

Sharing diagnosis records for patient care in the NHS: Report of a patient involvement workshop 3 April 2019

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Background

The way that diagnoses, symptoms and other clinically derived information are stored in NHS patient records is far from ideal. These records are typically stored separately in primary and secondary care, with no easy way to transfer or harmonise information between the systems. They are often in free text rather than in a structured form, which limits their accessibility for research and makes them difficult to use for clinical decision support. The lack of sharing leads to duplication of data entry and the risk of transcription errors, with multiple, potentially conflicting, records in existence for the same fact. There is no consensus among clinicians, policymakers or the clinical informatics community as to whether a single diagnosis record to which multiple organisations can contribute is preferable to maintaining separate lists.

A project on developing guidance for recording diagnoses (funded jointly by the Professional Record Standards Body and the Royal College of Physicians Health Informatics Unit) touched on this question, and noted the pitfalls of shared diagnosis lists such as lack of clarity over who is responsible for keeping the record up to date, and who is accountable for any errors [1]. Shared primary and secondary care problem lists do operate in some areas, such as areas using the TPP SystmOne electronic health record system, and other countries which have healthcare organisations that span primary and secondary care (such as Accountable Care Organisations in the U.S.).

To our knowledge, there have been no previous attempts to seek patient's perspective on the specific issues relating to sharing diagnosis records. This workshop therefore sought patients' views on how diagnosis information could be shared with contribution from healthcare professionals at more than one institution, typically a GP and a hospital specialist. Currently only GPs curate a longitudinal problem and diagnosis record. Secondary care organisations may have access to view the GP record and may keep separate problem lists, but the only way that information currently flows back to the GP is in the form of a human-readable letter. Harmonising the data models for problems and diagnoses between primary and secondary care, and the use of electronic messaging standards could potentially allow diagnoses to be recorded and transmitted in a more structured way.

Methods

Participant recruitment

Workshop participants were recruited from the patient involvement group of the University College London Hospitals National Institute of Health Research (NIHR) Biomedical Research Centre (BRC). Participants were invited to the half day workshop by email; there were 22 respondents of whom the first 20 were offered a place on the workshop. Seventeen participants were able to attend on the day.

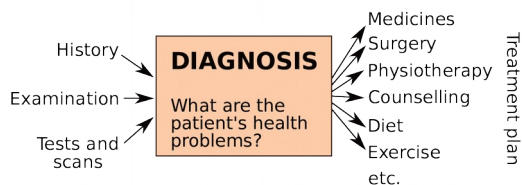
Ethics

As per INVOLVE guidelines, ethical approval is not required for patient and public involvement in a research project. All participants were informed of the aims and format of the workshop

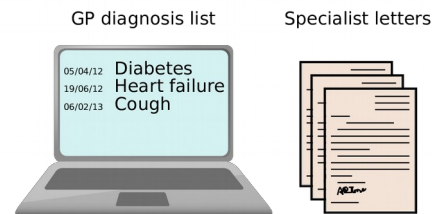
beforehand and freely consented to participate. Separate written consent was sought to be included in photographs taken at the workshop.

Introductory slides

Diagnosis is fundamental to clinical management. Doctors and other healthcare professionals have to make a diagnosis to work out what treatments might help a patient.



GPs keep a simple list of diagnoses and health problems on their computer, but detailed information such as subtype or severity is often 'hidden' in clinical notes and letters written by specialists.

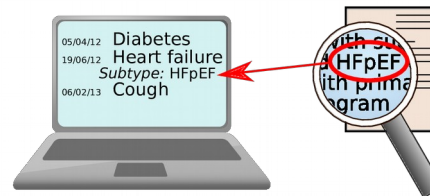
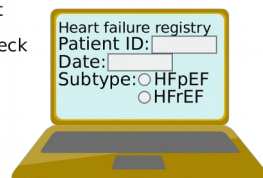


Detailed information is not easy to find in health records.

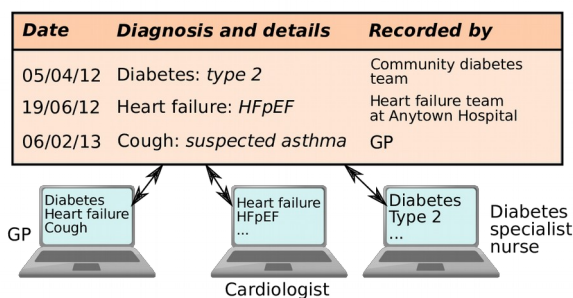
An up-to-date diagnosis list with extra detail can help. However, it is a lot of work for GPs to read all the specialist letters and manually add all the details.

Detailed information about diagnoses is also collected by disease registries to check quality of care and for research.

Data entry is a manual process, taking time and effort.

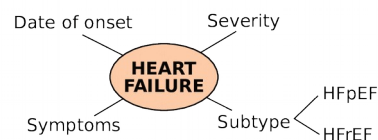


What if the GP and specialists could record all a patient's diagnoses and health problems, with details, in one place?

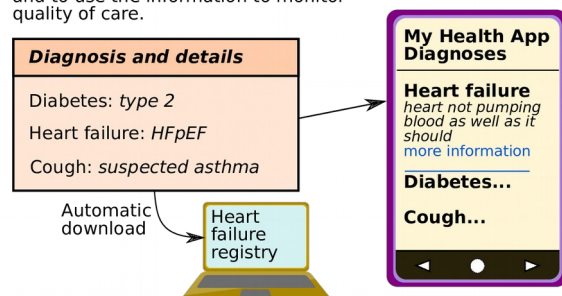


For this to work, health professionals need to agree what information it is important to record about each diagnosis, and how it should be organised.

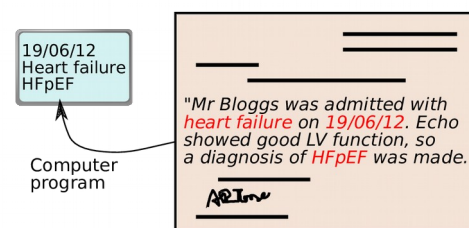
They also need to agree rules and systems for updating the diagnosis list, making sure it is tidy and organised.



Diagnoses are coded using SNOMED-CT terms. This makes it easier to link them to guidelines and patient information, and to use the information to monitor quality of care.



In the future, computers may allow doctors to update diagnosis records directly by typing or dictating text.



Workshop format

The workshop started with a brief presentation to introduce the topic areas of diagnosis record sharing, free text versus coded information, and use of free text in health research (Appendix 1). Questions from the participants were addressed in order to clarify any issues.

The two facilitators acted out a role play of different ways in which a diagnosis made in secondary care could find its way into the primary care record, according to the recording sharing arrangements. The options included no sharing (no ability for a specialist in secondary care to view the primary care record), 'view only' (the specialist can see the GP problem / diagnosis list but not make any structured suggestions or edits), 'view and suggest' (the specialist can suggest changes to the GP problem / diagnosis list but they do need to be 'accepted' by the GP before they are committed to the record) and 'view and edit' (the specialist can view and edit the GP problem / diagnosis list). Participants were asked to think specifically about the role of the GP and specialist in this interaction, rather than the sharing of diagnoses with patients (which is a separate issue, and was not the focus of this workshop).

Participants discussed the issues in two groups, each with a facilitator, and were then asked to vote on whether they supported the concept of using text in GP records for health research, and why, and also on their preferred option for sharing GP diagnosis records with hospitals. We also collected basic demographic information on participants (age, gender, ethnicity, town of residence) and feedback for the event itself. Demographic, voting and feedback forms were separate so that information cannot be linked across them, maintaining participant anonymity.

Results

Participant demographics

The participants ranged in age from 25 to 84, with a median age of 67 years. Eight participants were female (47%), seven were male (41%) and two had another gender identity or preferred not to disclose. The majority of participants (14/17, 82%) were White, two were Indian (12%) and one was Black African (6%). Five participants lived in inner London (29%), six in outer London (35%), three in an unspecified part of London (18%), one outside London (6%) and one did not disclose (6%).



The group raised issues to be considered including the GP's feelings about the record being updated without their specific consent, what happens if there is more than one change suggested, or of the GP does not agree with the change, and how information could be shared between different specialties. Ideas generated by the group are displayed below.

<u>view & suggest</u>	<u>view & edit</u>
<u>Advan.</u> <ul style="list-style-type: none"> more structured way of updating record - coded allows for difference of opinion improves quality of consultation doesn't rely on pat. memory / partial information access to complete record GP referral info limited to presenting complaint - access to whole record means holistic approach poss GP is may be right & more balanced approach / better if referring for 2nd opinion 	<u>Advan.</u> <ul style="list-style-type: none"> updated immediately consensus, one truth if good with hospital dr, give more info & this is reflected by record hospital dr has more specialist info & so their info/opinion has is based on better info holistic info embedded allows recording of up-to-date info & new info for GP from patients
<u>Disadv.</u> <ul style="list-style-type: none"> suggestions lost; not suggestions reviewed by GP & 'sits'; limited to GP data only unless GP actively accepts update Record of suggestions rejected 	<u>Suggestions:</u> <ul style="list-style-type: none"> show who updated keep audit trail of change (who made change, when + what was changed)

‘View and suggest’ model

The advantages of this model are that it is a more structured, coded way of updating the record than reading text in a letter, it allows differences of opinion and may improve the quality of consultations. Being able to view the GP record in secondary care reduces reliance on patient’s memory and enables a holistic approach to patient management. It also merges the GP’s balanced approach with specialist input.

The disadvantages are that suggestions may not be reviewed by the GP and may sit in limbo, and may be lost. It also means that the shared diagnosis record is limited to GP diagnoses unless the GP actively accepts the update.

The group suggested that a record of suggestions rejected could be kept for review and audit.

‘View and edit’ model

The advantages of this model are that it enables the GP record to be updated immediately, and there is consensus with a single source of truth. If there is a good relationship between the GP and specialist, the specialist can provide more information and this will be reflected by the record. Sharing GP information with specialists will enable them to make better diagnoses as they will have access to more information.

The group suggested that the record should show who updated it and keep an audit trail of changes (who made the change, when and what was changed)

Voting

The outcome of voting was that 11/17 (65%) supported specialist access to edit the GP diagnosis list, 4/17 (24%) supported a ‘view and suggest’ model and only 2/17 (12%) supported a ‘view only’ model.

Discussion

Workshop participants considered that lack of information flow between hospitals and GPs, and inaccuracy of medical records, were major problems, and they welcomed this opportunity to participate in work to try to improve the situation.

There are a number of initiatives in the Local Health and Care Record Exemplars to enable secondary care users to view a patient’s GP record. This is an important first step to improving the information available for care, but participants did not feel viewing alone was good enough. There needs to be a structured way to feed into the GP record, and the majority of respondents were in favour of specialists being able to edit the GP problem list, or at least being able to suggest changes in a structured way.

This question has been discussed in informatics, and the but to our knowledge it is the first time that patients have been specifically asked this question. The discussion among patients mirrored the discussions that have been occurring in the clinical informatics community. A shared diagnosis list requires agreements between NHS organisations to clarify who is responsible for correcting errors on the list.

Conclusions

Overall, patients were keen for improvements in the way information was shared between GPs and hospital specialists. They supported an option for specialists to be being able to edit the GP problem list directly, with the provenance of all changes clearly recorded, or at least suggest changes in a structured way.

Acknowledgements

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References

1. The RCGP Health Informatics Group. 2009. “Informing Shared Clinical Care: Final Report of the Shared Record Professional Guidance Project.” Royal College of General Practitioners.