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of Physicians**



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Glossary of Terms

Term / Abbreviation	What it stands for
AoMRC	Academy of Medical Royal Colleges
BA	Business Analyst
BCS	British Computer Society
BMA	British Medical Association
CCG	Clinical Commissioning Groups
CCIO	Chief Clinical Information Officer
CIO	Chief Information Officer
CDGRS	Clinical Documentation and Generic Record Standards
HER	Electronic Health Record
FHIR	Fast Healthcare Interoperability Resources
HIG	Health Informatics Group (of the RCGP)
HIU	Health Informatics Unit (of the RCP)
HL7	Health Level 7
LMC	Local Medical Committees
NIB	National Information Board
NHSCC	NHS Clinical Commissioners
PHR	Personal Health and Care Record
PID	Project Initiation Document
PRSB	Professional Record Standards Body for Health and Social Care
RCGP	Royal College of General Practitioners
RCN	Royal College of Nursing
RCOG	Royal College of Obstetricians and Gynaecologists
RCP	Royal College of Physicians
RCPCH	Royal College of Paediatrics and Child Health
RCPsych	Royal College of Psychiatrists
SNOMED-CT	Systematized Nomenclature of Medicine - Clinical Terms

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1 Introduction

1.1 Purpose of this document

This document is a summary report of the improving diagnosis recording project. It presents:

- Guidance for the recording of medical diagnosis and problem lists in electronic health records and supplementary guidance (See section 4 for a copy of the guidance)
- The methodology adopted to develop the guidance. (See section 2 and appendix 2 of this report)
- Recommendations on further work needed (See section 3 of this report)
- Recommendations for systems to improve the recording of problems and diagnoses (See section 5 of this report)

The guidance contained in this document has been developed following consultation. However, it is in draft form and requires review before wider dissemination. Therefore, this document is submitted to the Professional Record Standards Body (PRSB) Advisory Board with the recommendation that, following its review by the board, the board sends it to the Strategic Clinical Reference Group (SCRG), and then to the Academy of Medical Royal Colleges (AoMRC) and the Faculty of Clinical Informatics (FCI) for feedback.

This project has been led by Dr Anoop Shah, Consultant in Clinical Pharmacology and General Medicine, THIS Institute Postdoctoral Fellow and Clinical Fellow for the Health informatics Unit at the Royal College of Physicians.

1.2 Background

1.2.1 Project summary

The purpose of this project was to improve the quality of recording of medical diagnoses and problem lists in electronic patient records. The project aimed to develop system wide guidance for the recording of medical diagnoses and problem lists in a structured form in patient records to enable standardization and uniformity across primary and secondary care.

It is recognised that the way systems are used and the culture for recording information in primary and secondary care are different. The guidance needs to be suitable for and adopted by both, to support the creation of a record that contains reliable, accurate, structured medical data that is interoperable and not view only.

It is acknowledged that there is need for a wider programme of work on diagnosis recording beyond this project, e.g. defining the attributes of diagnosis and the educational support required to implement guidance on recording diagnosis. This report identifies the further work needed.

1.2.2 Project scope

This project was the first phase in what it is hoped will become a longer-term programme to improve diagnosis recording practice. It aimed to develop professional, system wide guidance for the recording of medical diagnoses and patient problems in a structured form in patient records, including how to maintain problems lists.

The scope of the project was limited to medical diagnoses and therefore excluded nursing, allied health professional and social care diagnoses. It was limited in this way to ensure delivery of the project within the resource and time constraints. However, the project team recognises the increasing role professionals in nursing, the allied health professions and social care have in recording diagnoses, that they already contribute to recording diagnoses

and problems in primary care records, and that for interoperability there needs to be consistency across disciplines. Therefore, the project was mindful of its impact on other work related to other health and care professions.

1.2.3 Objectives

The objectives of this project are set out below:

1. To define what is meant by problem, symptom and diagnosis.
2. To clarify the difference in recording problems, symptoms and diagnoses. This will include the evolution from symptoms and disparate problems to definite diagnoses.
3. To provide guidance on how to record differential diagnosis and refuted diagnosis.
4. To define the responsibility for curating a problem list and when this should be undertaken.
5. To provide guidance on how to record comorbidities and continuing documentation of long-term conditions in secondary care.
6. To clarify 'active' and 'inactive' problem status.
7. To outline the appropriate application of the guidance in different clinical contexts, for example, recording diagnoses and problems in episodic care and in longitudinal problem lists.
8. To provide professional guidance that reflects the findings of the project with a view to implementation as capabilities improve.

1.2.4 Exclusions

Diagnosis recording is a large and complex area. The following are out of scope of this project, but it is recommended that they are carried out in subsequent projects:

- The implications for coding, especially how coding terminologies are manipulated and used for problem titles.
- A robust clinical safety case for the guidance.
- Work to enhance the information model and develop condition-specific detailed information models for diagnoses, incorporating concepts such as severity and evidence.
- Implementing the guidance in clinical practice and in systems for recording diagnoses, so that they have excellent usability and are used in a consistent way by a wide variety of clinicians.
- Nursing, allied health professional and social care diagnoses.
- How diagnosis and problem concepts might be manifested in any given system.
- How terminologies, ontologies and knowledge bases may be used to optimise the display of problems, diagnoses and related information to assist clinical decision

making.

1.2.5 Project governance

Oversight of the project was provided by a project board. End user representation at project board level was provided by primary and secondary care doctors.

2 Methodology used to develop the guidance

2.1 Development of initial draft

The project clinical lead, Anoop Shah, undertook a review of existing guidance, capabilities of current systems and current problems with how problem lists are recorded (see section 6). The outcome of this review was used to inform the first draft of the guidance which was taken to the project board for review and updated.

2.2 Consultation survey

The following groups of people were invited to review the draft guidance via an online survey platform (SurveyMonkey) between 4 October and 16 November 2018. A copy of draft guidance consulted on can be found in Appendix 1; the survey feedback can be found in section Appendix 2:

- PRSB advisory board members who are AoMRC members
- Attendees at the RCP HIU's diagnosis recording workshop that took place in October 2017
- Specialist society informatics leads
- Non-medical clinical professionals
- Pharmacists
- Frontline junior and senior doctors in primary and secondary care
- General Medical Council
- BMA
- Industry and informaticians
- CCIOs via the DigitalHealth CCIO network.
- NHS bodies and HEE
- Commissioners
- Provider information teams and coders

2.3 Roundtable discussion

A roundtable meeting was convened on 4 December, which reviewed feedback from the British Computing Society Primary Health Care Specialist Group meeting that morning, at

which it had been discussed, and the survey responses. The workshop also considered how the guidance would be disseminated, and recommendations for the design of clinical systems. A list of roundtable attendees can be found in Appendix 3. Specific topics discussed in the roundtable are outlined below.

Is 'condition' an appropriate umbrella term for a problem or diagnosis-like concept?

Various terms have been recommended to denote an aspect of the patient's condition that is relevant to healthcare and could be included on a problem list. These may be symptoms, diagnoses, examination findings, abnormal investigation results, or social factors. The term 'problem' is often used, in the sense that these pieces of information may be items on a problem list, but some of them may not be considered 'problems' in the conventional meaning of the word. The term 'condition' has also been suggested, and is used in the title of the FHIR 'Condition' profile, but it was thought to be confusing and sometimes inappropriate to call all problems 'conditions'. The group decided that none of the terms completely and unambiguously described the concept, but 'problem' was the best available term, as the concept of a 'problem list' is already in common use.

Creating problem and diagnosis records

It is difficult to create precise guidance of which conditions should be included in a problem list. The opinion was that the guidance should focus on the functional requirements, i.e. what is the problem list to be used for, and use this to inform which conditions should be included in a particular use case. A coded problem list should be viewable in different ways to suit different user needs.

Maintaining problem and diagnosis records

There was some discussion about the feasibility of maintaining an accurate and up-to-date problem list in secondary care outpatients. This is a major problem with the disjointed electronic health record systems that are in use today, and also with the health system, where an individual patient may be under the care of multiple specialties in multiple institutions, none of whom share records with each other. It was decided that the emphasis should be on facilitating care, and clinicians should update problem list entries in their domain at each encounter, and systems should work towards more sharing of problem and diagnosis lists rather than clinicians being expected to retrieve and transcribe them at each site.

Certainty and verification status of diagnoses

It was considered important to be able to record the evidence underlying a diagnosis in a clear way. Some diagnoses may be uncertain (suspected, possible, probable, provisional or working). Various options for certainty qualifiers have been tested in the emergency care data set: 'possible / probable / proven' was thought to be too complicated, and the concept of a 'working' diagnosis was not understood. The current set of qualifiers is 'suspected' and 'confirmed', which seem to be well understood by a wide range of clinicians.

A certainty diagnosis qualifier is also relevant to coding and billing. A patient with a suspected serious diagnosis might consume as much resource as a patient with a confirmed diagnosis, but no such qualifier can be submitted in HES returns. This means that all suspected conditions are ignored in coding, unless the clinical notes state that the patient was 'treated as ...' (i.e. a working diagnosis).

An attribute to mark 'disputed' diagnoses (where there is persistent disagreement between the patient and healthcare team about the diagnosis, or disagreement between healthcare professionals) was thought to be potentially important, particularly in psychiatry.

Attributes of a problem or diagnosis

The group considered what other attributes were common to many diagnoses. The overarching requirement was that the attributes should be simple and unambiguous for clinicians. Laterality was considered to be an important attribute which should be standardised.

General discussion

The general discussion towards the end of the meeting raised the question of structured versus unstructured data in electronic health records. Although structured data has many advantages (it can be used for clinical decision support and audited), it may be time-consuming to enter. SNOMED-CT subsets may help clinicians to select appropriate codes, but differential diagnoses and other elements of clinical thought are best suited to free text.

A national approach to developing data standards for diagnosis records, with coordinated information models and SNOMED CT subsets was proposed. This should accommodate the information needs of primary and specialist care, disease registries and billing.

2.4 Finalizing the deliverables

The draft guidance was updated following the consultation exercises and reviewed and approved by the project board. A copy of the final guidance can be found in Section 5 of this report, and recommendations for systems in section 6.

3 Recommendations for future work

The guidance produced through this project is an important first step in improving diagnosis recording practice. Successful implementation of the guidance and continual improvement in the recording of diagnosis requires close attention to the following three 'pillars':

1. Professional definitions

The healthcare community needs to create consensus definitions for clinical information to be recorded, and these definitions need to be owned, curated and consistently used.

2. Information models and terminologies

Use of information model formalisms (such as openEHR) and terminologies (SNOMED-CT) to define the professionally curated definitions in a computable form.

3. Consistent implementation across systems

Technical interoperability standards (e.g. FHIR) must be implemented consistently across sites, avoiding local customisation or other unwarranted variation.

In order to support this work, the project board recommends to the PRSB Advisory Board and NHS Digital the following:

- Identification and exploration of the implications for coding, especially how coding

terminologies are manipulated and used for problem titles.

- Development of a robust clinical safety case for the guidance.
- Further work to agree the attributes to diagnosis and gain consensus involving specialist societies.
- To trial the professional guidance in several hospitals and embed it in electronic health record user guides. We recommend that medical schools and postgraduate training programs also include guidance and teaching on the appropriate use of problem lists to facilitate patient care.
- To agree a technical specification for a standard information model for problem lists in all electronic health records - this should be in the form of a profile of the FHIR 'Condition' resource and a corresponding openEHR archetype.
- To design a data sharing model which will allow problems and diagnoses to be shared between primary and secondary care.
- To engage specialist societies in the development of diagnosis archetypes within their domain, which will enable clinical data to be recorded in a consistent way across care settings and facilitate the use of the data for research and audit.
- To create an entity for central leadership of clinical modelling and developing diagnosis archetypes, ensuring that they follow a common pattern. This could be a collaboration between PRSB, NHS Digital, INTEROPen, the Academy of Medical Royal Colleges, HDR UK and the Faculty of Clinical Informatics.

4 Guidance for recording problems and diagnoses in electronic health records

4.1 Introduction

The purpose of this guidance is to provide principles and suggestions of good practice to help clinicians record problems and diagnoses in a way that supports good clinical care, audit, research and interoperability. Problem oriented records have been used for many years in primary care, but their use in secondary care and shared care are new, and this guidance aims to describe a common professional way of working with such records across clinical specialties.

The guidance may be useful for training clinicians in the use of electronic health records, and may be tailored to the features of the system used in a particular institution. Patients and carers are increasingly being enabled to access and engage with their health records, and this should be considered in the way information is recorded.

It is acknowledged that many existing systems lack important features or have poor usability, and the full report contains recommendations for health services, system developers and national bodies in improving systems in the future.

4.2 Scope

This guidance covers general recommendations for recording problems and diagnoses in all patient groups, care settings and specialties, choosing problem titles from a clinical terminology, and maintaining accurate records over time. It does not cover nursing or therapy diagnoses, or detailed specialty requirements for recording diagnoses in particular disease areas, although the intention is that the general principles will be applicable in many cases.

4.3 Definitions

Different electronic health record systems currently use different terminology to refer to problems, diagnoses, comorbidities, past medical history etc. To make this guidance clear, a brief description of the structure of electronic health records and a standard set of definitions is provided here.

4.3.1 Description of terms

Problem or issue: Any condition pertaining to a patient (such as a symptom, sign, noteworthy investigation result, risk factor, psychological factor, social factor, health-related issue or diagnosis) that the clinician feels is important enough to be entered in the healthcare record. Problems and issues may be active (currently relevant to care or under active healthcare management; prominent in the record) or inactive (past conditions or those which do not currently require active healthcare management; less prominent in the record).

Problem list: A current list of a patient's problems or health issues, ideally with dates and stating which are active and inactive, which is intended to give clinicians a quick and accurate summary in future encounters. Problem entries in the list may optionally have links to other information in the health record such as consultation notes, treatments or investigations. It may be possible to filter the list by active / inactive problem, or by date, diagnosis category or specialty.

Symptom: An abnormal experience perceived by a patient or subjective evidence that may be due to a disorder of structure or function of the body.

Sign: An abnormal finding on clinical examination or objective evidence that may be due to a disorder of structure or function of the body.

Noteworthy investigation result: A radiographic or laboratory finding, for example a shadow on a chest X-ray or a low blood sodium level. This may have no associated symptoms or signs but may need to be brought to the attention of clinicians, for example if there is a need for further investigation.

Diagnosis: A label assigned to a patient's health condition by a clinician based on clinical evidence and reasoning (e.g. type 2 diabetes). The diagnosis may describe the underlying disease process if known.

Confirmed diagnosis: Medical diagnoses can rarely be certain, but 'confirmed' means that the patient is being treated as though the diagnosis is true, and clinicians have sufficient confidence in the diagnosis that there is no current plan of further investigation to confirm or refute it.

Suspected diagnosis: A diagnosis which is thought to be a possibility, and for which further investigation may be planned.

Differential diagnosis: A list of suspected, unconfirmed diagnoses that the clinician is considering as possible causes of a patient's symptoms or other health condition.

Refuted diagnosis: A diagnosis which may have been suspected previously, but which is now known to be incorrect.

Disputed diagnosis: A diagnosis over which there is persistent disagreement between professionals or between professionals and a patient, which is important to know when making any clinical decisions relating to the diagnosis.

4.3.2 Structure of medical records

Medical records can be structured in different ways:

- **Encounter-based:** one record per healthcare visit (such as emergency department records, or secondary care outpatient records)
- **Longitudinal:** a continuous record over time (such as general practice records)
- **Problem-oriented:** longitudinal records where items of clinical information (such as prescriptions or consultations) are linked to entries in a problem list. This is intended to make it easy to view or filter information relevant to a particular problem or diagnosis.

General practice records have features of all three paradigms; individual consultations are recorded in an encounter-based way, but a sequence of consultations comprises a longitudinal record with the capability to be problem-oriented. The level to which clinical information is organised and linked to problems varies by practice and practitioner.

Secondary care organisations have different levels of maturity of electronic health records. Typically outpatient records are encounter-based and the inpatient record is longitudinal within admissions, but some systems have the ability to persist problem lists between encounters.

4.3.2.1 Encounter-based records

Records of healthcare encounters typically contain the following items of information:

Presenting complaint: The reason that a patient seeks a healthcare consultation, such as a symptom that is concerning them (commonly recorded in emergency care, but may not be recorded for routine appointments).

Encounter problems or diagnoses: The final problems or diagnoses for which the patient received care during this encounter.

Other problems: Problems that were not the particular focus of this encounter, sometimes referred to as 'comorbidities'.

4.3.2.2 Problem-oriented records

Clinical information in the health record is linked to a problem list which persists between

encounters.

Problem list: A summary list of a patient's problems, categorised as active or inactive.

Problem title: A word or phrase identifying or summarising the problem.

Active problems: Patient problems that currently require healthcare input, and a clinician considers that they should be prominent in the record.

Inactive problems: Problems that do not require ongoing healthcare input, and are less prominent in the record.

4.3.3 Clinical coding

Problems and diagnoses in encounter records and problem lists should be encoded with the prevailing methodology mandated by the NHS. In 2019 this may be achieved using either SNOMED CT (a structured clinical terminology vocabulary for use in electronic health records), or a statistical classification such as ICD-10 (International Classification of Diseases, World Health Organisation). Going forward the preferred route will be for clinicians to record entries based on a clinical terminology (SNOMED CT) with the electronic system handling the mapping / conversion to classification codes (ICD) in the background. The combination of these makes it easier to use this information for purposes such as identifying groups of patients with specific diagnoses, clinical decision support, audit and research.

4.3.4 Capability of clinical systems

Creating accurate problem and diagnosis lists requires time and resources at the point of data entry, but in well-designed systems it should reduce the need for subsequent duplication, repetition or transcription. This guidance does not specify a particular system but has implications for the functionality of such a system. It assumes that the electronic health record system allows the creation of a persistent longitudinal record of problems and diagnoses with dates, active / inactive status and additional information. The College is working with the Professional Records Standards Body and other agencies to promote improvements in the capability of electronic health record systems, as well as further work on defining the technical specifications of systems.

4.4 Principles and recommendations

Accurate and precise recording of problems and diagnoses is essential for safe patient care including clinical decision support, and to improve health, care and NHS services. Problem lists should be complete, consistent, accurate, relevant, accessible, timely, unambiguous, and where appropriate and possible, linked to treatments and other information. The indications for medication and other treatments that a patient is currently receiving should be included among the conditions listed in the problem list.

4.4.1 Creating problem and diagnosis records

4.4.1.1 *What to record as a problem*

Problem lists may be created incrementally, over a number of healthcare encounters, or may be created based on patient history and historical records when a patient presents to a new care setting.

The function of a problem list is to ensure that important summary information about a patient's past and present conditions, that is relevant to their current care, is readily available to clinicians treating the patient.

In order to fulfil this function, problem lists typically need to include the following:

- Any condition which is relevant to a patient's current care, such as those for which they are currently receiving treatment or follow-up
- Major past conditions that may have long term consequences or complications, such as myocardial infarction (heart attack).
- Chronic medical conditions (e.g. diabetes, hypertension).
- Operations that may have long term consequences or complications (unless these are recorded separately in a surgical history section).
- Any other issues that may impact on care, including social, psychological and lifestyle issues that are not recorded in immediately visible structured data areas. An example might be an abnormal test result which needs to be further investigated, flagging it as a problem would be a reliable way to alert the next clinician taking over care.

Electronic health records typically have structured areas for recording contact details, allergies and medication, and may have areas for recording family history, social history, health behaviours, referrals, care plans, patient preferences, reasonable adjustments and alerts. Using these structured areas will ensure that the information is available to different parts of the system, such as clinical decision support, and is aggregated correctly for audit and service planning.

However, it is good practice to also create problem list entries for information that needs to be brought to a clinician's attention quickly, such as history of a severe allergic reaction (anaphylaxis) or heavy drinking, but absence of a problem list entry should not be interpreted as absence of information in these categories.

When using a shared problem / diagnosis list, be careful not to create unnecessary duplicate entries.

4.4.1.2 Episode management and chronic problems

In a problem list there should be only one entry for each occurrence of a problem. Thus for chronic problems such as diabetes, there should only ever be one entry. Acute problems such as heart attacks may occur multiple times in the problem list, but each entry should represent a separate clinical event and not merely a new consultation relating to that event.

To support care for chronic conditions with exacerbations (such as asthma), the record should allow clinicians to easily identify the chronic condition as well as the dates and nature of exacerbations. This can be achieved by recording exacerbations as acute problems (inactive after the acute episode is over) linked to the problem entry for the chronic condition (which stays active). Some systems may have alternative specific ways to record this information, such as encounter-based records with attributes 'first', 'new' and 'continuing', which can be used to document the time course of a problem.

This will enable the number of acute episodes and the date of the most recent episode to be accurately represented. It will also allow other clinical information such as prescriptions and clinical notes to be linked to the correct episode of the problem in the record. This will assist clinical decision making and also enable accurate audit.

4.4.1.3 Accuracy and precision of problem titles

Summary views of the record may show only the problem titles, so it is important that they are correct summaries of the patient's condition, even if they are quite general. If coding using a clinical terminology such as SNOMED-CT, the term should be drawn from the correct part of the terminology hierarchy. For example, if a person has a family history of colon cancer, the problem title 'Family history of cancer' is acceptable (accurate but imprecise), but 'Colon cancer' is not, because it implies that the person has colon cancer, which may be untrue.

Problems should be recorded at the highest available level of precision and pathological understanding that is feasible within the care setting, but not at the expense of accuracy. For example, a histopathologist may be able to record a pathological subtype and genotype of a lung cancer, but an emergency doctor may record it simply as 'lung cancer'.

When updating a problem list, if you find more than one entry for one episode of a problem, possibly with different coded terms, the two entries should be merged and usually the onset date of the earliest entry should be made the onset date of the remaining entry.

If additional detail is required (such as laterality or severity), and there is no code or structured way of recording it, it should be added in a text comment. For example, the term 'Asthma' can be accompanied by text 'triggered by neighbour's cat'.

However, text comments associated with a term should never modify the meaning of the original term. For example, the term 'Asthma' should not be accompanied by text such as 'father has' (because problems should only apply to the patient), 'suspected' (see section 5.4.1.4 below) or 'excluded' (see section 5.4.1.5 below).

4.4.1.4 Suspected and differential diagnoses

It is important to record suspected and differential diagnoses in the clinical notes, but they must not be confused with confirmed diagnoses. They should be documented using a specific flag for suspected diagnoses, or a pre-coordinated SNOMED CT term for a suspected condition, or if there is no structured option they can be entered as text in the clinical notes alongside the symptom, sign or abnormal investigation result that suggested the diagnosis (e.g. Problem: Shortness of breath; Comment: Suspected heart failure).

However a text comment such as 'suspected' must never be used to try to change the meaning of a SNOMED CT term for the actual condition; this will convey an inaccurate meaning if the text is not shown and will be counted incorrectly when data are aggregated for audit or research.

4.4.1.5 Refuted diagnoses

When reviewing a problem list, remove any problems or diagnoses that are incorrect because they were entered in error, and add a text comment documenting why (the system will retain a log of the original entry in the audit trail). However, if a diagnosis is part of a

differential and is refuted, i.e. found to be untrue, or if clinical decisions were based on it when it was thought to be true, it is important to document that the diagnosis was actively refuted. This will help to inform further investigations.

If the system does not provide a structured method of recording refuted diagnoses, record as the problem title the symptom, sign or abnormal investigation result which originally suggested the diagnosis, and add a comment stating which diagnosis was refuted and why.

4.4.1.6 Disputed diagnoses

If there is persistent disagreement as to the nature of a diagnosis between healthcare professionals, or between healthcare professionals and a patient with capacity to understand the diagnosis, this should be documented in free text comments associated with the diagnosis. If the EHR has a flag to identify disputed diagnoses, it should be used in such cases, to draw this fact to the attention of healthcare professionals treating the patient.

4.4.1.7 Important attributes to record about problems

Record the date of onset (or an approximate date if the exact date is not known) for all problems and diagnoses, if possible.

Ensure that information about the care team responsible for managing a problem is easily accessible, if it is not the general practitioner or primary team for an inpatient. This may be recorded in a care plan linked to the problem.

For problems that are diagnoses, also record the following information about the diagnostic process, where possible and appropriate:

- A way to easily locate the evidence (such as history or investigations) underlying the diagnosis; this could be in the form of a link (if the system has the capability), or a brief statement.
- Which clinician, team or service made the diagnosis, if known.

The exact location where this information can be recorded will vary between electronic health record systems. If no structured field is available, record it in a comment associated with the problem.

4.4.2 Maintaining problem and diagnosis records

Problem list maintenance is essential in order to ensure that it remains relevant, up-to-date and uncluttered. Problem list maintenance should include the following actions:

- Add missing problems
- Delete incorrect problems
- Convert problems to inactive if they are no longer relevant
- Combine or merge problems that are duplicates
- Evolve each problem into the most up-to-date diagnosis
- Ensure that all problems have correct attributes

- Group related problems together

4.4.2.1 Problem list reviews

The general principle is that problem lists should be able to quickly provide appropriate information to clinicians who are seeing the patient, to support patient care. In order to achieve this, clinicians seeing a patient should review, verify and edit problem list entries within their domain, prioritising the most important problems and diagnoses.

Consider checking that the problem list is complete and up to date at any time the patient is seen by a clinician, but particularly at the following points in a patient's journey:

In primary care:

- First appointment after registration
- Review of chronic condition or medication review

In secondary care:

- Pre-admission clinic
- Admission to hospital
- Discharge from hospital

In any care setting:

- When writing a medical report based on the patient record, such as a transfer of care document
- When assuring the record for patient access
- When receiving a transfer of care document

4.4.2.2 Current, past, active and inactive problems

Clinicians should be able to rapidly assimilate important information needed to treat patients safely by viewing the active problem list. Problems that have resolved should be marked as such (or given a resolution date) so that they will appear as 'past' rather than 'current' problems.

Chronic conditions and past conditions requiring ongoing input or consideration in clinical care should be marked as 'active'. Classification of a problem as active or inactive is separate from the underlying disease activity. For example, cancer in remission that still requires ongoing follow-up should have a problem activity status of 'active'.

Problems should be marked as 'inactive' when they no longer require consideration during clinical care. Timely conversion of problems to inactive status is important to avoid cluttering the problem list, and to ensure that important problems are always prominent.

4.4.2.3 Problem lists in inpatient settings

Problem lists should be created or updated as part of the clerking process, taking into

account the patient's history, their general practice record (if available) and other previous documentation.

Problem lists should be kept up to date during the hospital admission, so that at any time a doctor called to see the patient can know what the active problems are.

Some systems allow diagnoses on the problem list to be transferred easily to a discharge summary. Before writing the discharge summary, the problem list should be updated, marking as inactive any problems specific to the hospital stay that are not relevant for the long term or for the GP to know.

4.4.2.4 Problem lists in secondary care outpatients

Outpatient secondary care episodes may be infrequent and relate to specific clinical issues, and patients may be discharged after one or two appointments. Given the time constraints in many outpatient clinics, it is unreasonable to expect clinicians to create and update a comprehensive problem list for all patients. However, it is important that conditions being actively managed in secondary care are included.

When viewing a problem list in secondary care, bear in mind when it was last updated and that it may not be comprehensive. Seek confirmation by asking the patient or reviewing the general practice record, if available, as it is likely to be more up to date.

4.4.3 Communicating problems and diagnoses

Encounter problems must be recorded on all discharge letters and clinic letters. Other problems should also be recorded if they impacted on the patient's care during the episode, but it is not necessary to include a comprehensive list of inactive problems that have no ongoing impact.

4.4.4 Using advanced features of problem-oriented records

Some electronic health record systems have the following features, which may be helpful to make the record easier to assimilate and search.

4.4.4.1 Linking documentation to problems

Problem oriented documentation (linking individual items of clinical documentation to problems) can be useful to link problems to:

- Medication
- Test results
- History and examination specific to the problem
- Clinical decisions
- Other clinical documentation

General information should not be forced to relate to a problem if it is inappropriate, and 'non-problems' should not be created purely to link to generic healthcare activities. If a consultation or intervention relates to multiple problems, and there is no facility to link it to multiple problems, it should remain unlinked, and if appropriate brief comments can be

entered alongside each problem.

4.4.4.2 Major and minor problems

Some systems provide the ability to categorise problems as 'major' or 'minor', or assign a priority number. 'Minor' problems may automatically become inactive after a period of time. The use of these classifications is not standardised, so it should not be relied upon to identify all serious conditions.

4.4.4.3 Relationships between problems

Merging, nesting and semantic linking functions of the electronic health record system can be used to improve the organisation of the problem list, to make it easier to understand quickly. For example, if a patient has angina and previous myocardial infarctions (heart attacks), they can be nested under 'ischaemic heart disease'. However, beware that nesting may result in serious conditions being hidden, so always expand the list to ensure that no problems are missed.

4.5 Example

A patient visits the GP and complains of shortness of breath. The GP examines the patient and suspects that s/he has heart failure, in which the heart is unable to pump enough blood to stay healthy. The GP also notes that the patient has an irregular pulse, and might have atrial fibrillation. These symptoms and signs are recorded in the problem list, with the suspected diagnoses in text comments:

Shortness of breath *suspected heart failure*

Irregular pulse *suspected atrial fibrillation*

It is important to note that 'heart failure' and 'atrial fibrillation' are not entered as diagnoses or problems in their own right, because they are not yet confirmed.

The patient undergoes relevant investigations (ECG, B-type natriuretic peptide and echocardiogram), which confirm these diagnoses. The GP updates the signs and symptoms to confirmed diagnoses, and links them to supporting evidence (investigation results), or adds a comment if the system does not have functionality for linking:

Heart failure *confirmed on echo <date>*

Atrial fibrillation *confirmed on ECG <date>*

The patient visits the cardiologist who refines the heart failure diagnosis based on the echo report, which shows that the heart pumps well but fails to relax properly (Heart failure with preserved ejection fraction, HFpEF). The atrial fibrillation comes and goes, and is labelled as 'paroxysmal'. After reviewing the outpatient clinic letter, the GP converts the existing diagnoses in the problem list to the more specific diagnoses given by the cardiologist:

HFpEF *confirmed on echo <date>, under Dr X's heart failure clinic*

Paroxysmal atrial fibrillation *confirmed on ECG <date>, under Dr X (cardiologist)*

5 Recommendations for systems

5.1 Executive summary

This project delivered by the Royal College of Physicians' Health Informatics Unit and the Professional Records Standards Body (PRSB) aimed to produce guidance for healthcare professionals in recording diagnoses and problems in a way that best supports clinical practice. The project also aimed to make recommendations for national data standards and electronic health record system design, to support better recording in the future, but the production of specific technical standards was out of scope of this project. However, the project has made some recommendations in this area and suggestions for future work, which are outlined in this document.

5.2 Information models for problem and diagnosis lists

Electronic health record systems should be clinically safe and should enable clinical meaning to be maintained faithfully whenever information is entered, viewed or transferred. Systems should be user-friendly and encourage clinicians to use them in the way they are intended to be used. Information should be recorded once and re-used as needed, without a need for duplication or manual transcription from one system to another.

Degradation of information will occur in transferring a patient's information from a system with particular capabilities to another system without some of these capabilities. In the short term the priority is to ensure that any such degradation is clinically safe, for example a suspected diagnosis should not be misinterpreted as a confirmed diagnosis simply because the receiving system is not able to store this attribute. In such a case the suspected diagnosis should be converted to text, which will lose the advantage of being able to process the information by computer, but will at least be safe for a clinician to read and interpret.

We strongly recommend that the capabilities for recording information in problem lists is standardised according to data models defined by the clinical community rather than by vendors, which accommodates the information models of data entered in systems in common use today. Information exchange standards for transfer of complete general practice records from one practice to another (GP2GP) should accommodate all these features. A generic information model should be defined for all problems and diagnoses, along the lines of the openEHR 'Problem/Diagnosis' archetype [1] and the HL7 FHIR 'Condition' resource [2], with more detailed disease-specific models being developed in the future.

5.2.1 Patterns of changes to problems

Systems should provide distinct ways of linking problem list entries in order to faithfully record the changes, and distinguish between the following three patterns of changes: corrections to the record (for audit and medico-legal purposes), changes in clinical thoughts (useful for clinicians and for studying healthcare processes), and changes in the underlying clinical condition (essential for clinicians and for studying biology; this is what should be retrieved by naïve searches on SNOMED CT codes).

'Nesting' of problems is not considered a change in this context; it is a way of grouping certain problems together for ease of display, but each retains its own identity as a distinct problem.

Correction of medical record: correct or delete

When correcting entries in the medical record, previous versions should be stored in the audit trail. These correction methods must not be used to document a change in clinical thought or clinical condition. The correction should be applied to the original entry, not a downstream copy, to avoid creating multiple versions of the truth.

Incorrect problem entry → (correct) Corrected problem entry

Incorrect problem entry → (delete) Deleted problem

Change in clinical thought process: update or refute

Suspected diagnosis → (update) Problem (confirmed diagnosis)

Vague problem → (update) Refined, specific problem

Problem 1 + Problem 2 → (update) Merged problems (all data items linked to the original problems are now linked to the merged problem. Systems should store the links to the original problems and be able to undo merges)

Problem / diagnosis → (refute) Refuted diagnosis

Change in clinical condition: evolve or resolve

Problem 1 → (evolve) Problem 2: change in the nature of a problem, recorded with the date that the change occurred

Problem → (resolve) Resolved problem

5.2.2 Suspected diagnoses

SNOMED CT contains pre-coordinated 'suspected' terms for a selection of conditions which are thought to be useful for documenting investigation and diagnostic workflows. A purist approach might advocate avoidance of these terms, and code the individual symptoms and signs as problems at the highest level of certainty (e.g. 'Shortness of breath' and 'Oedema'), but there are a number of such constellations where a summary term (e.g. 'Suspected heart failure') may be more concise. Pre-coordinated SNOMED CT terms exist for suspected cancers and other selected conditions. They can be used in problem lists in the usual way, but they only include a tiny fraction of all problems or diagnoses that a patient may have.

An alternative or complementary approach is to create post-coordinated SNOMED CT terms for suspected conditions, or include the SNOMED CT term in a structured data area where the information model specifies that it represents a suspected condition. This structure will inform the interpretation of the underlying SNOMED CT code for the condition, ensuring that it is not included in naïve searches of conditions by SNOMED CT code. Systems may enable suspected diagnoses to be recorded at the encounter level or the patient level, and they may optionally be linked to one or more symptoms, signs or noteworthy investigation results entered as problems. A suggested information model could be as follows:

Suspected diagnosis:

- Name: code or text (mandatory)

- Link to problem: symptom, sign, investigation result or general diagnosis for which this suspected diagnosis is an explanation, specific diagnosis or potential cause
- Status date (the date on which the diagnosis was suspected, usually the same as the date of recording)
- Date of recording (mandatory – from system, or inherited from the composition within which the suspected diagnosis is stated)

Clinical systems should contain user-friendly methods of converting a suspected diagnosis into a confirmed diagnosis and adding it to the problem list, but they must make it clear to users that this conversion is being done.

5.2.3 Refuted diagnoses

A problem may transition into a state of being 'refuted'. The information model and storage schema must ensure that refuted diagnoses, like suspected diagnoses, do not appear in naïve searches of condition by SNOMED CT code.

Refuted problems may contain all the attributes of problems that exist, as described below.

5.2.4 Confirmed problems and diagnoses

We recommend that each entry in a problem / diagnosis list has the following attributes, divided into 'essential' attributes (those that are needed for safe transfer of information), 'diagnosis' attributes (clinical facts that add detail to the diagnosis) and 'problem status' attributes (used to assist record navigation, prioritisation or task management; may differ between specialties or institutions, and should be handled separately when transferring information from one problem list to another):

Essential attributes

- Name: code or text (mandatory)
- Status date: defaults to the date of recording within the electronic health record system, but may need to be specified explicitly when entering historic diagnosis statuses
- Onset: structured date/time allowing various degrees of precision
- Resolved: structured date/time allowing various degrees of precision
- Unique identifier: this will allow multiple instances of the same diagnosis to be linked
- Date/time last updated: when the record was created or last modified
- Updated by: name, role, specialty and institution of the person who created or last modified the record
- Date/time of recording: when the record was imported into the current system (same as 'Date/time last updated' if the record was created in the same system)
- Recorded by: name, role, specialty and institution of the person who imported the record into the current system (same as 'Updated by' if the record was created in the

same system)

Diagnosis attributes

- Severity: code or text
- Body site: code or text
- Laterality: left or right (this could be either incorporated in body site or a separate data item. The advantage of a separate data item might be to facilitate implementation if systems do not have the capability to record structured body site, as this is essential to prevent the 'never event' of wrong side surgery)
- Stage: code or text
- Clinical behaviour: code or text
- Evidence: codes or text comments, or links to investigations or clinical notes
- Manifestation: codes or text comments, or links to other diagnoses
- Aetiology: codes or text comments, or links to other diagnoses
- Diagnosis details: structured details for particular diagnoses, to provide data for clinical decisions, research, audit and registries
- Description: text comment

Problem status attributes

- Active / inactive
- Priority (importance level, or major / minor)

Systems should be able to distinguish between current / past and active / inactive, in order that these attributes (which are used by many existing systems) can be faithfully transferred. A current problem is a chronic problem without a resolution date; a past problem is one which has resolved. However, whether a problem is active depends on the healthcare context; a 'resolved' cancer may remain an 'active problem' if there is a risk of recurrence or the patient is receiving surveillance monitoring.

The data types, value sets and terminology bindings for each of the items in these data models are out of scope of this project, but need to be specified and agreed upon. The underlying data should be viewable in different ways to facilitate clinical decision making.

Viewing options for the problem / diagnosis list should include:

- Chronological, by date of onset
- Problem oriented: active / inactive, major / minor, current / past
- By body system or specialty, optionally prioritising problems related to the current specialty

- Changes in problem evolution over time
- Changes in clinical thought over time or by encounter, showing who made each update (which user, role, specialty and institution)
- Audit view of corrections and changes over time, showing who made each edit (which user, role, specialty and institution)

5.3 Developing a framework for shared records

It is essential that systems should be able to carry over problems and diagnoses between one episode and the next. Another useful function, but more difficult to achieve, is to enable diagnoses to be shared between systems. Ideally, the diagnosis and problem list architecture within the NHS should follow the patient's journey through primary and secondary care, ensuring continuity across organisational boundaries. It should ensure that the provenance of data is clear, avoid duplication, and be safe and reliable. The overarching philosophy is to enter data once and re-use it many times.

Local health and care record sharing (LHCR) is being implemented in many areas, but there is a need for functionality to share data outside the region, for safe and effective care of complex patients who receive care from multiple institutions in different regions.

We propose the following functional requirements of the shared record framework:

- It should remove the need for manual transcription of problems or diagnoses; instead it should be enable them to be copied, linked or referred to from another system.
- It should enable any clinician to access a combined, detailed list of a patient's problems and diagnoses from different sources, including diagnoses embedded in communications such as discharge summaries (subject to consent for sharing). Information should be prioritised and presented in a way that is clinically safe and easy to assimilate.
- To avoid data degradation, it should ensure that dates and other important attributes of inpatient problems can be easily transferred to the GP record (currently discharge summaries contain diagnoses without dates).
- For audit purposes, it should enable the list of problems and diagnoses that were viewable by any clinician at any time in the past to be recreated.

5.3.1 Scenarios

The system should facilitate care in scenarios such as the following:

Inpatient admission

Currently the clerking process for inpatients involves a large amount of time spend on compiling background information (manually transcribing information from previous notes, correspondence, summary care record, conversations with the GP etc.) This is an inefficient and time-consuming process. Ideally, it should be possible to view previous problems and diagnoses recorded in any NHS system, and create a relevant summary without manual transcription. This could free up time for clinicians to focus on the patient's current story.

Inpatient discharge

A patient may have acquired a number of diagnoses or had problems updated during their hospital stay. Currently, these are communicated to the GP in a letter and the GP has to subsequently transcribe them into the problem list. This is a time-consuming process, and details such as disease subtype or date of diagnosis may not be transferred.

Outpatient care

Patients may be seen by a number of healthcare practitioners in different institutions, and diagnoses may change as more information is obtained (e.g. an episode of loss of consciousness may initially be thought to be a seizure but may turn out to be due to a cardiac problem). Currently this information is communicated via the GP, and only the GP can update the problem list, potentially creating delay in recording updates to clinical thinking. A better system of sharing information between secondary care organisations is needed.

5.3.2 Options for future systems

As a first step, we propose standardisation of the information model of problem and diagnosis records, and implementation of an application programming interface (API) which will allow the retrieval of diagnosis and problem lists from the GP record or any other NHS electronic health record system (with appropriate permissions). In the future, problem list entries with links to other parts of the record (e.g. investigations providing evidence for the diagnosis) should also be transferable between systems, using the National Record Locator Service.

There are a number of potential sharing options which could be explored for future systems, ensuring that patient safety is prioritised. These include:

Enable problems to be easily linked and transferred between systems

This proposal will provide the functionality to view and retrieve problem list entries from any NHS electronic healthcare record system. This will require a standardised format for recording problems and diagnoses, and a unique identifier to track different versions of a problem over time. This would enable clinicians to create problem lists by combining problem and diagnosis information from GP and secondary care systems, and merging them with entries already in the problem list. It would also enable diagnoses in discharge summaries to semi-automatically populate the GP record. It should be possible to view the provenance of problems (such as the user, role and institution attributed to each update) in a user-friendly way.

Enable the GP problem list to be edited by other organizations

A potential option is to enable the GP's problem list to be shared with other clinicians. Although this has advantages (it may enable the list to be more up to date and enable greater detail to be recorded), there is a risk that the problem list may become inaccurate if it is not curated correctly, and it is difficult to know who would be responsible for maintaining it. As an alternative to direct editing, the system may alert GPs to changes and allow them to edit or approve them, similar to their workflow for receiving laboratory results.

This arrangement would require professional agreement on how different organisations work with the problem list, and who has overall responsibility for ensuring the records are accurate

[3]. For example, the sharing arrangement might apply to only certain specialties from local hospitals, and require agreement of the GP and the patient.

A shared specialist diagnosis registry alongside the GP problem list

Specialist diagnosis data is currently submitted to registries in a process separate from clinical data. A shared record which acts as both a clinical record and a diagnosis registry could avoid duplication of data entry, and ensure that detailed diagnosis records are available to clinicians at the point of care. The specialist team would be responsible for the accuracy of diagnoses within their domain. Problem list entries in clinical systems could be linked to the detailed entry in the diagnosis registry, providing a single source of truth.

Patient views on mechanisms for diagnosis information sharing

There is lack of consensus among the clinical informatics community as to the preferred method for sharing, and we are not aware of any prior work with patients to explore their thoughts on this issue. We carried out a patient workshop on 3 April 2019 with 17 members of the University College London Hospitals Biomedical Research Centre Patient and Public Involvement group. They were invited to a session where options for sharing information between hospitals and general practices were demonstrated, and they were asked to discuss the options in two facilitated groups, with their final preferences collected by an anonymous vote.

Participants in the patient workshop were mostly in favour of having a GP problem list that is editable by specialists as long as the provenance of any changes was clearly recorded (11/17), with the second most popular option being a structured means of suggesting changes (4/17), and only 2 participants preferring a 'view only' option (Appendix 4).

5.4 Diagnosis archetypes for detailed phenotypes

Currently, detailed diagnosis records included in disease registries or used for specialist care are shared very little. Diagnoses are typically transcribed manually into discharge summaries and GP records, resulting in duplication and loss of detail. There is no standardisation between specialties, and key information is recorded in multiple locations.

We recommend that specialist societies should provide recommendations on the recording of diagnoses within their remit, both regarding terminology (creating a SNOMED CT subset), and information that make sense for clinical use and for research. They should engage with digital leaders in developing their requirements for registry data collection, aiming for this information to be collected in usual clinical care rather than as a separate process. This clinical modelling initiative would need buy-in from NHS Digital, PRSB, other national bodies and healthcare providers, and strong overall leadership.

The clinical community should also curate a list of important chronic medical conditions (e.g. diabetes) which it is always essential for clinicians to know in order to provide safe care, and which will always be considered as major active problems in problem lists. This will help to improve the consistency of the way in which these problem lists are viewed, and improve safety.

Diagnosis archetypes can be associated with profiles of the prominence and behaviour of each diagnosis to help automate curation of the problem list. An outline specification for the diagnosis archetypes could be as follows:

- Scope:
 - Linked to a broad SNOMED CT term (e.g. 'diabetes'), and triggered in the user interface by entry of the SNOMED CT term or its children
 - Encompassing all subtypes amongst which there may be diagnostic uncertainty (e.g. type 1 diabetes, type 2 diabetes, maturity onset diabetes of the young)
 - Looked after by a single clinical specialty
 - Requiring a single information model for all subtypes of the disease
- Information model:
 - Definition of which attributes from the diagnosis model are valid and relevant (e.g. laterality and body site are irrelevant for diabetes)
 - Value sets for severity and stage
 - Additional data points for specific conditions
- Terminology:
 - SNOMED CT subset that is valid for specifying a subtype of the condition
- Problem status:
 - A clinically safe problem status profile, either:
 - Always active (for serious conditions relevant to all care settings, such as diabetes)
 - Active for a clinically defined period of time after last update, or until manually inactivated (for acute conditions)
 - Default active, until manually inactivated (most conditions)
- Recommended linked conditions:
 - e.g. ischaemic heart disease to be included as a diagnosis for all patients with myocardial infarction, and linked to it
- User interface - specialty view:
 - Define which medication, tests and clinical measurements are relevant to the diagnosis

5.5 **References**

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6 Supporting evidence and rationale

6.1 Executive summary

This project, delivered by the Royal College of Physicians' Health Informatics Unit and the Professional Records Standards Body (PRSB), aimed to produce guidance for healthcare professionals in recording diagnoses and problems in a way that best supports clinical practice. The project also aimed to make recommendations for national data standards and electronic health record system design, to support better recording in the future.

General practice is more advanced than secondary care in the use of problem oriented records, and already has professional guidance in their use. This new guidance builds on the experience in general practice and is intended to encourage common understanding and practice across all medical specialties, which will be particularly useful for secondary care.

This guidance was developed based on a review of current guidance, published research and information models for current problem and diagnosis lists, an online consultation survey and a roundtable discussion with representatives from NHS Digital, other national bodies and a range of clinical specialties.

6.2 Background

In the UK, general practices (GPs) have been using computerised patient records since the 1980s [1]. All GP electronic health record systems currently used in the UK have the capability for problem-oriented record keeping. However, in secondary care, a diverse range of paper-based and electronic systems are used for recording clinical information, with no overarching guidance on how key information such as diagnoses and other health problems should be recorded.

6.2.1 Problem oriented records

Problem-oriented medical records have been recommended since the 1960s as a way to improve medical documentation to facilitate safe, effective care [2]. It was envisaged that future medical records would be computerised, with clinical assessments and treatment information categorised neatly by patient's diagnoses or problems. This would improve the quality and safety of care, and yield useful data for reporting, audit and research [3]. Without problem oriented documentation, health records may contain multiple episode-based diagnosis records for chronic conditions [4].

Fifty years on from the work of Larry Weed, there has been progress in implementation of electronic health records, but the recording of diagnoses and the use of problem lists is inconsistent across the NHS [5].

6.2.2 What are problem lists intended to achieve?

Problem lists are intended to provide a summary of a patient's main health conditions, diagnoses or other issues relevant to healthcare, so that clinicians seeing the patient can rapidly assimilate important information relevant to clinical decision making.

Problem and diagnosis lists, when used properly, can provide a longitudinal overview of a

patient's health events as well as an overview of current status and a way to organise other information in the health record in a meaningful way. This is useful for creating disease registries, audit, linking medication and procedures to the reason for them, and research.

6.2.3 Problems with problem lists

Issues in the current use of problem-oriented records have been identified by studies on the content of problem lists [4,6–10], surveys of healthcare professionals [5,11] and literature reviews [12–14]. A Royal College of Physicians workshop for medical specialty informatics leads in October 2017 also identified weaknesses in the ways existing electronic health record systems record details about problems and diagnoses.

The problems can be summarised as follows:

- **Problem lists need to fulfil the purpose of assisting clinical care, but there is lack of consensus on what they should contain in order to do so** - inter-rater agreement in unstandardized problem lists is moderate [9,15], as clinicians have different opinions as to what should go on a problem list [5]. Surveys found widespread agreement that active, ongoing, chronic problems should be on the problem list, but there was uncertainty whether resolved problems, self-limiting problems, family history, surgical history, symptoms, medical devices, or social issues were permitted on the problem list [5,11].
- **Problem lists may be incomplete, with important diagnoses missing** - if important problems are not recorded or are recorded in an unexpected location they may be overlooked, with adverse consequences for care.
- **Problem lists can become cluttered with minor or inactive problems** - these may make the list unfocused and incomprehensible. A study in a Buenos Aires hospital found that problems generated for attendances as children (e.g. fever) persisted for years, with 97% of all diagnoses regarded as being 'active' [8]. Without stewardship, a problem list can easily become untidy and cluttered, but it may be unclear whose responsibility it is to keep a problem list tidy, and how this activity fits into clinical workflows [5].
- **Problem headers may not be coded** - Problem list functionality is much reduced if free text entries are used instead of entries coded using a terminology, or if the term is imprecise and key information is in free text [7].
- **Lack of consensus on the recording of recurrent conditions** - according to clinician preference, these may be recorded as inactivation and reactivation of the same problem, or as individual problems each with a resolution date, which may affect incidence estimates [16]. Inappropriate use of new problems for multiple consultations related to a single problem, or a single problem used to record multiple instances of a condition (e.g. multiple heart attacks), can also cause problems.
- **Different electronic health record systems have different levels of problem list functionality** - well-organised records in one system may become disorganised and unwieldy when transferred to another, and clinicians need to record information in different ways based on how the vendor's has designed the system.

- **Lack of training and guidance in the use of problem lists** - general practitioners are trained in the use of their computer system including problem lists, although centralised NHS funding is no longer available and the availability of training is now variable. Secondary care clinicians generally have not had specific training, and problem list management is not taught at medical school [5,11].

6.2.4 Problems with problem-oriented records

Problem oriented records (linking individual items of clinical documentation to problems) can improve problem list utilization and accuracy [10], although there is no robust evidence for its superiority over conventional documentation. Links between problems and therapies may be useful if they are not obvious. However, if a medication treats two problems (e.g. a statin for diabetes and hypertension) links to a single problem may not be useful, and some systems do not enable linking of such information to more than one problem.

Where a patient's narrative does not cleanly fit into a specific problem, some clinicians have created problem list items which are categories of healthcare activities rather than conditions of the patient. For example, the Read code 'Had a chat to patient' has been used inappropriately in primary care to group together general health conversations [12].

6.2.5 Improving the quality of problem lists

A systematic review of determinants of a successful problem list suggested that if problem lists are to be used more effectively, a system-wide multidisciplinary approach is needed that is led by clinicians and includes training and support [13]. Educational interventions can be more effective when combined with improvements in the functionality and usability of the records [17]. Financial incentives, problem-oriented recording, proactive identification of missing problems (gap reporting), and shared responsibility among healthcare professionals may also help [18].

In the future, technology such as natural language processing may be utilised to help improve the completeness of problem lists [19–22]; this would require a workflow to be developed with a user interface that enables the entries to be verified before being committed to the record.

6.2.6 Capabilities of current systems

Electronic health record systems in the UK provide different ways of recording information about problems and diagnoses, with different underlying data models and different sets of problem attributes available in each system. This inconsistency means that optimal practice in clinical record keeping is system-dependent. We recommend long-term standardisation of the information models used within electronic health records and in transfers of care, but in the meantime the guidance will recommend how the most common data elements in problem lists should be used.

Most current UK electronic health record systems do not publish their data models publicly. However, indicative information models for problem lists were offered by vendors in the INTEROPen CareConnect programme, which aimed to develop a standardised data interchange profile for diagnoses and other information.

6.2.6.1 Primary care systems

General practice electronic health records contain a structured area to record coded

information (including diagnoses); each entry is coded using the Read Clinical Terminology [23] and associated with an optional date of onset. Clinicians can denote some of these conditions as ‘problems’, in which case they are viewable in the problem list and can be linked to clinical notes, prescriptions and investigations.

The basic attributes of problems are consistent between systems, but more advanced features such as the ability to merge problems, record the evolution of a problem (e.g. ‘shortness of breath’ to ‘heart failure’) and nest problems under a broader heading, are inconsistent.

Problem attribute	Primary care electronic health record system			
	EMIS	Vision [24]	Microtest	SystemOne
Major / minor	Yes		Yes	Yes
Active / inactive	Yes	Yes	Yes	Yes
Whether confirmed / certainty				
Severity				Yes
Onset date	Yes	Yes	Yes	Yes
Resolution date	Yes	Yes	Yes	Yes
Acute / chronic				Yes
Sensitive		Yes		
Merge	Yes			
Evolve	Yes			
Nesting	Yes			
Semantic links (e.g. ‘caused by’)				

In EMIS, ‘minor’ problems automatically have a default active duration of 28 days. In SystemOne, minor problems can revert to inactive status after a period of time defined by the practice. In Vision, the diagnosis that underlies a problem can have an attribute of a priority, but not the problem title itself.

6.2.6.2 Secondary care systems

Hospitals have been slower to adopt electronic health records, and most of the clinical documentation is currently done on paper. Some organisations use paper problem lists, which may be a different colour and in a prominent position at the front of the notes.

In some systems, diagnoses recorded in discharge summaries or clinic letters can persist and be used as a basis for preparing diagnosis lists in documentation for future encounters. These lists may be limited to a particular specialty. System-wide problem lists as in primary

care systems are, however, available in more comprehensive newer electronic health record systems. However, their use is inconsistent, particularly for patients who have brief interactions with the hospital for a particular specialist problem. There is currently no automated or semi-automated method for populating a secondary care problem list from the primary care record, or for sharing problem lists between primary and secondary care.

Problem attribute	Hospital electronic health record system			
	Cerner	DXC	Epic	IMS Maxims
Major / minor			Yes	
Active / inactive	Yes	Yes	Yes	Yes
Whether confirmed / certainty	Yes	Yes		
Severity	Yes			
Onset date	Yes	Yes	Yes	Yes
Resolution date	Yes			Yes
Acute / chronic		Yes	Yes	
Sensitive	Yes		Yes	
Merge				
Evolve				
Nesting				
Semantic links (e.g. caused by)	Yes			

6.2.7 Existing guidance

US guidelines recommend that problem lists should include chronic or recurring medical conditions likely to affect patient care for multiple visits, active problems likely to require ongoing medication or diagnostic monitoring over time and persistent symptoms affecting patient care over time [3,25].

Individual electronic health record systems have guidance for users on how to record problems and diagnoses, some of which are publicly available (e.g. Vision [24]). Good practice guidance for primary care states that each episode of illness should be coded with only one diagnosis code, to avoid multiple diagnoses being counted [26].

The lack of standardisation of information models for problems is a concern, and this project aims to define the functional requirements for such a specification. The professional guidance assumes that the most basic problem list features are available in the electronic health record system.

6.3 Generation of the guidance

The guidance was developed in an iterative process guided by the literature, existing recommendations, capabilities of different systems, and personal clinical experience of using

different types of paper and electronic health records. The draft of the guidance as disseminated for consultation is given in Appendix 1.

An online consultation was carried out using the SurveyMonkey platform between 4 October and 16 November 2018. The survey was sent to clinicians in a range of specialties who were on the HIU mailing list, were informatics representatives for their specialty or had otherwise expressed an interest in this area. We also invited lay representatives to comment on the draft guidance for clarity, although it was not aimed at patients.

We received 198 individual responses. The responses were broadly positive (70-80%) in respect of each individual section, but there were some comments about the strength and feasibility of the recommendations, particularly given time constraints in the clinical setting, the applicability to fields outside internal medicine (such as mental health), and the clarity of some of the wording.

A summary of responses to the survey is given in Appendix 2. Issues raised in the survey responses were discussed at a roundtable workshop on 4 December 2018, described in section 3.1.3.

6.4 Rationale for final guidance

The rationale for the text or recommendations in the final guidance is given below.

Scope

It was decided that the scope should include diagnoses recorded in all medical specialties, as this would be a natural extension into specialist care from the existing use of problem lists in general practice. Problem lists in other care disciplines such as nursing and social work are out of scope; the principles are likely to be similar but it may create additional work and complication to consider them in detail at this stage.

Definitions

A section on definitions was included because in early discussions it became clear that there were differing opinions in the project team on fundamental concepts such as the distinction between a problem and a diagnosis. The guidance originally distinguished between suspected, provisional, working, and confirmed diagnoses, as in the openEHR 'Problem/Diagnosis' and 'Problem/Diagnosis qualifier' archetypes [27], but this was modified based on feedback from testing different modifiers in the emergency care dataset. Clinicians had found it difficult to distinguish between 'possible' and 'probable' diagnoses, and the term 'working diagnosis' was also poorly understood. A two-level classification of 'suspected' or 'confirmed' was accepted by clinicians in emergency care, and is included in this guidance. At the roundtable discussion, it was thought very important to be able to convey information about refuted diagnoses, and it was suggested that the concept of a 'disputed' diagnoses was also important to record in some cases (particularly from a mental health perspective where a patient may lack insight into their illness).

Clinical coding

A paragraph on clinical coding was included to draw clinicians' attention to important uses of the data other than direct clinical care. Accurate coding at the point of care can in future drive automated classification and coding for reimbursement and secondary uses.

Capability of clinical systems

Many of the electronic systems currently used in secondary care are document repositories rather than full electronic health record systems, and do not have the functionality for maintaining problem lists. This paragraph explains the functionality that is needed for this guidance to be applicable.

Principles and recommendations

The overarching principle was initially written in an aspirational way, but feedback from the survey was that it was too idealistic. The principle was rewritten to emphasise the functional importance of a well-maintained problem list.

Creating problem and diagnosis records

There is much debate as to what exactly should go in a problem list. The guidance therefore stresses the functional requirement for the problem list to be useful for care, and that conditions or health issues that are particularly important should be readily visible. Many of the recommendations are similar to those in general practice guidance. The recording of diagnosis modifiers is described both for the case of existing systems (most of which cannot record suspected or refuted diagnoses in a structured way) and for future systems. Both the roundtable and the previous workshop on diagnosis recording held in October 2017 reported the importance of recording evidence (or a link to evidence) for diagnoses and their provenance. This is essential to facilitate future clinical decisions.

Maintaining problem and diagnosis records

There was much discussion throughout the project on how and when problem lists would be reviewed to ensure that they are accurate and concise. This task is potentially time-consuming and may be difficult to prioritise if a clinician is busy. In the future, some aspects of problem list review may be automated (e.g. conditions which are defined as minor could automatically become inactive after a period of time unless the clinician specifies otherwise). Secondary care can cover such a wide range of specialties that some may not be able or willing to curate a comprehensive list of diagnoses and health issues.

Therefore the guidance aims to be pragmatic and feasible, with the emphasis on maintaining a comprehensive problem list for inpatients and prioritising problems under specialist care in outpatients.

Communicating problems and diagnoses

This paragraph emphasises that the encounter problem or diagnosis should be prioritised for sending in communications to the general practitioner, but it is not necessary to list all inactive problems, which the general practitioner is likely to already know about.

Using advanced features of problem-oriented records

Electronic health record systems differ in their ability to record additional attributes of problems, or to link problem titles with other information. Existence of these features may affect the way clinicians wish to use the record.

6.5 Conclusion

This project has highlighted the challenges and opportunities in recording problems and diagnoses in electronic health records. A consensus has been reached among clinical

professionals on some key aspects of professional practice and key requirements for systems. However, guidance for clinicians is just the start of this process, and improvements in system capability, interoperability and usability are essential to realise the vision of better diagnosis information for patient care. This will require an ongoing programme of work involving collaboration between NHS Digital, the Professional Records Standards Body, the Faculty of Clinical Informatics, INTEROPen (vendors), Health Data Research UK, the Medical Royal Colleges and specialist societies.

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7 Appendices

7.1 Original draft guidance (before consultation)

See appendix 1 (separate document)

7.2 Outcome of consultation survey

See appendix 2 (separate document)

7.3 List of roundtable attendees

Adam Dagnoor	Informatics Lead, Association of Cancer Physicians
Anoop Shah	Anoop Shah, Consultant in Clinical Pharmacology and General Medicine and project lead
Asif Bachlani	Consultant Psychiatrist and CCIO, South West ondon and St George's Mental Health Trust
Geoff Hall	Senior Lecturer in Medical Oncology and cancer informatics lead, University of Leeds and medical oncologist
Harpreet Sood	Associate Chief Clinical Information Officer, NHS England
Iain Moppett	Deputy Director of NIAA-HSRA, Royal College of Anaesthetists
Ian Gaywood	Consultant Rheumatologist (retired)

Jan Hoogewerf	Programme Manager, Health Informatics Unit, Royal College of Physicians
John Williams	Director, Health Informatics Unit, Royal College of Physicians
Julian Costello	Health Informatics Group, Royal College of General Practitioners and JGPITC
Katie Martin	Consultant Liaison Psychiatrist, Tees Esk and Wear Valleys NHS Foundation Trust
Martin Orton	Director of Operational Delivery, Professional Record Standards Body
Martin Severs	Chief Medical Officer, NHS Digital
Michael Lumb	Consultant Obstetrician and Gynaecologist, Peterborough and Stamford Hospitals NHS Foundation Trust
Michael Thick	Chief Medical Officer, IMS MAXIMS
Munish Jokhani	Clinical Lead, NHS Digital
Rina Dutta	Senior Clinical Lecturer/ Consultant Psychiatrist, King's College London
Sebastian Hendricks	Informatics Lead, British Association of Audiovestibular Physicians
Tom Hughes	Chair of Informatics, Royal College of Emergency Medicine

7.4 Patient workshop on sharing diagnosis records

See appendix 4 (separate document)