PATIENT ONLINE FOR DEMENTIA

RCGP, 2018

"The word dementia describes a set of symptoms that may include memory loss and difficulties with thinking, problem-solving or language. These changes are often small to start with, but for someone with dementia they have become severe enough to affect daily life. A person with dementia may also experience changes in their mood or behaviour. Dementia is caused when the brain is damaged by diseases, such as Alzheimer's disease or a series of strokes."

- *What is Dementia*, *Alzheimer's Disease Society*

Dementia

Dementia is typified by increasing memory loss and intellectual impairment that creates difficulties for patients, their families and carers, and health professionals alike. A patient's capacity to care for themselves and make decisions about their health may fluctuate. There may be a narrow window in time between diagnosis, especially if this is delayed for any reason and causes a permanent loss of capacity to consent to treatment. Therefore, It is important to take opportunities for advanced planning. Early referral to local memory services, placement on the practice dementia register with annual reviews, and involvement of family members and carers with a shared understanding of the patient's priorities and preferences are at the core of good healthcare.[1]

As patients begin to lose the mental capacity to understand the decisions that are necessary for their health and social care, family and carers may have to make decisions on their behalf, with appropriate consent in accordance with previously known wishes. As capacity declines Patient Online becomes increasingly helpful to the patient and ultimately to those caring for them. An indicator of a person needing help in planning and other more complex activities of daily living may be difficulty managing bank accounts or increased inability to manage payments with credit or bank cards, perhaps forgetting their PIN.

Over 90% of patients with dementia have at least one co-morbidity, with a median number of three co-morbidities for each patient.[2] Primary care consultation rates, hospitalisation, prescribing rates, frailty and mortality increase with additional co-morbidities. The complexity may be difficult for patients and their families and carers to understand and manage. Access to Patient Online appointments, prescriptions and up-to-date information from the practice record can be invaluable to patients and carers.[2a]

This guidance describes how Patient Online can help both patients as well as family and carers of those with dementia to understand and manage their healthcare in the face of complex multimorbidity and failing or fluctuating mental capacity. It also describes how Patient Online can be used to support family members and carers helping the patient as the patient loses mental capacity, as well as how practices can provide access to their Patient Online services safely and effectively. This guidance is intended for GPs, practice nurses and other healthcare professionals involved in the care of patients living with dementia in the community.

There is detailed information about how Patient Online works and how to manage patients' access safely and effectively including those with sensory or learning disabilities in additional guidance in the toolkit.

Patient Online for patients with dementia

Patients with cognitive impairment who are suspected of having dementia may be recognised during long-term condition reviews and NHS Health Checks. Screening for dementia is important, as people at risk of dementia may have multiple factors that contribute to their cognitive impairment, including physical illness, medication side-effects (cholinergic index), sensory impairment, and mental health issues.

As these conditions should be alleviated as well, early referral to a local memory service is usually indicated.

Once a diagnosis is confirmed there is an opportunity for forward planning, both in terms of the patient's wishes as well as the designation of family or carers to make decisions on the patient's behalf should they lose the capacity to do so. This also presents the opportunity to discuss the benefits of using Patient Online with proxy access for the designated individual trusted to act on the patient's behalf, as it is wise to make arrangements for proxy access before patients lose the capacity to give consent.

Appointments
Online access to appointments enables patients with mild cognitive impairment to book and remind themselves of appointments. Over 20% of patients with dementia may have hearing loss[2] and may prefer to book appointments online rather than over the telephone. The online booking service can also help carers, with consent of the patient, to check when an appointment has been
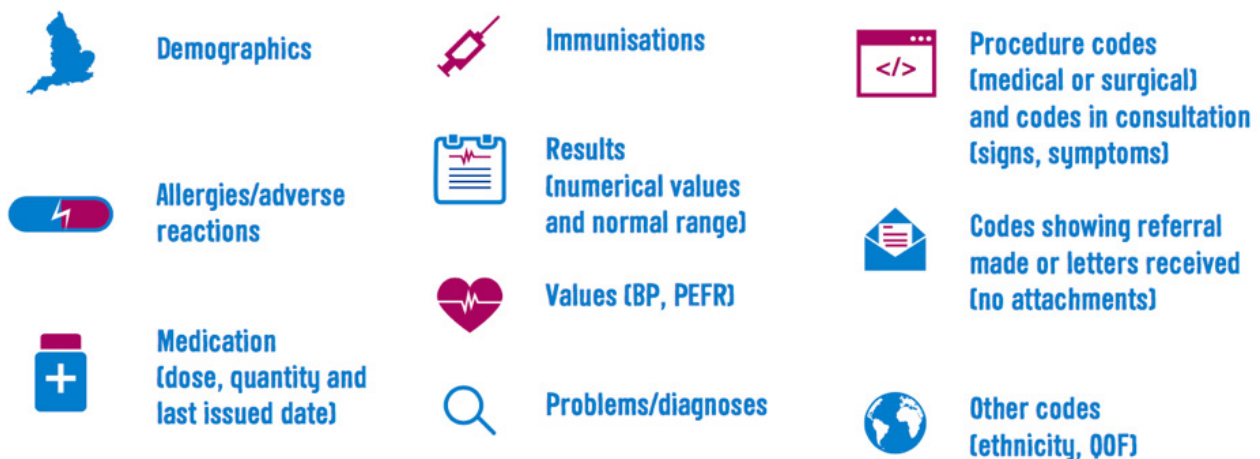
scheduled as well as confirm that an appointment has been booked. As capacity fails, carers can use proxy access to manage appointments on the patient's behalf.

Repeat prescriptions
Patients with dementia frequently need assistance with medication changes and adherence to treatment regimes. As multimorbidity is common, dementia is associated with polypharmaceutical intervention, or the regular consumption of four or more prescription items.[2] However, dementia may make it more difficult to remember drug names, doses, and determine when repeat prescriptions and medication reviews are due. Patient Online can improve adherence to prescribing plans.

Patient Online systems indicate when medication items were last issued, helping to reduce the chance of early requests and warning carers that items have not been requested on time. They also help to remind about medication reviews, showing how many times items may be issued before a review is due and/or the date when the review is due.

The detailed coded record

Demographics

Allergies/adverse reactions

Medication (dose, quantity and last issued date)

Immunisations

Results (numerical values and normal range)

Values (BP, PEFR)

Problems/diagnoses

Procedure codes (medical or surgical) and codes in consultation (signs, symptoms)

Codes showing referral made or letters received (no attachments)

Other codes (ethnicity, QOF)

Coercion risk: Step 1 Practice staff when registering a proxy must be aware of any safeguarding signs to look out for. Ask the question: "Do you think that you may come

Coercion risk: Step 2 If a GP or other health professional suspects that a patient is being coerced, they should try to establish the true position with the patient before

Coercion risk: Step 3 If after discussion with the patient and colleagues who know the patient and their circumstances, you believe there are good grounds to suspect the

Detailed coded record

For patients and their proxies, online access to the coded information in the GP record gives them an up-to-the-minute view of the core data in the record (see diagram above).

In England, GPs are required by their contract with the NHS to offer access to all the coded data in the record unless there is evidence that it would be harmful to the patient. This may include circumstances where the patient may be coerced to share their access with someone else unwillingly or may be unable to maintain the security of their access. Both are more likely if the patient has dementia. If a patient does acknowledge a risk of coercion, they should be referred to a senior clinician to consider safeguarding measures.

Both maintenance of a dementia diagnosis register as well as annual face-to-face reviews of dementia care plans are indicators in the Quality and Outcomes Framework. If all the important information about the patient's dementia and healthcare is coded, Patient Online access to the detailed coded record becomes very useful to the patient and their proxy. Most of the core information in dementia care plans, advanced care plans and the Care Plan for all long term conditions that brings together care with a person-centred focus can be coded.[3,3a] These can help patients to keep up-to-date with their care, determine priorities, and collaborate with their healthcare professionals. Further information regarding Patient Online's utility in accessing coded care-plan data with full record access and care plan documents held by the practice are available via Patient Online.

Access to diagnosis and problem lists provide clarity about multimorbidity and major operations. NHS England estimates that approximately two thirds (67.6%) of people aged 65 and older with

dementia have a recorded diagnosis of dementia.[4] They can view their recorded preferences and advance decisions about their care to make sure that they are complete and up-to-date

Patients can also use the coded data to view the latest and trends in test results to prepare for consultations and review their self-management of their dementia and co-morbidities.

Data about past immunisations, adverse drug reactions and allergies, screening procedures, and referrals help to inform and remind patients about other aspects of their healthcare.

Full record access

Access to consultation text, scanned images, and other files attached in a patient's record can be very useful for patients with dementia and their carers, as patients with dementia are more likely to forget new information and decisions made in consultations. Full record access enables them to review consultation notes and hospital letters and remind themselves of what was said and done. It can be very helpful to carers who might otherwise struggle to understand what is happening and it can be invaluable to share information with healthcare professionals when the patient is away from home.

Privacy and data security

GP systems are flexible in how they deliver Patient Online, which allows the practice to tailor patients' and proxies' access to information to the needs and safety of the patient. It is helpful to have these discussions with the patient before their dementia diminishes their capacity to engage in such important decision-making.

Checking and redacting potentially harmful data or confidential third-party data before full record access is activated can be difficult to do

Online appointment booking → Online prescription access and management → Record access to coded data or the full record

reliably. This is especially true when the record is large, as full removal can take a long time to achieve. Restricting access to information added after full record access is activated, referred to as "prospective access", reduces the risk of inadvertent access to data that should have been redacted while still allowing patients and proxies to benefit from access to important information relating to their future care.

As it is not feasible to know who has and does not have Patient Online record access, it is important to maintain a high standard of data recording for all patients. It is particularly important to be wary of recording any confidential third-party data, as well as any data which may be harmful to the patient without redacting it or discussing it with the patient first.

Proxy access where the proxy has their own login credentials makes it possible to tailor the proxy's access to the needs and wishes of the patient. The proxy's access may be restricted to prescriptions and appointments, or to the detailed coded record but not the full record.

Whatever level of access the proxy is allowed, there may be information on the record that the patient does not want the proxy to know about. There may also be information that the patient wants to add or change. It is helpful to have a conversation with the patient about this before activating proxy record access.

Care planning for dementia

Planning for the future is an integral part of living with dementia, as there are many things for the patient and their carers to consider. Given the often complex and challenging nature of these issues, they are often increasingly difficult for patients to undertake as their condition progresses.

The Alzheimer's Society offer booklet for patients offers advice on strategies to plan ahead for things like working, driving, financial matters, benefits and legal matters such as a lasting or enduring power of attorney, a will and advance statements about likes and dislikes, priorities and preferences and advance decisions about healthcare. It emphasises the importance of identifying trusted third parties who will support the patient as they lose the capacity to manage their own affairs.[5]

Personalised collaborative healthcare planning is also part of routine healthcare for these patients.

Data from NHS England for 2017-2018 shows that approximately 70% of patients with a recorded diagnosis of dementia had an annual review at their GP practice.[6] Online record access is important to effective implementation of care plans. It can act as an aide memoire for patients and carers. Patients and carers can check the plan, remind themselves of the agreed steps and ensure that the GP record matches their preferences and advance decisions.

Dementia care plans supported by Patient Online		
Care plan item	**Coded data**	**Patient Online role**
Dementia diagnosis	Symptom codes until the diagnosis is confirmed, e.g. mild cognitive impairment. When the diagnosis is certain: a definitive diagnosis code which will place the patient on the dementia register	Offers the patient clarity and a reminder about the diagnosis, Offers the patient a reminder about implications of the diagnosis; proactive approach to ongoing care plans and things like advice about driving
Carer information	Add carer to to carer register Carer details including relationship to the patient should be coded. Carer's name is usually free text Carer annual health check Patient permission to discuss health with the carer	Patient and carer can check that the practice has up-to-date and complete information and ask for changes if necessary Reminder of when a carer health review is due
Legal and financial information	Lasting or enduring power of attorney for health and welfare and property and finance[9,11] Court appointed deputies Living wills Driving and DVLA referral Capacity assessments under the Mental Health Act 2005 At risk of Deprivation of Liberty [7]	Shows what the practice is aware of and has recorded Documentary evidence recorded by the practice may be visible to the patient through Patient Online with full record access
Forward planning for failure of mental capacity	End of brain life care plans End of life care plans Has advanced statement Has advance decision Preferred place of death Has capacity to consent Lacks capacity to consent Note: Capacity needs to be assessed for each decision; people may be capable of capacity for some things and not in others	Shows what the practice is aware of and has recorded Enables the patient to ask for changes if the information is out-of-date Offers the patient a reminder about implications of the diagnosis; proactive approach to ongoing care plans and things like advice about driving

Dementia care plans supported by Patient Online		
Care plan item	**Coded data**	**Patient Online role**
Research	Consent and dissent codes to use of confidential patient information for research in general or for specific research projects Registration with Join Dementia Research[8]	Shows what the practice is aware of and has recorded The national data opt-out will not be recorded in the GP record
Dementia review	Dementia assessment tool scores can be coded Activity, diet, alcohol, smoking Height, weight, blood pressure Blood test results Immunisations Proxy access consent or intentions and other permissions to share confidential health information	Helps the patient and carer to engage in healthcare decisions and may stimulate behavioural change to reduce the rate of dementia progression They may use the information to consider priorities for their next consultation Opportunity to consider proxy access currently or in the future and capacity (including capacity to consent) is lost
Comorbidity: a person-centred care view of the patient's health-related problems including long term conditions and psychosocial problems	Active and inactive diagnoses and problems, including major operations and psychosocial events. The problem list must be kept up to date and accurate to avoid misleading the patient	Reminds the patient and informs carers of all the health-related issues that the practice is dealing with or has addressed. This allows them to assess what matters to them and to consider the impact of dementia on their other long term conditions and their effect on the dementia
Data related to co-morbidities,	Includes latest long term condition reviews and important symptoms, signs and test results	Multimorbidity is complex and difficult for people to understand, especially if they are living with dementia. Presenting the key information help patients focus on what matters to them They may use the information to consider priorities for their next consultation Reminder to attend routine checks for eyes, ears and feet

Dementia care plans supported by Patient Online		
Care plan item	**Coded data**	**Patient Online role**
Latest medication review	Medication review completed with date Adverse reactions to drugs and allergies Assistive aids to help manage medication	Evidence that a medication review was carried out and an opportunity to check that previous adverse drug reactions and allergies are recorded, medication aids recommended and treatment regime simplified if possible
Referrals and interventions	Referrals to relevant allied health professionals and social care colleagues can be coded. Full record access is required to see referral letters, scanned hospital reports and other files Assistive technologies	Makes it clear that referrals have been done and is a reminder of where referrals have been made by the practice
Mental health screening, related diagnoses and referrals	Mental health screening and diagnoses and referrals to relevant agencies	Mental health problems commonly accompany dementia. Patient Online makes it clear that referrals have been done and is a reminder of where referrals have been made by the practice
Additional risk factors	Frailty Risk of falls Acute confusion Hallucinations Continence Nutrition and hydration Tissue viability Safeguarding issues Accessibility needs Environmental needs Carer stress and support	Communicates concerns to patients and carers Safeguarding concerns may need to be redacted, at least until discussion with the patient and/or carer They may use the information to consider priorities for their next consultation
Social care and support	Social care and voluntary sector support Benefits Housing Mobility	Patients and carers can check that the list is accurate and up to date They may use the information to consider priorities for their next consultation
Living well: interests, hobbies, social functioning, activities of daily living that are important to patient[4]	Code key activities that are important to the patient. Personal health budgets	Patients and carers can check that the list is accurate and up to date They may use the information to consider priorities for their next consultation

Proxy access when mental capacity is impaired

When patients begin to lose the capacity to manage their own health or use Patient Online themselves, proxy access can be very helpful. There are benefits for the patient, their carers and the practice, including patient safety and improved communication and convenience, there are also risks that must be assessed and mitigated before proxy access is granted, even if the patient is able to consent.

If it is clear that the patient is not being coerced to agree to proxy access unwillingly, that the proxy will not misuse their access or breach the patient's privacy, and that the record has been clinically assured for online access, proxy access can be activated. If there is evidence of coercion, it may be best to switch off Patient Online for the patient and refuse proxy access until the situation can be clarified satisfactorily. A safeguarding referral may be indicated.

Once proxy access has been granted, it can be withdrawn at the patient's request or if there is evidence of abuse of the patient or misuse of Patient Online by the proxy. It should also be withdrawn if the proxy ceases to be responsible for the patient or chooses to stop using Patient Online.

Each proxy should have formal proxy access: that is their own account and their own login details. This may not be possible if the patient already has a Patient Online account with their own passwords, as not all GP systems currently allow for multiple persons to create separate passwords for access to an individual patient's Patient Online services. The benefit of the patient and the proxy having different passwords is that the proxy's may have a different level of access to the patient and their access can easily be withdrawn without affecting the patient's access.

Patients should be advised of the risks of sharing their login details with anyone else and must understand their responsibility for protecting the privacy of their health data.

Family and close friends are the most common proxies. They may be involved in the day-to-day care of the patient, or they may live a distance away and use proxy access to keep up to date with the patient's healthcare to remain informed as to when help is needed. As patients who are losing capacity may not be able to clearly remember

consultations with their health professionals, test results, management plans or medication changes, proxy access can serve as a means of assisting the patients to facilitate best care. At its core, proxy access serves to improve communication between careers and health professionals, not just in the practice, but also hospital departments if the proxy has access to recent clinical correspondence.

If the patient has the capacity to consent to proxy access, confirmation can be attained which maintains that proxy access is in the patient's best interests, and the risks are minimal, the decision to grant proxy access is fairly straightforward. It is important to review the patient's wishes about proxy access on occasion in case the patient's circumstances have changed or they no longer want or need the proxy to have access. Review of proxy access should also occur promptly whenever there is a suggestion that a proxy may be misusing their access.

If there is uncertainty about the patient's capacity to consent, the practice must satisfy themselves that the patient is capable of giving consent. This may require a formal assessment of capacity in line with the Mental Capacity Act 2005.

When capacity to consent is lacking and it is clear that it would be in the patient's best interests for a particular person to have proxy access, then the practice may allow that person to have access to Patient Online services on behalf of the patient. The decision to allow proxy access is easier to make if the patient indicated that they would like the proxy to have access before they lost the capacity to consent. This should be part of the forward planning process for dementia.

Legitimate reasons for the practice to authorise proxy access without the patient's consent where the patient has been assessed as lacking capacity to consent may exist if:
1. in accordance with the Mental Capacity Act 2005 code of practice,[10] the GP considers it in the patient's best interests to grant the requested access to the applicant
2. the applicant is registered to have a lasting power of attorney for health and welfare with the Office of the Public Guardian
3. the applicant is acting as a Court Appointed Deputy on behalf of the patient
4. the applicant is a health professional who has a legitimate relationship with the patient for

providing direct care to them, such as a nurse working in a nursing home

5. the patient is a child or young person who has been assessed as not competent to make a decision on granting proxy access and the applicant has parental responsibility for the child.

When someone requests proxy access on the basis of an enduring power of attorney, a lasting power of attorney for health and welfare, or as a Court Appointed Deputy, their status should be verified by requesting a search of the registers held by the Office of the Public Guardian.[12] This is a free service. The result of the check should be recorded in the patient's record.

When a patient loses capacity to review the proxy access decision but has already granted proxy access to someone, the practice should review and consider whether to withdraw the proxy's access. Proxy access may continue if it is still in the patient's best interests, especially if the patient's prior consent to it continuing has been recorded in the GP records.

The level of access to book appointments, order prescriptions or view some or all of the clinical record should be limited to those parts of Patient Online that will clearly help the proxy care for the patient.

Proxy access to patient's clinical record carries a much greater risk of misuse or breach of the patient's privacy. The record should be checked, with the patient if possible, to ensure that data that the patient wishes to keep confidential are redacted before proxy access is activated. If the patient does not have the capacity to do this, the practice should use their best judgement to redact data that they suspect the patient may want to be private. See the guidance in the toolkit on redacting sensitive data.

Proxy access should not be granted in dementia if:
- practice staff have good grounds for suspicion that the patient is not giving access freely
- there is a risk to the security of the patient's record if the person being considered for proxy access is given it
- the patient has previously expressed the wish not to grant temporary or permanent proxy access to specific individuals should they lose capacity; this should be recorded in the patient's record
- the patient's GP assesses that it is not in the

best interests of the patient.

Proxy access for health and social care professionals

Sometimes practices are asked for proxy access by health or social care professionals who have a legitimate relationship with the patient to provide regular direct care. For dementia, these requests most commonly come from nursing homes. Oftentimes, these requests are for minimal permissions, such as the ability to order repeat prescriptions, and are fairly straightforward. The response to a request for access to a patient's detailed coded record or complete GP record including hospital correspondence is more complicated.

The reason for record access is usually to keep up to date with the patient's NHS care. This may benefit the patient if it improves communication between the nursing home and the NHS but there are risks to the practice, the patient and the institution or organisation requesting proxy access. Not least, the information available to the organisation staff may not be complete or clear enough to be used safely to support clinical decisions without prior discussion the patient's GP. There are also risks to the security and privacy of the patient's personal information.

If nursing home clinical staff or members of any organisation are to be allowed proxy access to Patient Online, it must be covered by a data sharing agreement that deals with all these risks.

Data sharing agreement for proxy access for direct care

Before establishing an agreement for proxy access with another health and social care organisation for Patient Online proxy access, consider seeking advice from the General Medical Council, British Medical Association or their medical indemnity organisation on the specific circumstances of the data sharing proposed. This guidance suggests the scope of an agreement for proxy access to health and social care professionals outside the practice for patients with dementia, using nursing homes as the commonest example, but may not be suitable in all circumstances.

The agreement should be reviewed regularly by the practice and the organisation to ensure that any changes in circumstances are included. This should happen whenever another patient is considered

for Patient Online or at least on a regular agreed date.

Scope of the agreement
Consider having a separate agreement for each patient.

These agreements should include the name of the patient, the practice and the organisation seeking proxy access, and the purpose of the data sharing and its legal basis, which may be patient consent if they have capacity to consent.

The agreement should describe the level of access for the proxies that it covers, including but not limited to: appointments, prescriptions, detailed coded records or full record access and the purpose of proxy access.

It should be clear who is to have proxy access to the patient's account or specify who must agree to named individual's having proxy access, including the patient, the practice and the organisation, and the circumstances under which access may be withdrawn.

Consent and capacity
If the patient lacks capacity to consent, and consent is given by someone with a lasting power of attorney for health and welfare, and enduring power of attorney or is a court appointed deputy, their consent should be recorded.

It may be helpful where a patient lacks consent, but there is an entry in the GP record that the patient previously indicated that they consented to the proposed proxy access of where close family members agree to the access and who they are should be recorded in the agreement.

Individual proxies
The agreement should state that only individuals with a legitimate relationship for providing care to the patient will be allowed proxy access. Each should have their own personal login credentials and should not share them with anyone else in the organisation.

The agreement should include a statement of when and how the organisation providing care to the patient will inform the practice that a member of staff who has Patient Online access no longer has responsibility for the patient or has left the organisation so that the practice can withdraw access to their account.

The agreement must clearly indicate that patient and practice objections to specific individuals having proxy access will be observed by all parties.

Security and data protection
The agreement should describe how the organisation will protect the security and confidentiality of the patient's online account and confidential information.

Each member of staff who will have access should have their own login credentials and personal level of access. They should be named in an addendum to the agreement or in the agreement itself, and their agreed level of access should be recorded.

The practice must be informed immediately if login details are lost or it is suspected that someone else may have gained access to them. In addition to the noted instances, any other potential breaches of data security or protection affecting Patient Online should be promptly reported.

Clinical decision support
The agreement should explicitly state that the information available to the organisation staff through Patient Online may not be complete or whole enough to be used to support clinical decision making. The organisation should agree not to use Patient Online to help make clinical decisions.

Summary
Patient Online offers many benefits to patients living with dementia and their carers. Dementia is progressive disorder that leads to a loss of mental capacity and difficulties in self-care. It will affect the patient's ability to consent to help and support from carers and health professionals. Patients and their carers alike should be encouraged to plan ahead to maximise patient involvement in their own healthcare, including Patient Online.

It offers the convenience and clinical safety of online repeat prescription requests and access to key health data including the latest care plan.

Dementia is also commonly a part of a complex multimorbidity picture. Patient Online can help patients and their carers navigate complex care pathways and collaborate with the NHS staff

to establish their priorities. It encourages and supports a person-centred approach to care. They can use it to share the health information with health professionals outside the practice.

Allowing proxy access to health professionals outside the practice for direct care requires careful planning, but is possible if carefully established and kept under regular review.

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