PATIENT ONLINE: PERSON-CENTRED CARE AND DIABETES MELLITUS

RCGP, 2018

Patient Online

Patient Online refers to the online services that GP practices offer their patients to book and cancel appointments, order repeat prescriptions and access their GP clinical record. In England GPs have a contractual requirement to offer access to most of the coded data entered in the patient's record, referred to as the "detailed coded record" or DCR. Practices may also choose to allow patients access to the full GP record including consultation notes and clinical correspondence.

Purpose of this document

This guidance is meant for GPs and practice nurses caring for patients with all types of diabetes mellitus to help you offer your patients online access to their record safely and confidently. The purpose of the document is to describe how access to GP online services contributes to providing person-centred care to patients with diabetes. It presents the case for recommending online record access to patients with diabetes and gives advice about how the practice can help patients use it to prepare for consultations and improve their ability to self-manage their condition.

Where does this guidance fit in to toolkit

The principles discussed can be applied to any long-term condition but the toolkit also includes guidance about using Patient Online in other clinical scenarios: dementia, end of life care, inflammatory arthritis, mental health and multimorbidity.

There is more information about registering patients for Patient Online and providing online services in the sections of the toolkit on Setting up Patient Online Services and Registering New Patients for Patient Online. How to provide safe and effective record access is discussed in detail in the Record Access section of the toolkit.

Learning objectives

- To be able to explain the benefits of using GP online services to patients, to encourage them to sign up for record access
- To be able to help patients use GP online services to access and understand diabetes test results and care plans
- To understand the benefits to the practice, in improving the efficiency and effectiveness of care
- To be able to realise these benefits safely and securely without adding to GP workload

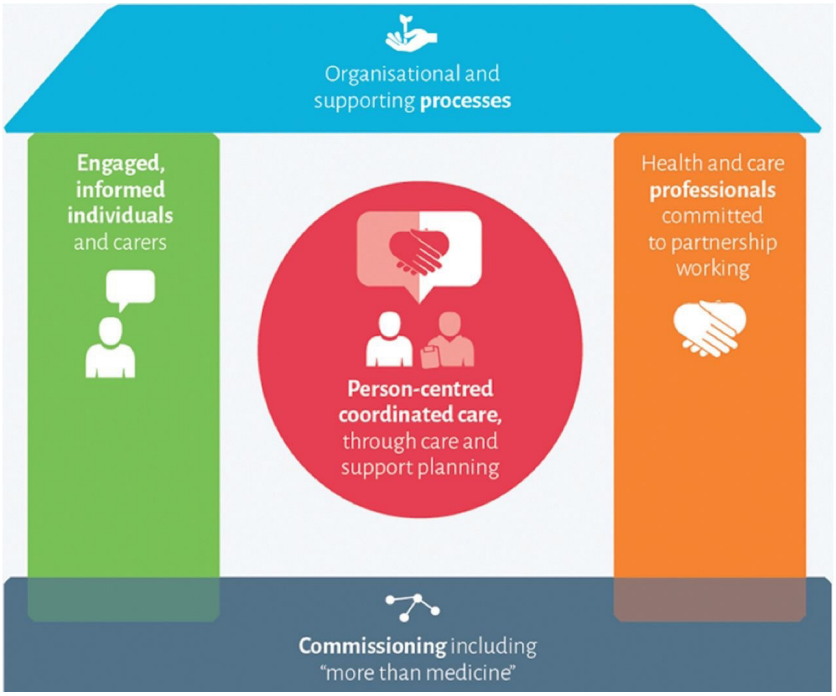


Figure 1: The House of Care framework[1]

The role of Patient Online in diabetes mellitus

The overall purpose of healthcare of patients with diabetes is to maintain their health and well-being, preventing or delaying the onset of complications. Day-to-day decisions that patients make on things like diet, exercise, smoking, alcohol, foot care and adherence to their prescribed medication matter, but at any one time they may not all matter equally to individual patients. Their priorities or understanding of their health may differ.

Diabetes can be complex for patients, nurses and doctors. Patients with diabetes visit their GP practice and the local hospital frequently; they often have co-morbidities; and they have many blood tests, scans, x-rays and other investigations. It is no wonder they sometimes find it difficult to understand and retain all the information they are given about their health, to the detriment of their ability and motivation to make the daily decisions that are needed for healthy outcomes.

If they have all the information they need at their fingertips, they can see what is going well, what may not be going so well, monitor the effect of their self-care. They are more able to assess their health-related priorities and make decisions based on what matters to them. Rather than being solely recipients of health care they can become engaged partners in the maintenance of their health. This applies to other long-term conditions as well.

The role of Patient Online record access for patients with diabetes is to make their health information available to help them participate in their care. It is a pillar of person-centred care (see figure 1). It can promote a better understanding of long term effects that their choices about lifestyle and medication make to their health and help them assess their priorities and make the best decisions about their self-care.

In summary Patient Online can support informed decision-making and collaborative problem-solving with the healthcare team, improving clinical outcomes and quality of life.

Do you know what your patients can see in their record online?
Patient interpretation and understanding of the coded record may depend on how the data is displayed online. To help patients understand their record it is helpful to be familiar with what the patients will see. Using a test patient on your GP system, you can create and change the record to see how your system supplier or third-party apps suppliers configure their 'Patient Online' display. Practice team members can log in and see how the different record access settings available in the clinical system affect what the patient sees and enable you to explore the different options. You can also use the test patient to show patients how to use the system themselves.

Record access and diabetes mellitus

Patients can use access to their GP record to improve their understanding of their diabetes, the progress on risk factors and the reasons for the changes they have to make and the treatment they are recommended to take.

Improve their health literacy. By focusing on the meaning of the diagnoses, complications, test results and treatments that the find in their record, patients can concentrate on learning about what matters to their health. Some online systems offer a suite of useful patient information leaflets about diabetes but patients may need help. This can be time-consuming. Tried and tested techniques such as "chunk and check" and "teach back" help to explain important terms in the record. By encouraging patients to engage with their own health record, they are more likely to become inquisitive and engaged with their diagnoses, investigations and treatments that they identify within their record itself. This also allows them to engage with other aspects of their health not directly related to their inflammatory arthritis. See the RCGP Person-Centred Care toolkit for more information.

Detailed coded record. Experience has shown that the first thing that patients do when they first get Patient Online record access is what is in their record. They may recognise that something important is missing such as an adverse drug reaction. Knowing that the information their GP holds 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. This is particularly important when patients have complex conditions such as diabetes with complications and co-morbidities.

There is more about recording coded data in the patient records for Patient Online in the Data Quality guidance in the toolkit. There is also advice on how to manage data which may upset or harm the patient or data that is confidential information about a third party in the guidance on Practice and Patient Safety - Sensitive Data.

Additional access to free text and clinical correspondence. This enables patients to take ownership of their wellbeing by easily accessing written communications between health care professionals (HCP) involved in their care; keep track of their latest care plan and improve communication and continuity of care with their carers, other HCPs and carers and when they need healthcare abroad.

Summary of information about diabetes mellitus online

Detailed coded record

- Diagnosis
- Complications of diabetes
- Major procedures and investigations related to their diabetes
- Lifestyle records: exercise, smoking and alcohol consumption
- Examination results: height, weight, body mass index, blood pressure
- Test results: HbA1c, lipid profile, blood glucose, urine albumin-creatinine ratio and renal function, foot and eye checks
- Codes relevant to their diabetes code plan (see patient scenario below)
- Records of health prevention activities, such as screening and immunisations
- Their recorded preferences about their healthcare
- Allergies and adverse reactions
- Current and past prescribed medication

With access to clinical correspondence and consultation text

- Their latest care plan
- Relevant hospital reports and letters

Information for patients with diabetes on test results and care plans

- Information prescriptions, Diabetes UK
- Diabetes and checking your blood sugars, Diabetes UK
- Meeting your healthcare team, Diabetes UK
- UK Lab Tests Online UK

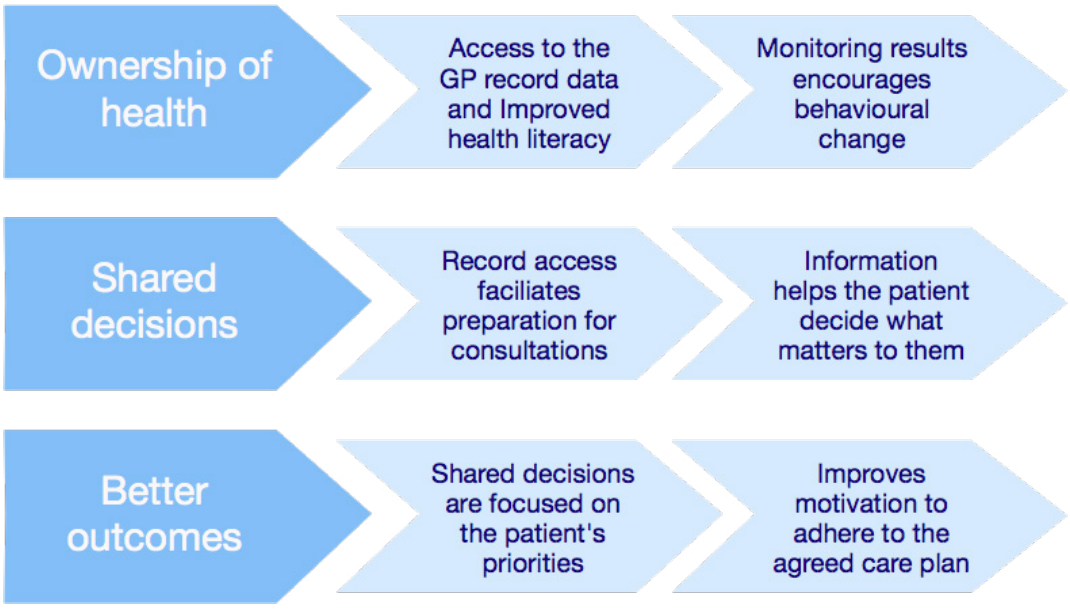


Figure 2: Shared-decision making

Patients' preparation for consultations

Access to the detailed coded record and medication alone can be very useful for patients wanting to prepare for consultations.

Access to the latest **test results** used to monitor their diabetes helps them to understand if control is improving or getting worse. These include height, weight, body mass index, HbA1c, total cholesterol, glucose, blood pressure, urine albumin-creatinine ratio and renal function. Online they can view trends over time to assess the effects of new medication (e.g. a fall in total cholesterol after starting a statin, or a fall in HbA1c after a change in hypoglycaemic treatment) or the effect of efforts to improve their self-management of diabetes, such as weight control or blood pressure control.

With prior knowledge of these results, **the consultation can focus on the anomalies** and help patients understand the important issues, remember information and advice given to them and participate fully in decisions about their care. This encourages patients to take greater ownership of their condition and fosters a healthier HCP-patient-relationship.

Some patients struggle to describe their health problems, test results and medication clearly to their carers. **Carers with proxy access** (see glossary) may be able to play a greater part in the healthcare of the patient.

Patients with record access can stay up-to-date with **immunisations and screening tests** and when are due. They can also check that their allergies and adverse reactions are recorded and that the practice has a record of their data sharing preferences or arrangements for a lasting power of attorney, and use the opportunity to ask for the record to be updated if they wish.

Patients may benefit from access to scanned documents, practice word processed documents or consultation text. They can see hospital reports, which are particularly important for patients with complications of diabetes or co-morbidities, not all hospital department copy GP letters and reports to their patients. They can also see **their latest care plans**. However, providing access to clinical correspondence and consultation notes can present challenges for the practice.

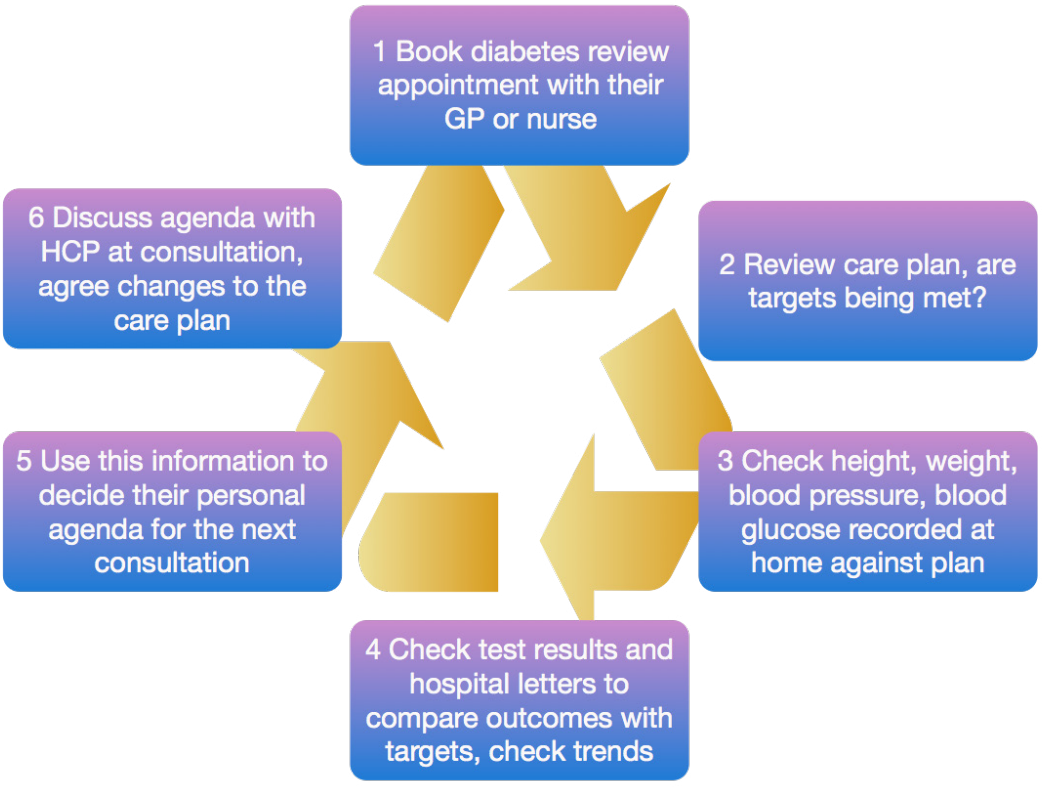


Figure 3: Patients' preparation for diabetes review appointments

Diabetes care plans online

The goal of a written personal care plan is to improve health outcomes and encourage positive behaviour changes. It may focus on medical, therapeutic and psychosocial problems. It should reflect what matters to the clinician and the patient.

Even with the best preparation, all information discussed and plans made in a consultation may not be remembered by the patient. Paper care plans can be lost and can only be replaced when the patient visits the surgery or by posting or emailing them to the patient. Care plans that can be accessed online are always available to the patient and can be updated at any time. They do depend upon recording all the necessary information in the GP record, preferably in a coded form in a suitable template. There is a list of the important codes for diabetes in the box below.

To be **available to the patient online** the care plan may be written in a consultation note in the electronic patient record. It may also be presented as a formal written plan, automatically populated with test results and other coded data merged into the document. This may be printed and scanned into the patient's record or attached to the patient's notes as a Word document according to the GP system functionality. As long as the patient has been given online access to clinical correspondence, the care plan will be available to the patient whenever they wish. They can also share it with anyone, family, carers or other health professionals, who they trust to help them with their diabetes by allowing them proxy access to their record (see the Proxy Access guidance in the toolkit).

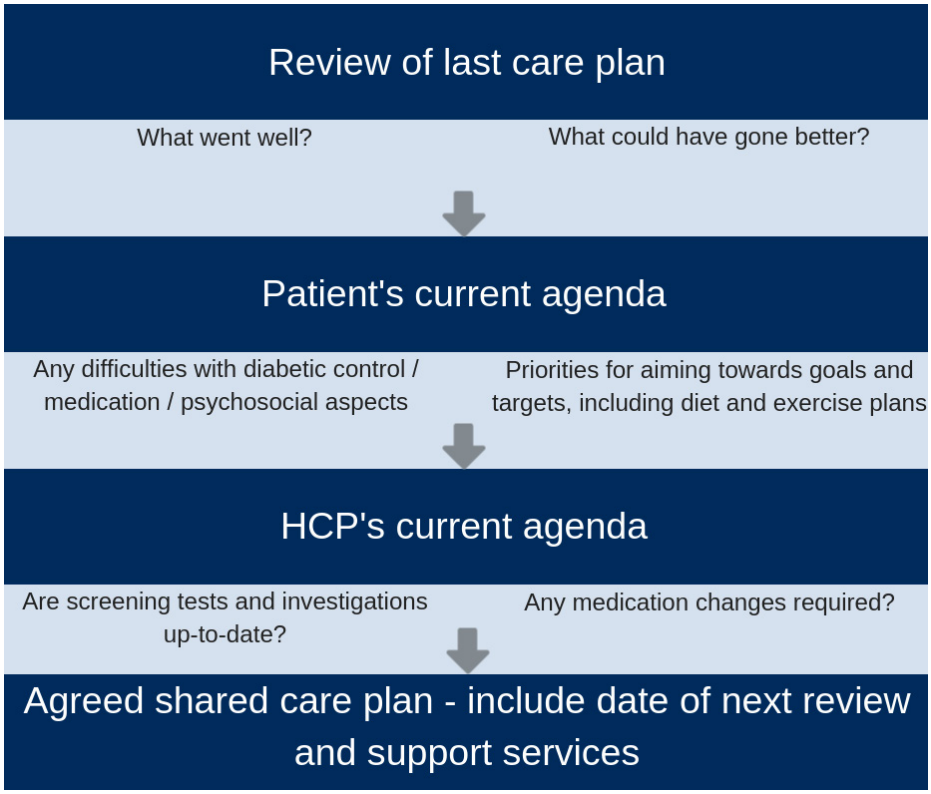
There are many resources that are available online to help you develop a diabetes care plan if you do not have one. See the Resource section below.

Designing a personal care plan for diabetes mellitus

Codes relevant to diabetes care include the following SNOMED CT terms and codes:

Diabetes self-management plan agreed	811981000000102
Diabetes mellitus diet education	284350006
Diabetic lipid lowering diet	315207000
Diabetic weight reducing diet	315208005
Diabetic dietary review declined	754141000000100
Exercise education	304507003
Goal achieved	390802008
Goal not achieved	390801001
Identifying personal goals	928061000000100
Assessment of Year of Care goal importance	842271000000109
Identifying barriers to goal achievement	811791000000103
Review of patient goals	775501000000108
HbA1c (haemoglobin A1c) target level - IFCC	446074002
3 month target weight	918691000000107
6 month target weight	918711000000109
12 month target weight	918731000000101
Target weight to achieve five percent weight loss	923881000000105
Target weight to achieve ten percent weight loss	923901000000108
Target body mass index	838441000000103
Target cholesterol level	390896004
Target physical activity	391105003

Figure 4: Formulating an agreed shared care plan



Summary

Patient Online encourages patient engagement by allowing easy access to appointments, medications and the patient's record. Diabetes mellitus is a chronic condition, often associated with complications and other co-morbidities. Patients can have a better outcome in their healthcare is focused on what matters to them and patients are engaged in participating in their healthcare. Record access allows patients to monitor their healthcare and decide their priorities with accurate and timely information. They can prepare for consultations and check their care plans. In a wider context, Patient Online also allows patients to share access with family members and carers, and their wider healthcare team, who help them with managing their diabetes. The purpose of this guidance is to assist you to help your patients with diabetes benefit from access to their online record safely and confidently.

Resources

This section lists useful resources related to diabetes and person-centred care. Further information and resources are also available on the RCGP's Patient Online toolkit in the diabetes section.

Type 2 diabetes in adults: management, NICE

Type 1 diabetes in adults: diagnosis and management, NICE

Cardiovascular disease: risk assessment and reduction, including lipid modification, NICE

RCGP Person-Centred Care toolkit - The RCGP programme for Person-Centred Care offers a good overview of the purpose of care planning

Diabetes care planning - Diabetes UK is a good place to start to design a care plans specifically for diabetes

Year of Care, Diabetes UK

10-Year Follow-up of Intensive Glucose Control in Type 2 Diabetes, Rury R. Holman RR, Paul SK, Bethel MA,David R. Matthews, F.R.C.P., and H. Andrew W. Neil, F.R.C.P., New England Journal of Medicine, 2008;359:1577-89. accessed on 2 April 2018 at http://www.nejm.org/doi/full/10.1056/NEJMoa0806470

Despite an early loss of glycemic differences, a continued reduction in microvascular risk and emergent risk reductions for myocardial infarction and death from any cause were observed during 10 years of post-trial follow-up. A continued benefit after metformin therapy was evident among overweight patients.

Effects of Intensive Glucose Lowering in Type 2 Diabetes, The Action to Control Cardiovascular Risk in Diabetes Study Group, New England Journal of Medicine, 2008;358:2545-59, accessed on 2 April at http://www.nejm.org/doi/full/10.1056/NEJMoa0802743

Follow-up of Blood-Pressure Lowering and Glucose Control in Type 2 Diabetes, ADVANCE-ON Collaborative Group, New England Journal of Medicine, 2014, DOI: 10.1056/NEJMoa1407963, accessed on 2 April 2018 at http://www.nejm.org/doi/full/10.1056/NEJMoa1407963

The combination of perindopril and indapamide reduced mortality among patients with type 2 diabetes, but intensive glucose control, targeting a glycated hemoglobin level of less than 6.5%, did not.

Role of self-care in management of diabetes mellitus. Shrivastava SR, Shrivastava PS, Ramasamy J. Journal of Diabetes and Metabolic Disorders. 2013;12:14. doi:10.1186/2251-6581-12-14, accessed on 2 April 2018 at https://jdmdonline.biomedcentral.com/articles/10.1186/2251-6581-12-14

Seven self-care behaviours in people with diabetes which predict good outcomes (healthy eating, being physically active, monitoring of blood sugar, compliance with medications, good problem-solving skills, healthy coping skills and risk-reduction behaviours). are all positively correlated with good glycemic control, reduction of complications and improvement in quality of life.

The Diabetes Control and Complications Trial/ Epidemiology of Diabetes Interventions and Complications Study at 30 Years: Overview, Nathan DM for the DCCT/EDIC Research Group, American Diabetes Association, Diabetes Care 2014 Jan; 37(1): 9-16. https://doi.org/10.2337/dc13-2112, accused on 2 April at http://care.diabetesjournals.org/content/37/1/9

The Diabetes Control and Complications Trial and the Epidemiology of Diabetes Interventions and Complications demonstrated the effectiveness

of intensive therapy (INT), aimed at achieving levels of glycaemia as close to the non-diabetic range as safely possible in reducing the long-term complications of T1DM and improving the prospects for a healthy life span.

References

1. Mathers N, Payton D. *Rhetoric and reality in person-centred care: introducing the House of Care framework*. Br J Gen Pract 2016: DOI: 10.3399/bjgp16X683077