

USING PATIENT ONLINE IN END OF LIFE CARE

RCGP, 2018

Purpose of this document

This guidance is for GPs and practice nurses caring for patients approaching the end of life irrespective of underlying condition or co-morbidities. The aim is to describe how access to GP online services contributes to person-centred care in this context and to present the case for recommending online record access to patients and their families and carers at the end of life.

It describes how you can help them make use of online access to information about their healthcare to improve their ability to self-manage their condition and help to co-ordinate their care. It will describe how carers or relatives can use Patient Online on behalf of patients without capacity. It will explain how patients can share access with supporting family members, carers and the multidisciplinary health care team to help them look after the patient safely and confidently.

End of life care in the UK

The Gold Standards Framework¹ established a system of multidisciplinary working that has helped end of life (EOL) and palliative care in the UK to be widely regarded as amongst the best in the world.² The RCGP is piloting new UK General Practice Core Standards for Advanced Serious Illness and End of Life Care — the ‘Daffodil Standards’. They apply to the care and support of patients with advanced serious illness who have palliative care or end-of-life care needs; they include the support of families and carers. The standards were piloted at selected practices from spring 2018, with subsequent wider implementation from autumn 2018.

As the numbers of people living longer with multiple co-morbidities and requiring palliative care is predicted to rise by 25% in the next twenty years, the difficulty in providing high quality care will increase. One solution is to emphasise the importance of personalised care and support planning for people living with a terminal illness.³ Patient and carer online access to their GP practice records has an important part to play.

Patient Online at the end of life

It is clear that early identification of the approach of the end of life is crucial to the timely implementation of effective care planning. Throughout end of life care, patients who are well informed about their condition are better prepared for consultations with healthcare professionals

The Daffodil Standards’ Core Domains³

1. Professional and competent staff
2. Early identification
3. Carer support — Before and after death
4. Seamless, planned, coordinated care
5. Assess unique needs of the patient
6. Quality care during the last days of life
7. Care after death
8. General practice being hubs within compassionate communities

and better equipped to make decisions about their care. Record access can play an important part in facilitating this, especially if the patient is supported to develop their understanding of what the content of their record means.

Multiple health and social care organisations are involved in end of life care and communicate via the GP practice. The information builds up the GP record and can be seen by the patient. With online access the patient can show or share access to their GP record online, at home, at the hospital, hospice or away from home where the data may otherwise be wholly or partially unavailable. This is not limited to data about the terminal diagnosis but includes all co-morbidities.

A time will come where family or carer support of the patient will become crucial to the patient’s well-being. Planning for proxy access can help carers understand the patient’s illness and assist with basic matters such as ordering repeat

prescriptions. This may be helpful from the outset or may only become necessary when the patient loses physical or mental capacity. An early discussion about this with the patient may make their wishes clear.

There are other well-established methods of sharing patient information for individual care of the patient. In approaching 50% of localities in England, Electronic Palliative Care Co-ordination Systems (EPaCCS) are used by local health and care organisations. Some methods use shared views of the GP record through systems such as the EMIS Medical Interoperability Gateway⁵ or TPP SystemOne Palliative Care⁶ to facilitate sharing information about the patient between health professionals providing individual care. These systems may not be available to every healthcare organisation in a locality and are unlikely to be available if the patient travels away from home. They may focus on end of life issues to the exclusion of data about co-morbidities. In these circumstances, Patient Online can fill the gap.

The patient's Patient Online system may offer another method for patients to quickly and easily share their medical record via a time-limited secure website link or QR code. Doctors and other NHS staff can then be given full access for 24 hours to vital medical information from the GP record - including latest medications, allergies, test results, coded data and documents (dependent on the level of online access enabled by the practice). The GP record is then accessible to the healthcare professional regardless of whether an EPaCCS system is in place.

Patient Online record access

Patients and their carers who have access to Patient Online can use it for appointments and repeat prescriptions as might anyone else. It can be particularly helpful for accurate prescription requests when patients are on multiple and often similarly named medication. It is record access that is particularly helpful.

Detailed coded record

Patients can use Patient Online detailed coded record access to see if the GP record is complete and contains their most recent preferences and circumstances related to their end of life care, such as choices about place of death and interventional care. They may ask for the record to be updated and the practice should be willing and ready to discuss changes with the patient. The practice is

Proxy access in end of life care

The provision of Patient Online access to somebody who will use it on behalf of the patient at the end of life is an important benefit at end of life for patients. It is called proxy access and may be offered to relatives or carers who live some distance from the patient and is an excellent way for them to keep in touch with the patient's care.

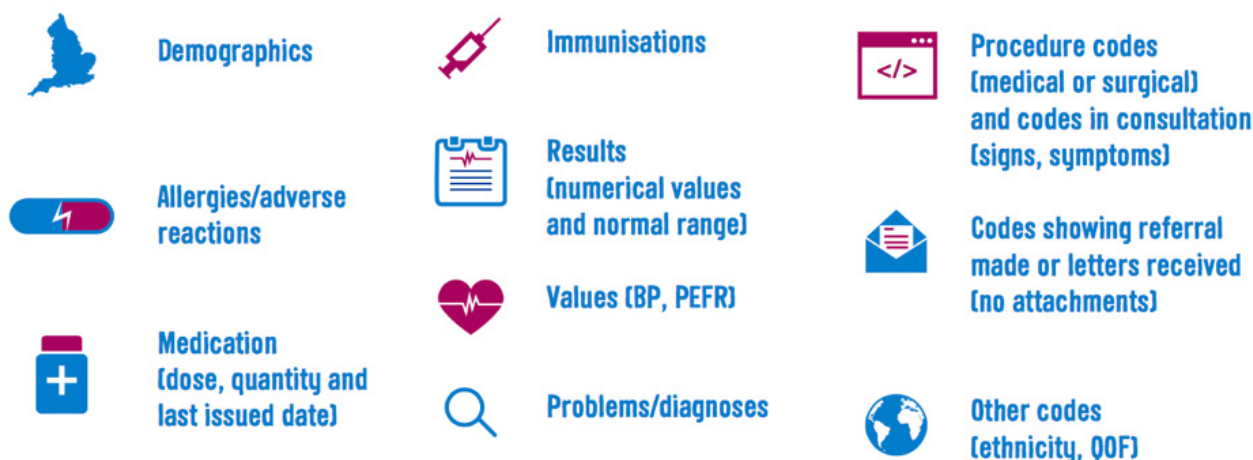
The process of setting up proxy access for a third party acting in the patient's best interests is discussed in the Proxy Access guidance in the toolkit. Ideally the proxy should have their own login credentials so that their access to appointments, prescriptions and records can be tailored to the patient's wishes; the patient may not want the proxy to have full access.

Some patients may simply share their login credentials with others and often this is a reasonable thing to do, but formal proxy access where the third party has their own login credentials is a safer option because the patient and the practice had more control of the access to the patient's Patient Online account and, where system functionality allows, an audit trail of the use of Patient Online.

Clearly setting up proxy access is more straightforward when the patient themselves has capacity and can authorise proxy access themselves. There are legitimate reasons for the practice to authorise proxy access without the patient's consent once the patient has lost capacity to choose. In this instance the GP is able to grant access in the patient's best interests in accordance with the Mental Capacity Act 2005 code of practice, especially if the patient has previously expressed a view about who may be allowed proxy access in these circumstances.

In discussing and setting up proxy access remember the possibility that the access may be misused by the proxy or that the patient may be coerced in to allowing proxy access against their will. There is more information about this in the Coercion guidance in the toolkit.

The detailed coded record



not obliged to change the record or add data at the patient's request. If the practice chooses not to, it is reasonable to record the patient's opinion in their notes.

There is more about this in the guidance on Data Quality and the Detailed Coded Record in the toolkit. There is also advice on how to manage data which may upset or harm the patient or data that is confidential to a third party in the guidance on Practice and Patient Safety - Sensitive Data. This may be particularly relevant in end of life care when patients are often cared for by family members or carers.

Knowing that the information their GP holds about them and makes available to others is accurate can help the patient feel confident that those making vital decisions about their care are well-informed and there is no need for the patient to keep explaining their history.⁷

Most GP systems have templates or structured data entry forms that facilitate coding this important information.

View test results

The detailed coded record includes test results. Patients will probably need help to understand the meaning of the results. You may be able to use free text attached to laboratory results to communicate with the patient to explain the meaning of specific results or recommend action for the patient to take. There is more about this in the guidance on Diabetes Mellitus, Chronic Inflammatory Arthritis and Laboratory Results in the toolkit.

Extended record access

Extended record access to clinical correspondence and possibly consultation notes, helps patients to view with hospital reports, care plans and DNACPR documents.

Improve their health literacy

By focusing on the meaning of the diagnoses, complications, test results and treatments that the find in their record, the task becomes manageable. Some online systems also offer a suite of useful patient information leaflets about long-term conditions and the meaning of test results but patients may need help to find the most reliable information that will help and not mislead them.

Preparation for consultations

The availability of the latest test results and hospital reports through Patient Online and the assist offers with health literacy helps patients to prepare more effectively for consultations. They can focus on what matters to them and may be more able to understand and remember advice given in the consultation. It may be that time has to be spent explaining the information that they have seen in their records but the time can be used to boost to their health literacy. There is more about this in the guidance on Diabetes Mellitus in the toolkit.

Check and share care plans

Many of the features of end of life care plans are coded in the EPaCCS dataset and GP system template systems but more complex care plans may rely on additional text to describe the patient's history, circumstances or preferences. If these are recorded in consultation notes or word-processed or scanned documents they can be available to

the patient, carers and healthcare professionals through Patient Online.

Electronic Palliative Care Co-ordination Systems

Electronic Palliative Care Co-ordination System (EPaCCS)⁷ are designed for communication between health professionals providing individual end of life care to the patient, including ambulance services, community nurses, and hospices but not normally the patients themselves.^{3a} They are made up of data mainly sourced from GP systems, based on the National Information Standard SCCI 1580. The EPaCCS Requirements Specification is available on the NHS Digital website.⁴

EPaCCS systems use a standard data set (SCII 1580). Most of the content can be coded using standard templates in GP systems and shared automatically once a patient is registered with the system. Examples include CPR and place of death preferences, advance statement and lasting power of attorney. By coding the information, ideally with template-driven processes, the patient can also see it if they have Patient Online detailed coded record access.

EPaCCS systems have some limitations when used alone.

Although in some systems data is uploaded close to real time, in some data may only be updated once a month, and so they may not be up-to-date when it is viewed. The patient sees the data unless the local area has developed a

patient portal for their EPaCCS. If the data in the EPaCCS is not accurate complete and up-to-date, health care professionals relying on it to make clinical decisions that affect the patient may not get them right. If a patient changes their mind about whether to remain at home at the end of life or go into a hospice or hospital, the EPaCCS may not be updated for some time and health care professionals may be misled. Because the patient cannot see the data they cannot play their important part in making sure that it is accurate.

EPaCCS may not be available or compatible with all the electronic patient record systems used locally.

Finally, the EPaCCS record of each patient is often only available in their home area and are of no use if a patient moves out of their home area during their end of life care. Where the EPaCCS is based on additional data added to the patient's Summary Care Record this may not be a problem.

Instead of using an EPaCCS database some areas, services share a real-time view of the GP record. This has two advantages. The view of GP record is up to date and offers information about co-morbidities. Again, not all local healthcare computer systems may be able to link with the GP systems if their technology is not compatible. Patient Online record access and can use it to share information can overcome this and is the only option if there is no other form of local data sharing.

Benefits and problems associated with EPaCCS and GP record sharing systems	
Benefits	Problems
Accessible from multiple agencies	Only contain a subset of the GP coded data
Live system across care boundaries	Can be difficult to keep up-to-date
Multidisciplinary access (may be read-only access, may be able to add to the record)	Can have data integration and migration issues
May share information from multiple specialities	Patients and carers may not have access to the information held
Facilitate communication across care settings	Systems may vary considerably across localities

Iterative use of Patient Online to support end of life care

Figure 1 illustrates how Patient Online record access can be used in end of life care. Typically, early in the process of end of life care, the GP and patient compile a care plan. This is an opportunity to highlight or signpost the patient to Patient Online transactional services and record access. It may also be an opportunity to discuss proxy access, a service that may be useful in the future. Discussing this at an early stage can avoid some of the problems associated with establishing proxy access when the patient no longer has capacity to consent.

At a later consultation the GP may update the relevant care plan and the coded data. If the patient was Patient Online record access at this stage they can help to correct any, errors, omissions

or ambiguities that they have found, or ask for updates of their recorded preferences if they have changed their mind or their circumstances have changed. The increased data quality, accuracy and timeliness can be invaluable, particularly if the record is shared in unscheduled care settings.

Clinical Scenarios

The following two scenarios look at how the same patient and their carer may use Patient Online record access in end of life care when an EPaCCS system or data sharing agreement or health and care organisations to view the GP record are in place (Scenario A) and when there is no local data sharing agreement or the patient is using a health and care service which has no access to the GP record (Scenario B).

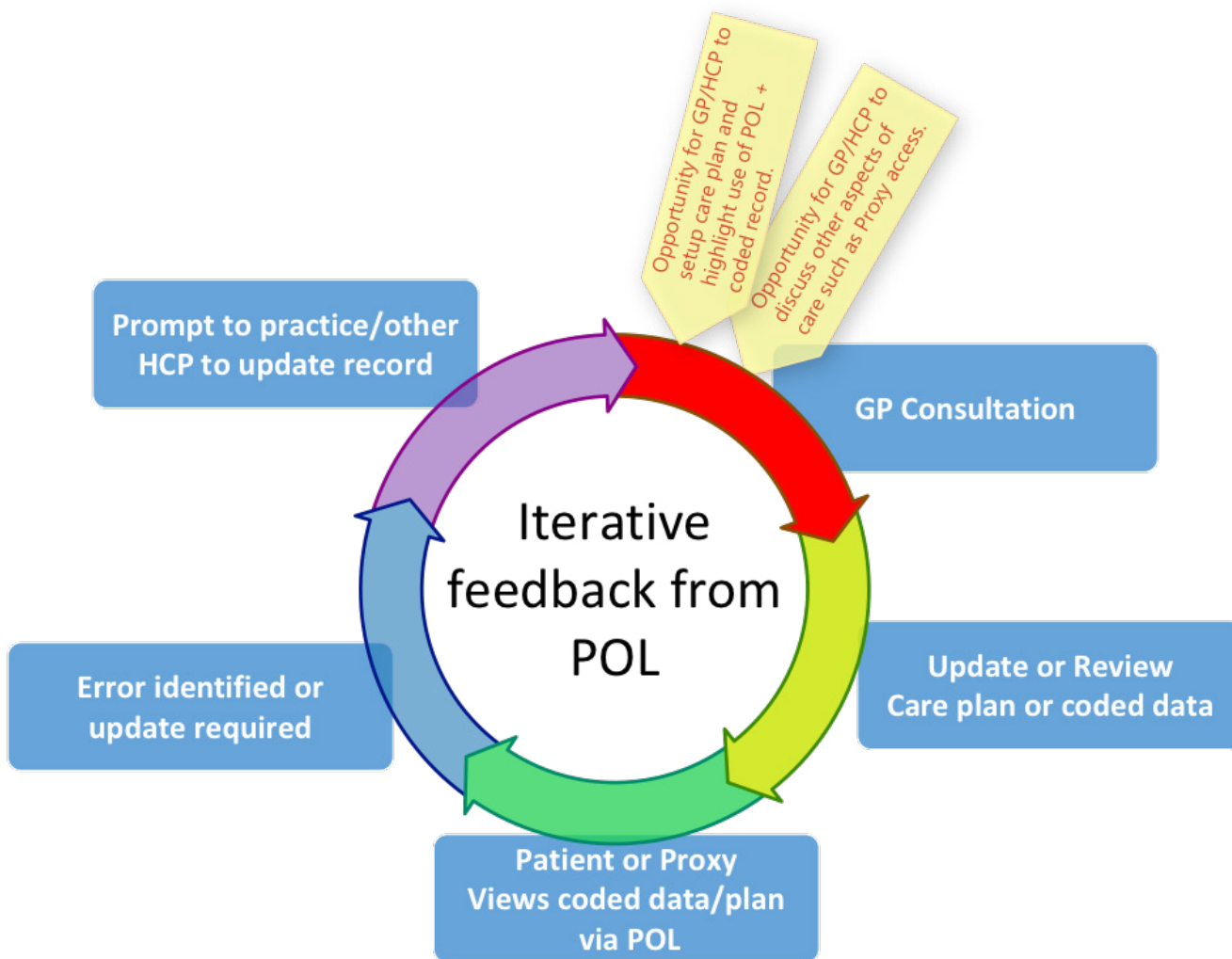


Figure 1: How Patient Online can be used in end of life care

Scenario A (Assuming a fully operational EPaCCS system)

Mrs EB is a 76yr old lady who has a background of mild COPD and recently been diagnosed with carcinoma of the bronchus. She has been living with her daughter since her diagnosis and is receiving active treatment for her cancer. At this point she does not have a DNACPR in place. She consults her GP with her daughter and an agreed care plan is produced. The local EPaCCS system is populated with her details including her diagnosis. The GP suggests that they should keep the care plan under review and that it may be a good idea to arrange proxy access so that her daughter can order repeats and remain up to date about her care by viewing her record online. This level of access is shown in Figure 2 “Patient Online with EPaCCS” and is represented by the yellow region.

Unfortunately, six months later Mrs EB develops a pleural effusion and is hospitalised for several weeks. She is found to have metastatic disease. On discussion with the hospital consultants it is denied that further active treatment would be unhelpful. On further discussion, Mrs EB decides that resuscitation is no longer wanted and she is discharged with a DNACPR and the GP is informed. The GP updates the patients record to reflect the DNACPR status.

Mrs EB’s condition slowly deteriorates. Her daughter continues to book repeat medication and view the GP record online (as shown as proxy access in Figure 3) including recent correspondence and latest care plan. She is pleased to see that the DNACPR is coded but has noted that her mother is still for full escalation of care which is no longer wanted. This prompts discussion with Mrs EB and her GP and an amended care plan is made, recording that Mrs EB would no longer wants to be admitted to a hospital if her condition deteriorates. The EPaCCS system is updated to reflect this.

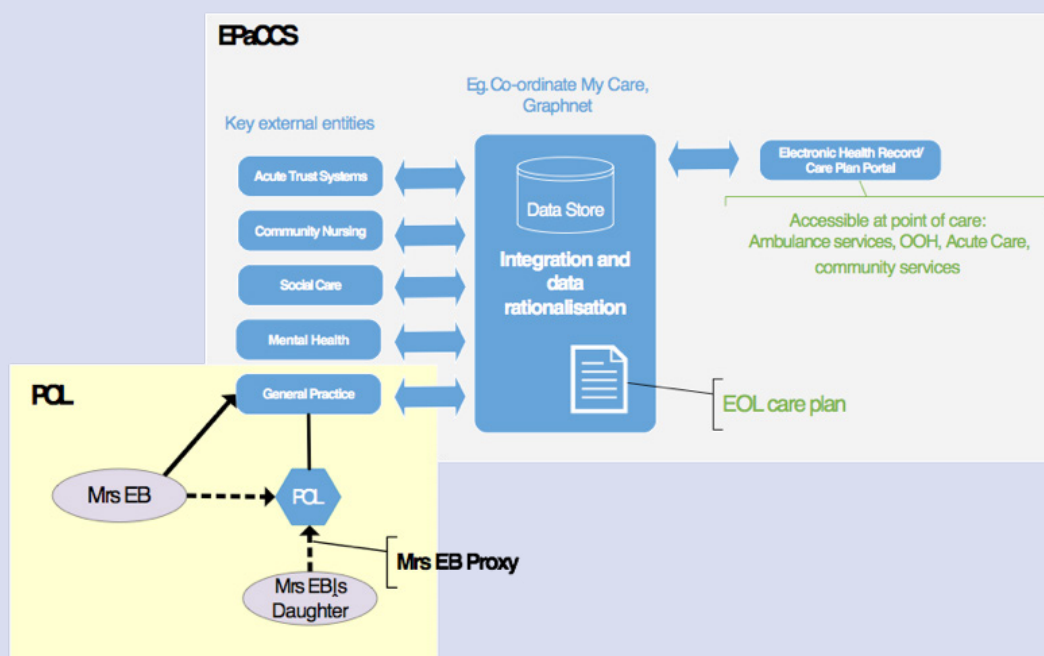


Figure 2: Patient Online with EPaCCS

Scenario B (Assuming an EPaCCS system not in operation/available)

Mrs EB is a 76yr old lady who has a background of mild COPD and recently been diagnosed with carcinoma of the bronchus. She has been living with her daughter since her diagnosis and is receiving active treatment for her cancer. At this point she does not have a DNACPR in place. She consults her GP with her daughter and an agreed care plan is produced. The GP populates a locally generated care plan and updates all the relevant coded information and files a copy of the care plan in the patient's documents. The GP suggests that they should keep the care plan under review and that it may be a good idea to arrange proxy access so that her daughter can order repeats and remain up to date about her care by viewing her record online.

Unfortunately, six months later Mrs EB develops a pleural effusion and is hospitalised for several weeks. She is found to have metastatic disease. Mrs EB's daughter allows the admitting hospital team to view the patient record by giving them an authorisation code, equally this could have been done informally by either the patient or their carer physically showing a logged in device their health professionals (both shown in Figure 3 Patient Online without EPaCCS). On discussion with the hospital consultants it is denied that further active treatment would be unhelpful. On further discussion, Mrs EB decides that resuscitation is no longer wanted and she is discharged with a DNACPR and the GP is informed. Usually the GP will have to update the patients record to reflect the DNACPR status. The information is not usually received electronically from the hospital record.

Her daughter continues to book repeat medication and view the GP record online (as shown as proxy access in Figure 2) including recent correspondence and latest care plan. She is pleased to see that the DNACPR is coded but has noted that her mother is still for full escalation of care which is no longer wanted. This prompts discussion with Mrs EB and her GP and an amended care plan is made, recording that Mrs EB would no longer wants to be admitted to a hospital if her condition deteriorates. The GP amends the care plan and coded information in her record.

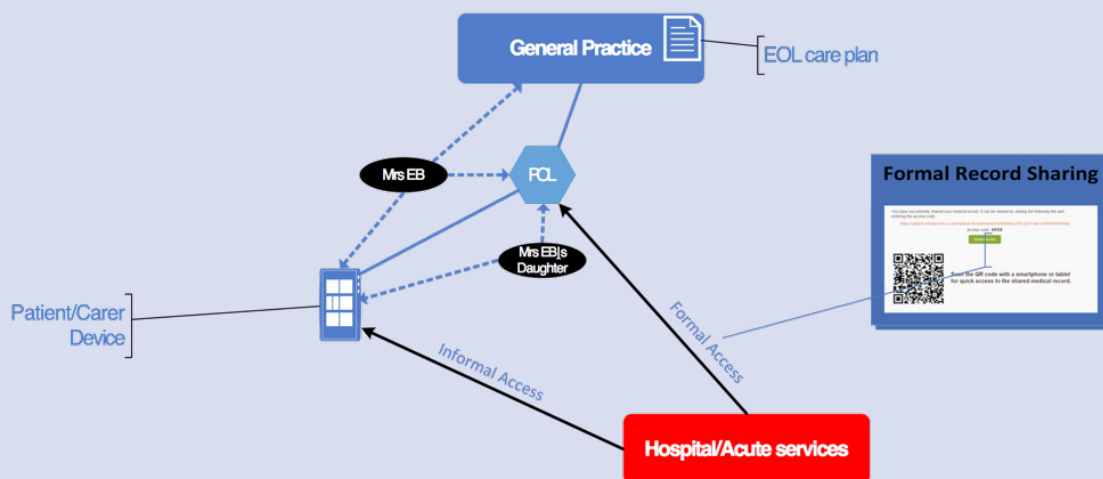


Figure 3: Patient Online without EPaCCS

Summary

End of life care has become more complex with an increasing number of community services, allied health professionals and information technology involved. It is also a period where the patient and their family/carers have more interaction with their own GP services. There are obvious advantages to the patient/carer having access to transactional services through POL but as this document has shown, there are potential benefits to the patient accessing their own coded information to ensure information is correct, up-to-date and reflects their current shared end of life decisions. As health professionals involved with patients in the end of life care, it is important we encourage patients to use online services and record access as it does improve care in the end of life.

References

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