

PATIENT ONLINE AND MENTAL HEALTH CONDITIONS

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Purpose of this document

This guidance is for GPs and practice nurses. Its purpose is to describe how access to GP online services contributes to person-centred care for patients with mental health conditions, and to present the case for recommending online record access to these patients.

It describes how you can help patients use Patient Online to access information about their healthcare to improve their ability to understand and self-manage their condition; in particular, how patients can use access to test results and other health information to prepare for consultations, enabling them to be more engaged in their care.

It also describes the specific risks that online record access may hold for patients with mental health conditions and the practice, and offers advice about how they can be addressed.

Some of the conditions covered in this guidance include anxiety disorders, schizophrenic disorders, bipolar disorder/related conditions, eating disorders and personality disorders. Dementia is covered in separate guidance.

For the purposes of this document, patients with serious mental illness (SMI) are considered to be those with schizophrenia, bipolar affective disorder, other psychoses and other patients on lithium therapy or antipsychotic medications.

Patient Online for patients with a mental health condition

It is estimated that by 2026 9.5 million people in England will be suffering from a mental health condition. This will cost public services, including the NHS, £32.2 billion a year.¹ With these costs rising, there is a need to allow patients to become more engaged in their own care and manage their own condition. Patient online facilitates person-centered care and contributes to this by allowing patients to become more empowered and more engaged in their own care.²

Transactional services - Many patients appreciate being able to use the internet to access GP services and avoid having to visit or telephone the surgery. Booking and cancelling appointments online is simple and convenient. Patients with anxiety may be intimidated by the normal booking process face-to-face or via telephone and the opportunity to use the internet may be very helpful, particularly for younger patients very familiar with using smartphone apps.

Patients with mental health problems often have complex medication regimes. Doses may be adjusted frequently. Online access to their prescription list helps to prevent patients becoming confused about what their current regime calls for and what they can request without seeing their doctor. Some online systems also provide a reminder of when they last requested a prescription and when a review with their GP is due.

It does put the onus on practices to keep the repeat list up-to-date when a patient's medication regime is changed, but it means that the patient will not be able to request prescriptions that have been stopped. Patient Online systems generally have a one-way messaging facility that can act as a useful backstop. It enables patients to ask questions if something they think they should have on repeat is missing from the repeat list.

Detailed coded record - Coded data is any data

within the GP record system with an attached code. This can include anything from allergies, medications, immunisations, test results, specific recorded values (such as blood pressure/heart rate/weight etc), problems and diagnoses.

There is more information about access to the detailed coded record enables patients to see online in the Detailed Coded Record guidance in the toolkit.

Experience has shown that the first thing that patients do when they get Patient Online record access is to check the accuracy of their record. 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 decisions about their care are well-informed and there is no need for the patient to keep explaining their history. This is particularly important when patients have complex mental health conditions, complicated medication regimes and shared care.

According to the 2013 national survey by the Office of National Statistics, 43% of the British population used the internet for health-related information, and around 35% of these searches are related to mental health conditions. Patients with a mental health diagnosis use the internet to search for information about their diagnosis, their treatment and possible side effects of their medication.³ The next step is to use the internet to look for information in their own GP record.

Patient Online provides an ideal starting point for patients to become familiar with their diagnosis and background health information. Having an accurate starting point enables them to search

more effectively for supplemental information to understand what it means to them and therefore increase their health literacy.

Full medical record access - Full medical record access includes access to the consultation notes, scanned letters and other documents containing clinical correspondence, referrals, multidisciplinary care reports including social care reports and care plans.

Patients can use this extra information to keep up-to-date with investigations and reports from secondary care and other health and social care organisations. It helps them understand the roles of the different health and social care teams they meet and all aspects of their care including who is involved, how it is delivered and how it is being recorded and communicated. It gives them the best opportunity to assess the clinical advice they are being given and make their own healthcare decisions.

There are problems with full record access that have to be managed carefully. Consultation notes and clinical correspondence about serious mental illness are sometimes couched in terms that patients may see as derogatory or stigmatising and it is essential to remain aware that any patient with mental health problems may ask to see their record, online or on paper. Records and correspondence should be made with this in mind (even though it can be difficult to predict what a patient will find upsetting).

Although such sensitive data can and should be redacted (see below) so the patient will not see it if it is going to cause them harm, it is not always clear during a consultation if the patient has online record access or if they will have online record access in future and record keeping should reflect this fact. It is good practice to discuss the content of letters and reports openly and answer every question that the patient has about them.

There is more information about enabling access to the full record in the guidance on Applications for Online Record Access – a step-by-step guide and Safe Patient Online Record Access in the toolkit.

Information for patients with mental health conditions

General information

[Royal College of Psychiatrists](#)

[Mental Health Foundation](#)

[Mind](#)

[Rethink Mental Illness](#)

Lab Tests

[Lab Tests Online](#)

General information on record access

[Rethink Mental Illness - record access](#)

[Mental Health and Learning Difficulties](#)

Summary of information relating to record access

Detailed coded record

- Diagnoses and problem lists, including relevant psychosocial circumstances and substance abuse
- Hospital admissions and referrals including use of the Mental Health Act
- Codes relating to physical health risk factors, e.g. cardiovascular risk, and events, Lifestyle records: exercise, smoking and alcohol consumption
- Mental health questionnaire scores e.g. PHQ 9, GAD 7
- Employment and disability details
- Examination results: height, weight, body mass index, blood pressure
- Test results: Full blood count, inflammatory markers, lipid profile, blood glucose, urine albumin-creatinine ratio and renal function
- Records of health promotion activities, such as screening and immunisations
- Allergies and previous adverse drug reactions
- Current and past prescribed medication

Full medical record

- Relevant referrals and hospital correspondence and reports, multidisciplinary team meeting reports, CPA documents, etc
- Consultation notes and full care plans

Mental illness and co-morbid long-term physical conditions

There is strong evidence that people with long-term conditions are 2-3 times more likely to experience mental health problems than the general population.^{7,8,9} There is good evidence that integrating mental health support with chronic disease management improves care and outcomes.⁹

Patients with serious mental illness (defined for the Quality and Outcomes Framework in England as schizophrenia, bipolar affective disorder, other psychoses and mental health condition requiring lithium or antipsychotic medication) have a 15-20 year reduction in life expectancy compared to the general UK population. This is often due to poor physical health.⁵

Patient online helps patients manage long-term physical and mental health problems and can help them cope with the complexity of multimorbidity. Access to problem lists, test results, care plans and hospital reports helps them monitor their progress

and prepare for consultations. Access to preventive health interventions and screening can help them remain up to date. Checking the practice has up-to-date records of adverse drug reactions and allergies, personal preferences about their care and their social circumstances can help to make sure that the record is a reliable tool for providing care across health settings.

There is more information about how patients can use Patient Online to help them manage their long term conditions in the guidance on Diabetes Mellitus, Inflammatory Arthritis, Dementia and Multimorbidity in the toolkit.

Safe use of record access in serious mental illness

Patients with serious mental illness (SMI) may be particularly at risk of having problems with Patient Online, particularly record access. Every decision about whether to enable Patient Online for a patient with an SMI must therefore be made on an individual basis carefully balancing the potential benefits with the possible risks. It may be in the patient's best interests to refuse Patient Online if you feel that the risks to the patient are too high.

Patients with an SMI are more vulnerable to coercion to share their access to their record unwillingly. They may be unable to protect the security of their health data. The content of their record could be conceivably embroiled in their delusional thinking.

Patients with mental health conditions may be particularly sensitive to certain information in their coded record which they could find particularly upsetting, stigmatising or contentious. Some people may find the application of a psychiatric diagnosis undermining. Where diagnoses are made in secondary care and added to the record from a hospital report, the practice cannot be sure what the patient understands their diagnosis to be.

There is more information about enabling access to the full record in the guidance on Applications for Online Record Access – a step by step guide, Coercion and Safe Patient Online Record Access in the toolkit.

There are number of ways that practices can help patients with SMI who request Patient Online, particularly record access, use it safely.

Application process

- Offer clear, accessible information about how to apply for and use Patient Online. There is more information about this in the guidance on Patient Information in the Toolkit.
- Make the Patient Online sign-up process itself straightforward and non-threatening. It may help to allocate and train a specific member of staff to help the patient with SMI complete the application process.
- It is essential to enquire about whether the patient suspects they may be subject to coercion or abuse. It may also be helpful to ask other practice team members or other health professionals, such as members of the community mental health team, who know the patient well, if this may be the case.
- Careful clinical assurance of the patient's record before record access is agreed and switched on is essential, particularly looking for information or opinions that may be upsetting or harmful to the patient. Clinical correspondence from mental health and social care services is particularly important to check if full medical record access is being considered. Sensitivities to the content of the record may be personal and idiosyncratic. It is also important to avoid confusion arising from poor data quality.
- Potentially harmful data should be redacted during clinical assurance (along with any confidential third-party data), that is hidden from view from the patient though not from the practice. It may be possible to remove the redaction after discussion with the patient. If there is data that may cause harm to the patient that cannot be redacted, it may be necessary to refuse record access.
- When adding new data to the record (including new consultation notes or hospital reports if the patient has access to the full record) they should be carefully considered for redaction, at least until it has been possible to discuss them with the patient.
- If potentially harmful data cannot be redacted, you can refuse to allow record access in the patient's best interests. Over time fluctuations in mental health may require Patient Online access to be switched off temporarily.
- Carefully discuss the content of the record if there is anything that you think the patient may misunderstand or misinterpret. They may not be aware of the level of detail about their mental health that they may find in the GP record. The GP that knows the patient best is likely to be best placed to have this discussion.

- Whether Patient Online access is allowed, refused or limited, ensure that the patient understands and hopefully accepts the practice's decision and reasons for it. The discussion may include a carer or representative if appropriate and with the patient's consent.

Once a patient has online record access

- Take care that the patient knows how to raise concerns with the practice about anything missing or incorrect in their online record. The practice should welcome the feedback and attempt to meet patients' requests whenever possible. The final decision about the content of the record does lie with the health professionals who created the record, but if the patient disagrees with anything they see in their record it is good practice to add a note about it to the record.
- Like other illnesses, mental health illness may fluctuate and the level of concern for the patient's mental state, their capacity and the risks of having a Patient Online account, particularly record access may vary. This must be borne in mind for all patients with unstable mental health problems as it may not be clear in the record who has Patient Online.
- Digital exclusion is a barrier for a significant number of patients, especially those affected by chronic and severe mental health problems. This should not be the sole reason not to grant Patient Online access. The Good Things Foundation and NHS Widening Participation programme have networks of learning centres whose goal are to tackle digital and social exclusion by providing people with the skills and confidence they need to access and utilise online technology including GP online services.^{10,11}

Proxy Access in mental health conditions

An option to consider for some patients with SMI is that someone such as a close family member or carer who can act on their behalf in the patient's best interests, may be able to support the patient by using Patient Online access to the patient's transactional services or records. This should only normally be done with the patient's consent. It is called proxy access. It may be reserved for use only when the patient is too ill to manage their own health or agrees to accept help.

The support that this offers can be very valuable to

someone with a serious mental illness when there is someone that they trust to be their proxy. It is possible to switch on proxy access temporarily to help a patient through an episode of poor mental health.

The proxy should have their own login credentials so that the access can be tailored to suit the patient's needs and wishes.

Some patients may simply share their login credentials with others and sometimes this is a reasonable thing to do but ideally the proxy should have their own personal credentials if the GP clinical system has that functionality. This is a safer option because the patient and the practice have more control of the access to the patient's Patient Online account. It can be tailored to the patient's wishes. For example, the patient may not want the proxy to have full access but would like to have help with appointments and repeat prescriptions. Currently not all GP systems will allow more than one set of login credentials for one patient.

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.

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 considering a request for proxy access, remember that the access may be misused by the proxy or that the patient may be coerced to allow proxy access against their will.

There is more information about this in the Coercion guidance in the toolkit.

Summary

This document has shown how Patient Online record access can be useful to patients and practices in Mental Health conditions. It supports person-centred care by allowing the patient to

Record Sharing

Patient online records can be shared with third-party's informally or formally. This could be anyone from district nursing, community mental health team staff or an admitting hospital team. This would allow the third-party to see information held within a detailed coded record including their coded medical history and most up-to-date medications. This information can often be helpful especially in an acute setting.

Informally: This is where the patient or their carer physically show a logged in device and allow the third party to view the record as the patient would on their device.

Formally: Most providers of patient online services allow patients to give third-party access often through time limited single-use access to their patient online record. This is commonly in the form of a web link and authorisation code which is given to the third-party.

be more empowered and engaged in their own health. It also highlights the use of GP online services in managing co-morbid disease.

Clinical scenario A: New depressive illness

Andrew Mason is a 32-year-old man who over the last few months has problems with his mood. He presents to his GP with multiple symptoms of depression including feelings of helplessness, sleep difficulties, poor concentration and generally low energy levels. He does not have any psychotic features or other signs of severe depression. There is no suicidal ideation and he has a stable social background. He reports that he drinks more than previously at 22 units per week and smokes 20 cigarettes day.

During the initial consultation, the GP carries out a PHQ-9 and a GAD-7 assessment. Andrew scores 19 and 11 respectively. The GP codes this information along with his alcohol intake and smoking. The GP diagnoses depression and discusses antidepressants and referral to local IAPT services. Andrew agrees to start antidepressants return for review in two weeks. The GP issues an acute prescription for sertraline 50mg once a day and codes depression as the problem for the consultation.

The GP recommends that Andrew signs up for Patient Online with access to the detailed care record, which he does before he leaves the practice. When his Patient Online account is switched on, he sees his recent diagnosis of depression, his PHQ-9 and GAD-7 scores, and his alcohol and cigarette use. His medication list includes an acute prescription for sertraline 50mg daily, but he cannot order a repeat. This reminds him to make an appointment for review with his GP, which he does online. In the meantime, he contacts his local IAPT provider.

Two weeks later, Andrew sees his GP again. He reports that his mood has improved and he has CBT arranged with his local IAPT provider. The GP repeats the PHQ-9 and GAD-7, now 9 and 6 respectively and records the results. Andrew agrees to continue the sertraline and return to the GP in six months for review, or earlier if there are any problems. The GP codes the consultation and adds sertraline to Andrew's repeat list with a six-month review date.

Six months later Andrew is feeling well. He tries to re-order the sertraline but realises he is no longer able to order it online. This reminds him to make a follow-up consultation with his GP which he does using Patient Online. At this point he also looks at his detailed coded record again and notes his smoking and alcohol intake which his GP suggested he could consider cutting down. This prompts him to make contact with smoking cessation services.

Clinical scenario B: Bipolar affective disorder with co-morbid disease

Gillian Gray is a 49-year-old lady with a background of diabetes and a twenty-year history of bipolar affective disorder. She has been on lithium for 15 years without problems and her bipolar disorder has been stable for 12 years. She has an annual review in secondary care.

Gillian does however have ongoing problems with her diabetes control and this this year her HbA1c has climbed to 56. Her weight has increased as well, her BMI is now 33. Her blood pressure has risen to average 148/85. She has been taking metformin and ramipril.

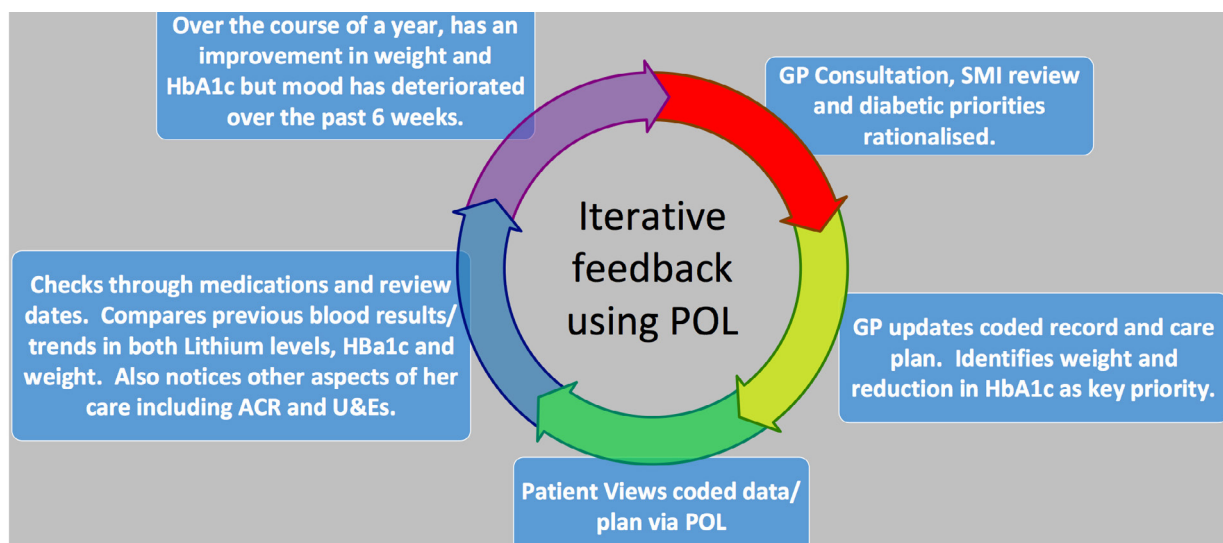
Gillian has complex co-morbid disease and her SMI places her at a much higher risk of complications and mortality from the physical health problems. Patient Online presents an opportunity for Gillian to become more engaged in the self-management of her health.

Being able to monitor the coded data in her record, including her physical health risk factors, she is more likely to take ownership of her health maintenance strategies. She can read her test results and monitor trends in her weight, blood pressure, cholesterol and HbA1c. This helps her decide on her health priorities and the relative needs of her co-morbidities.

There is more information about using Patient Online for care planning in the Diabetes guidance in the toolkit.

Online record access helps Gillian to focus on what matters to her. As her bipolar disease is stable, Gillian decides that her priority is her physical health (red section in the accompanying care planning diagram). With her GP's help, she decides to concentrate on weight reduction first, and reduce her alcohol intake as part of that. The GP updates her record and care plan. Over time Gillian is able to see a reduction in her body mass index and a parallel reduction in her HbA1c without a change in her medication. Her blood pressure remains a little high and she is not surprised when her GP recommends adding a second anti-hypertensive drug.

Unfortunately, her mood begins to deteriorate making it harder to maintain her weight and limit her alcohol consumption and prompting further contact with her GP to review her bipolar disorder (purple section). The process then repeats allowing Gillian and her GP to address the changing priorities.



Clinical scenario C: Paranoid schizophrenia (Proxy access)

Alex Murphy is a 28-year-old man with a background of paranoid schizophrenia. He has a long and complex history with multiple Mental Health Act admissions under section. He is currently under the care of a consultant psychiatrist and his parents are his main carers. Alex's medication regime is complex and has changed frequently as his condition fluctuates.

When he is well, and his condition is well controlled, he can use the online transactional services to ensure he follows the medication plan and can order repeats in a timely manner. When he is not well his parents help him manage his concordance with the regime so he gives his consent for them to have Patient Online access to manage his GP appointments and repeat prescriptions until he recovers.

Because of the severity of his condition, his GP has decided that record access has the potential to become incorporated in Alex delusional ideas and would not be in his best interests. Enabling Patient Online only for transactional services (appointments and prescriptions) for Alex and his parents provides some of the benefits without exposing Alex to some of the risks of record access.

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