA guidelines [9] and the «Arbeitsgemeinschaft der Wissenschaftlichen Medizinischen Fachgesellschaften e.V.» (AWMF) online [10] for German guidelines.

Study selection

One reviewer identified eligible studies by first screening the titles and abstracts of all records retrieved by the searches based on the inclusion criteria. All potentially eligible abstracts were rated manually from 1-5 stars according to their relevance for this review. The stars were assigned by the mention of the key terms “indicator”, “monitoring”, “assessment”, “management” and “guideline”. The ranking was assigned as follows:

- One star: Remote reference to the key terms, no indicators expected in full text
- Two stars: Little reference to the key terms, indicators in full text unlikely
- Three stars: Reference of at least one key term, indicators in full text possible
- Four stars: Reference of at least one key term, indicators likely
- Five stars: Reference of indicators or monitoring or interval of measuring indicators
The full text of all studies with an abstract rated with at least two stars were obtained if available and further evaluated based on the reporting of indicators. For studies for which the full text was not available, but which were deemed important to inform our study, we used the data reported in the abstract. If necessary, during the evaluation process the study team was consulted to confirm eligibility.

Data extraction and synthesis

For each included study, we extracted the bibliographic details (author, year, country of origin), all monitoring indicators reported, and the guideline on which these indicators were based as well as country of origin of the guidelines for each of the five chronic diseases. One reviewer extracted all data, and another reviewer verified the extracted data. We compiled a data profile of the studies and generated a dataset of indicators using Microsoft Excel. We provided a descriptive summary of the indicators according to disease condition.

Assessment of the monitoring indicators

Experts in the relevant chronic diseases evaluated this dataset of indicators by means of an adapted Delphi procedure. In a first round, the indicators were evaluated by our study group consisting of experts in general practice (MZ and CC), who discussed the indicator's relevance for general practice. The condensed table of indicators was thereafter discussed in a second round, together with one consulting expert of each specialty (see acknowledgement section for the consulted experts). In a third round, the condensed table was again re-evaluated by the study group.

Design and development of the monitoring tool

Based on the condensed table of indicators we developed a framework table for each condition, divided in one to four sublayers giving an overview on the type of indicators. We designed the monitoring tool in a format enabling incorporation into an EMR.

Results

Systematic review of the literature
Our literature searches identified 795 original records (Figure 2). After deduplication and perusal of titles and abstracts, we screened 621 records (range by disease: 33 to 180), excluding 408 records that did not meet our inclusion criteria (e.g. focus on specific therapy or medication or otherwise do not meet the topic). We examined in detail, if available, the full-text of 213 publications (range by disease: 13 to 82).

Figure 2. Flow chart demonstrating the identification and selection of evidence.

We included 87 original publications, five in abstract form only, reporting indicators for diabetes mellitus [11-64], asthma [61, 65-71], arterial hypertension [11, 36, 40, 72-82], heart failure [34, 83-93], and osteoarthritis [94-97]; of whom, five reported indicators for more than one chronic disease [11, 34, 36, 40,
The number of included publications by disease with at least one indicator ranged from 4 to 54. Most records (n=54) were published on diabetes mellitus Type 2, while osteoarthritis was the most underrepresented of the five diseases with only four records. 74 of all 87 included studies contained process indicators, the most significant type of indicators. Concerning Diabetes mellitus, a third of all publications reported at least one indicator. For arterial hypertension and heart failure, only 8% of all publications reported at least one indicator. Concerning the guideline's country of origin, overall most records used guidelines from the United States of America, followed by the United Kingdom. For diabetes mellitus, the American diabetes association (ADA) and National Institute for Health and Care Excellence (NICE) were the most used guidelines.

Another finding of our literature review was that the term “monitoring”, in the sense of long-time patient care, is not widely used and not even indexed as a medical subject heading (MeSH) term in databases. Although publications reported the actual monitoring indicators, the process of monitoring for the different diseases, including, for example, the potential risks associated with over monitoring was only scarcely addressed. The publication by Glasziou et al was the only publication to give a broader overview of the topic. The full list of included studies with evidence on the monitoring indicators for the five diseases is available in Appendix 2.

The monitoring tool

Based on the results of our systematic literature review, we conducted a discussion on relevant indicators by means of a Delphi procedure, which resulted in a condensed list of relevant and practicable indicators as part of an EMR monitoring tool. During the Delphi procedure, not only the relevance of the indicators itself was discussed, but also the ergonomics of how the indicators should be displayed were identified as an essential element for achieving acceptance for the new monitoring tool. These discussions resulted in the displayed design of the tool (Figures 3-7).
Figure 3. Diabetes Mellitus Type 2.
### Diabetes mellitus type 2

<table>
<thead>
<tr>
<th>cockpit</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>• target HbA1c</td>
<td></td>
</tr>
<tr>
<td>• self monitoring indicated? (type, frequency)</td>
<td></td>
</tr>
<tr>
<td>• target blood pressure</td>
<td></td>
</tr>
<tr>
<td>• interval of monitoring</td>
<td></td>
</tr>
<tr>
<td>• free text</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>additional tab</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>• personal history</td>
<td></td>
</tr>
<tr>
<td>• medication (including insulin therapy)</td>
<td></td>
</tr>
<tr>
<td>• compliance (how confident are you that you take all the medication as prescribed? (on scale 1-10))</td>
<td></td>
</tr>
<tr>
<td>• BMI (date of last measurement)</td>
<td></td>
</tr>
<tr>
<td>• waist/hip ratio (date of last measurement)</td>
<td></td>
</tr>
<tr>
<td>• blood pressure (date of last measurement)</td>
<td></td>
</tr>
<tr>
<td>• heart rate (date of last measurement)</td>
<td></td>
</tr>
<tr>
<td>• breathing rate (date of last measurement)</td>
<td></td>
</tr>
<tr>
<td>• allergies/side effects</td>
<td></td>
</tr>
<tr>
<td>• smoking, alcohol, drugs</td>
<td></td>
</tr>
<tr>
<td>• vaccination</td>
<td></td>
</tr>
<tr>
<td>• special features of patient (e.g. difficult to treat disease?)</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>blood glucose levels</th>
<th>eye examination (date of last examination)</th>
</tr>
</thead>
<tbody>
<tr>
<td>morning/lunch/evening/before bedtime</td>
<td>• retinopathy</td>
</tr>
<tr>
<td></td>
<td>• laser treatment</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>severe hypoglycaemia</th>
<th>albuminuria (last measurement)</th>
</tr>
</thead>
<tbody>
<tr>
<td>• frequency</td>
<td>• more than 30mg/d proteinuria: ACE inhibitor indicated</td>
</tr>
<tr>
<td>• symptoms</td>
<td>• creatinine clearance (CKD-EPI)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>physical activity</th>
<th>injection site</th>
</tr>
</thead>
<tbody>
<tr>
<td>type? frequency?</td>
<td></td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>HbA1c</th>
<th>complications</th>
</tr>
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<tbody>
<tr>
<td></td>
<td>• coronary heart disease</td>
</tr>
<tr>
<td></td>
<td>• peripheral artery disease</td>
</tr>
<tr>
<td></td>
<td>• cerebrovascular disease</td>
</tr>
<tr>
<td></td>
<td>• autonomous dysregulation</td>
</tr>
<tr>
<td></td>
<td>• nonalcoholic steatohepatitis</td>
</tr>
<tr>
<td></td>
<td>• erectile dysfunction</td>
</tr>
<tr>
<td></td>
<td>• check Vitamin B12 deficiency if Metformin is taken</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>foot examination (date of last examination)</th>
<th>nutrition counselling</th>
</tr>
</thead>
<tbody>
<tr>
<td>• foot care</td>
<td></td>
</tr>
<tr>
<td>• deformation and pressure marks</td>
<td></td>
</tr>
<tr>
<td>• hyperkeratosis</td>
<td></td>
</tr>
<tr>
<td>• ulcers</td>
<td></td>
</tr>
<tr>
<td>• peripheral pulses (right/left)</td>
<td></td>
</tr>
<tr>
<td>• neuropathy</td>
<td></td>
</tr>
<tr>
<td>• monofilament</td>
<td></td>
</tr>
<tr>
<td>• vibration (right/left)</td>
<td></td>
</tr>
<tr>
<td>• achilles tendon reflex (right/left)</td>
<td></td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>diabetes counselling</th>
<th></th>
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</thead>
</table>
Figure 5. Arterial Hypertension.
Figure 6. Chronic Heart Failure.
Figure 7. Osteoarthritis.
For each selected disease, the indicators were categorized and linked into sublayers, which can be accessed depending on the requirements of the user. The first layer is meant to give an overview of the
most important indicators or categories. Clicking on each layer opens a list of further indicators. For a
clear design and ergonomic use, we did not exceed four layers.
The tool is further supplemented by an additional tab, which contains non-disease specific information as
for example allergies, smoking or drinking habits. This tab can be accessed at any point of the tool.
The tool is completed by a “cockpit” which serves as a guidance in the process of disease management.
The cockpit includes individually predefined treatment goals and thus enables benchmarking in the
monitoring process. In addition, the monitoring interval can be documented as well. To guarantee
individual adjustments there are blank spaces added in every list.

Discussion
To our knowledge, this study represents the first scientific recommendation for a generic, standardized
monitoring of chronically ill patients in general practice by means of EMR.

Monitoring in literature
Long term care of patients with chronic diseases is challenging and deficits exist regarding monitoring
and structured follow up. The fact that chronic care often involves the collaboration between several
people, who are involved in the treatment process, is only one reason for its complexity. Interpersonal
differences in monitoring can decrease the quality of monitoring processes. Surprisingly, currently no
standards exist in literature regarding the systematic monitoring of patients with chronic diseases,
especially by means of EMR. To efficiently monitor patients with chronic diseases, a well-structured and
organized EMR is crucial to ensure that all necessary information can be easily entered and retrieved and
no essential information is missed. Therefore, our study comprised of a two-step procedure (1.
Systematic literature review, 2. Creation of a monitoring tool), is a first initiative towards the urgent need of
standardization in monitoring of patients with chronic diseases in primary care.

A systematic literature review showed that the term “monitoring”, in terms of disease management and
long-time patient care, is not widely spread. The medical subjects heading (MeSH-term) called
“physiological monitoring” in terms of measuring physiological parameters as for example blood pressure
exists. However, a MeSH-term called “monitoring” in terms of long-time care does not yet exist. A plethora
of literature exists on quality indicators, which might have the potential to improve the outcome of a
disease. An example here fore is the “Quality and Outcomes Framework” (QOF) in the United Kingdom [99]. Our goal was to search as well for literature that mentions indicators for long term monitoring beyond those which can be easily measured and to create a tool for practitioners, that brings the important indicators into a system, that enhances an efficient workflow of the physician in monitoring complex chronic diseases depending on the experience and the working habits of the general practitioner.

So far, only few authors focused on the topic monitoring of chronic diseases. According to Glasziou et al, the process of monitoring aims to establish the response to treatment, detect the need to adjust treatment and detect adverse effects [98]. The process of monitoring can be divided into different phases, pre- and during and after treatment, each phase requiring different intervals of measurement. When analyzing different diseases, monitoring is probably most widely mentioned in blood pressure management. Various publications exist on the optimal way and interval of measuring blood pressure [77, 100, 101]. However, beyond the indicator of blood pressure measuring literature remains scarce. Concerning diabetes mellitus an extended monitoring tool exists, which was designed as a disease management tool for practice nurses, based on a traffic light scheme to detect any deficit and need for action [102]. In addition, a detailed guideline on how to monitor the diabetic foot is provided by the International Working Group on the Diabetic Foot [103]. As for bronchial asthma, two study groups have addressed the optimal way and potential problems of finding and evaluating indicators to monitor patients with asthma, including an overview of the most important indicators [67, 104]. Similarly, for osteoarthritis, Grypdonck et al present a short list of indicators for monitoring patients with osteoarthritis of the knee [94]. Surprisingly publications concerning monitoring of chronic heart failure seem to be scarce [91]. The underrepresentation of osteoarthritis and chronic heart failure is also reflected in the number of detected indicators in primary literature, compared to abundant records of indicators concerning Diabetes mellitus type 2.

Monitoring Tool

To our knowledge, so far no generic template for an EMR-based monitoring tool exists, that includes all relevant monitoring indicators for the treatment of chronic conditions in general practice. The monitoring tool we developed facilitates the monitoring of patients with chronic diseases by providing a list of all essential monitoring indicators, which should be assessed in regular intervals according to the current evidence. All indicators are arranged in up to four sublayers, which contain only the most relevant indicators. This layout avoids a surplus of information and hence ensures that the patient remains in the
center of the consultation and not the screen, while on the other hand making sure no indicator is missed. Therefore, all sublayers exceeding the first one are displayed only if actively clicked on. The cockpit serves as an overview of all pre-set goals and the current situation and therefore serves as benchmarking. Further, the cockpit facilitates a practice handover or holiday replacement by saving time not having to review medical records and therefore enables to continue care at the same point. Pre-set goals also help to overcome clinical inertia, a widespread problem in care of patients with chronic diseases [105]. In long-term care, the involvement of several people of different disciplines is not uncommon. Skill-mix models involving non-physician disciplines such as practice nurses, dieticians or physiotherapists are on the rise, but due to different national regulations about allocation of responsibilities and work it is not feasible to establish an international standard. The tool will thus have to be adapted according to the national health care systems Additional tabs, which contain non-disease specific information as for example allergies or body mass index, serve as an overview of basic but relevant patient information. As for measurable indicators, such as body mass index or blood pressure, the further objective is to not only show single measurements but to display regular measurements in the course of time. In future, we hope the tool will be an integral part of a clinical decision support system, including direct links to access current guidelines and algorithms with therapy suggestions.

**Strengths and limitations**

To our knowledge, this study represents the first scientifically founded recommendation for the standardized long-term monitoring of chronically ill patients in general practice. The extensive systematic review was performed for primary literature but not for guidelines since most guidelines are not indexed in databases. In order to nevertheless gain maximal insight into existing literature we additionally used guideline search programs such as National Guideline Clearinghouse for American guidelines and AWMF online for German guidelines and added a substantial amount of manual searches within reference lists and search engines. Possible confounders are that publications and guidelines reporting in other languages than German and English were excluded. The ergonomic layout of the monitoring tool enhances user friendliness and facilitates chronic care by means of an EMR. This layout offers a practical approach for implementing scientific results into everyday practice. Involving generalists with extensive practice experience as well as specialists in the different medical fields in the Delphi procedure, resulted
in a condensed set of indicators relevant for everyday use in primary care. The Delphi procedure has been proven a feasible method for selecting indicators of a chronic disease [94, 104].

**Conclusion**

Our generic template can improve care for patients with chronic diseases, since for the first time it systematically summarizes the existing scientific evidence for the standardized long-term monitoring of chronic conditions by means of an EMR in general practice.
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Competing interests

The authors declare that they have no competing interests.

Authors’ contributions

LF was involved in designing the search strategy, performed the systematic screening and review of the literature, the selection of monitoring indicators through the Delphi procedure, and the writing of the manuscript. MZ was involved in study design, took part in the Delphi procedure and revised the manuscript. NAGM provided input on study design and search strategy, and contributed to improving the manuscript. TR supervised the development and methodology of the study and helped improving the final version of the manuscript. CC was involved in study design, the study selection and prioritization, verified the extracted data, took part in the Delphi procedure, supervised and revised the manuscript. All authors read and approved the final manuscript.
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