Dementia care with Patient Online

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“Two years ago I was at a stage in my understanding … that was so limited it placed the entire weight of responsibility for my care on the doctors treating my condition. I was a passenger, along for the ride.

Access to my medical data … in short I am no longer a passenger, I am now very much part of the management team for the effective treatment of my condition.”

O.C. Manchester Oct 2017
Recommend Patient Online for patients with dementia

1. What are the benefits for patients and carers
2. What are the benefits for practices
3. The place of Patient Online in advance care planning for dementia
4. Safe and secure proxy access to patients and carers
5. Using Patient Online for sharing data with nursing homes
Aim - to increase awareness and confidence in using Patient Online in patient care
Intended for the whole practice team

Toolkit of guidance documents and templates
Events and presentations
Webinars and podcasts

Input from other medical royal colleges, the RCN, and academic voluntary sector groups organisations and other individual health professionals and patients
Webinar programme

1. Patient Online for beginners
2. Benefits for patients living with dementia
3. Advance care planning for future incapacity
4. Proxy access for carers
5. Proxy access for nursing homes
Patient Online services

• Book and cancel appointments
• Order repeat medication
• Detailed care record
• Extended record access (all or part)
Patients registered for Patient Online

Patient online management information (POMI)
National summary

Select reporting period: 28 February 2018
Select system supplier (optional): All

Online appointment booking/cancelling:
The percentage of patients registered to book/cancel appointments online:
- 23.75%

Online repeat prescription ordering:
The percentage of patients registered to order repeat prescriptions online:
- 23.45%

Online detailed coded record view:
The percentage of patients registered to view detailed coded records online:
- 4.31%

Number of transactions this month:
- 1M
Patients registered for Patient Online

Patient online management information (POMI)

Online appointment booking/cancelling:
The percentage of patients registered to book/cancel appointments online:
24.67%

Online repeat prescription ordering:
The percentage of patients registered to order repeat prescriptions online:
24.33%

Online detailed coded record view:
The percentage of patients registered to view detailed coded records online:
5.91%

Number of transactions this month:
1M

3M

646K
Patients registered for Patient Online
RCGP Survey, August-Sept 2016 (n=211)

- GP (30%)
- Practice Manager (54%)
- IT
- Reception
- Secretary
- Other (9%)

Record Access Offered

- Clinical correspondence
- Detailed coded record
- Medication, ADR and allergies
Reasons to recommended record access … (%)  n=84/211

- See test results
- See what is in their record
- Self manage long term conditions
- View long term condition care
- Support family and carers
- View clinical correspondence
- Prepare for consultations

0. 17.5 35. 52.5 70.
Record access application steps

1. Inform the patient, verbally and leaflet - security, record content and discuss concerns with practice,
2. Receive and scan completed application form (coercion question),

   “Do you think that you may come under pressure to give access to someone else unwillingly?”

3. Check records for sensitive data - redact as necessary,
4. Consider if there are grounds to refuse record access,
5. Verify the patient’s identity.

Provide log-in details and switch on access
Summary

- The purpose of the RCGP Patient Online programme
- National uptake of Patient Online in England
- Reasons for recommending record access
- The application process
Patients with dementia are vulnerable

**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 under pressure to give access to someone else unwillingly.”

**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 making a decision about proxy access.

**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 for suspicion that the patient is not consenting freely, **you have grounds to decline access**.
Dementia is complex and progressive, co-morbidity is common

Patient involvement in early planning
- shared and advance decisions with better outcomes

As patients lose mental capacity,
- family and carers make decisions on their behalf
Benefits online record access for dementia

Appointments and prescriptions

Detailed coded record

Clinical correspondence and consultation records

Complements paper care plans
### Detailed coded record for dementia

<table>
<thead>
<tr>
<th>Problems and diagnoses</th>
<th>Reminder of co-morbidities and complications</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medication</td>
<td>Complex polypharmacy</td>
</tr>
<tr>
<td>Advance decisions</td>
<td>Carer, nursing home, LPA, end of life preferences</td>
</tr>
<tr>
<td>Behavioural and social record</td>
<td>Alcohol consumption, smoking</td>
</tr>
<tr>
<td>Immunisations and allergies</td>
<td>Influenza, pneumoccal, shingles vaccines</td>
</tr>
<tr>
<td>Test results</td>
<td>View latest test results…</td>
</tr>
<tr>
<td>Care plan data</td>
<td>…</td>
</tr>
</tbody>
</table>
Dementia Care Plans

- Coded data
- Medication reviews and dementia reviews
- Test results
- Legal information
- Advanced statements/decisions
- Carer review
- Additional risk factors
Dementia care planning

Care planning

Diagnosis Review
Effective support for carers review
Medication review
Evaluate risk
New symptoms enquiry
Treatment of medical conditions
Individual issues
Advance care planning
Care Planning

- Therapeutic interventions
- Dementia practice co-ordinator
- Support for carers
- Person-centred approach
- Co-morbidity review
- Mental health care review
- Aids and technology
- Community connections

Royal College of General Practitioners
Collaborative Care and Support Planning

A proactive consultation model for long-term conditions

Patients prepare for consultations

- Online to access relevant information before the consultation.
- Better prepared to make informed choices
- Consultations can focus on what matters
- Collaborative personalised care plan
- Helps carers provide support
Summary so far

• Uses of Patient Online in dementia
• Value of access to the detailed coded record
• Dementia care plans and advance planning
• Preparation for consultations
Proxy access

- Access to the patient’s account for carers
- For someone acting on behalf of the patient
- Separate login credentials - if possible
- Patient consent and capacity
- Advance planning for dementia
- Patient Online for nursing homes
Why proxy access?

- For carers it offers confidence about the patient’s care
- Carers may live some distance away
- Enables carers to act on patient’s behalf
  - Manage appointments and medication
  - Shared care plans and advance planning
  - Preparation for consultations
Who can have proxy access?

- Family and close friends
- Professional carers
- With patient consent while patient has capacity
When to decline proxy access

- Lack of consent and no clear alternative
- Suspicion of coercion of vulnerable patient
- Risk of security to patient’s record
- Knowledge of patient’s previous wishes
- Not in the best interests of the patient
Proxy access in a patient lacking capacity

- In the best interest of the patient
- Recorded advanced decision
- The applicant have authority
  - Lasting power of attorney for health and welfare
  - Court appointed duty
- Is the applicant a health professional offering direct care to the patient?
Nursing homes

Purpose
Order prescriptions
Up to date with results and/or hospital reports

Legal basis
GDPR and DPA 2018
Common Law

Access
Named health care professionals
Personal log in details
Manage access withdrawal
Data sharing agreements

- Agreement to cover all patients vs each individual patient
- Name(s) of patients and nursing home staff
- Legal basis for data sharing (GDPR art 6 and 9)
- Level of access required
- Protecting data security/confidentiality
- Arrangements for staff changes
- Access review period
Summary

The benefits for patients and carers

The benefits for practices

Patient Online in advance care planning for dementia

Safe and secure proxy access to patients and carers

Patient Online for sharing data with nursing homes