Patient Online

in end of life care

RCGP Webinar, 16 May 2018
End of Life 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
End of Life Care Learning Objectives

1. Use Patient Online safely and effectively
2. GP record data quality
3. Health literacy and digital inclusion
4. Care planning and co-ordination
5. Proxy access for families and carers
Webinar programme

1. Introduction to Patient Online for beginners
2. Direct benefits for patients at the end of life
3. Person-centred care planning and collaboration
4. Safe and effective proxy access to Patient Online

Type in your questions bottom left of screen
Patients registered for Patient Online
RCGP Survey: “Views on record access”

Summer 2016 (n=211)

- GP (30%)
- Practice Manager (54%)
- IT
- Reception
- Secretary
- Other (9%)
RCGP Survey: “Views on record access”

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- GP (30%)
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- IT
- Reception
- Secretary
- Other (9%)

Record Acess Offered

- Clinical correspondence
- Detailed coded record
- Medication, ADR and allergies

Bar chart showing the distribution of record access offered.
<table>
<thead>
<tr>
<th>Reason</th>
<th>% Respondents giving each reason</th>
</tr>
</thead>
<tbody>
<tr>
<td>See test results</td>
<td>52.5</td>
</tr>
<tr>
<td>See what is in their record</td>
<td>69.0</td>
</tr>
<tr>
<td>Self manage long term conditions</td>
<td>70.0</td>
</tr>
<tr>
<td>View long term condition care</td>
<td>50.0</td>
</tr>
<tr>
<td>Support family and carers</td>
<td>40.0</td>
</tr>
<tr>
<td>View clinical correspondence</td>
<td>30.0</td>
</tr>
<tr>
<td>Prepare for consultations</td>
<td>0.0</td>
</tr>
</tbody>
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RCGP Survey: “Views on record access”
Patient Online Services

1. Book and cancel appointments
2. Order repeat medication
3. Detailed care record
4. Extended record access (all or part)
Read V2 EOL codes

- Palliative care: Zv57C
- Preferred place of death: 94Z
- Primary contact: 918x
- Lasting power of attorney property and affairs: 9W4

Not for resuscitation: 1R1

Preferred place of care: 8Ce

Have a carer: 918F
Coded information in End of Life Care

- Template entry of coded information
- Encourages uniform information entry
- Build summaries in the patient record
- Suitable for data sharing (e.g. EPaCCS)
- Patient Online detailed coded record

Read V2 EOL codes

Palliative care: Zv57C
Preferred place of death: 94Z
Primary contact: 918x
Lasting power of attorney property and affairs: 9W4
• Ordering repeat prescriptions, polypharmacy
• Access to coded information means patients can be more informed about their condition and care
• Increased health literacy promotes well informed shared decisions
• Empowered individuals take an active role in managing their own care
Smartphone and web access 24/7
What does good EOL Care look like?

- Coordinated and collaborative care
- Shared decision-making at the end of life
- Timely information
- Personalised care planning
- Access to the information at the point of care
- Family/Carers involved
1. Professional and competent staff
2. Early identification
3. Carer Support - before and after death
4. Seamless, planned, coordinated care
5. Assessment of unique needs of the patient
6. Quality care during the last days of life
7. Care after death
8. General Practices being hubs in Compassionate Communities
Daffodil Standards for EOL Care

Patient Online can be used to inform patients and empower them to be more involved in their own care and care planning.

4. Seamless, planned, coordinated care
5. Assessment of unique needs of the patient
6. Quality care during the last days of life
7. Care after death
8. General Practices being hubs in Compassionate Communities
EOL Care Plans

- Personal details
- Carer information.
- Care preferences/choices
- Future care decisions
e.g. escalation levels, DNACPR
EOL Care Plans

- Personal details
- Carer information
- Care preferences/choices
- Future care decisions
e.g. escalation levels, DNACPR
Electronic Patient Care Co-ordination Systems

Currently implemented EPaCCS System

Key external entities:
- Acute Trust Systems
- Community Nursing
- Social Care
- Mental Health
- General Practice

Integration and data rationalisation:
- Eg. Co-ordinate My Care, Graphnet, EMIS Web

Data Store

Electronic Health Record / Care Plan Portal

Accessible at point of care:
- Ambulance services, OOHC, Acute Care, community services

EOL care plan
Electronic Patient Care Co-ordination Systems

Currently implemented EPaCCS System

Key external entities:
- Acute Trust Systems
- Community Nursing
- Social Care
- Mental Health
- General Practice

Integration and data rationalisation

Data Store

Eg. Co-ordinating Care, Graphnet, EMIS Web

Not implemented in all CCGs

EOL care plan

Electronic Health Record Care Plan Portal

Accessible at point of care: Ambulance services, OOH, Acute Care, community services

POL Interface part of the GP IT system
## Pros and cons of separate EPaCCS

<table>
<thead>
<tr>
<th>Benefits</th>
<th>Problems</th>
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<tbody>
<tr>
<td>Accessible by multiple agencies.</td>
<td>Only a subset of the GP coded data.</td>
</tr>
<tr>
<td>Live system across care boundaries.</td>
<td>Can be difficult to keep up-to-date.</td>
</tr>
<tr>
<td>Multidisciplinary access (read access or also able to add additional information).</td>
<td>Data integration and migration issues.</td>
</tr>
<tr>
<td>Can aggregate information from across multiple specialities.</td>
<td>Patients and carers may not have access to the information held.</td>
</tr>
<tr>
<td>Facilitate communication across care settings.</td>
<td>Can vary considerably across localities.</td>
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Royal College of General Practitioners
Scenario A (fully operational EPaCCS)

Mrs EB is a 76yr old lady with mild COPD
Recently diagnosed carcinoma bronchus
Living with her daughter
On active treatment
No DNACPR
Proxy access

- When should we recommend it?
- Formal vs informal proxy risks
- Patient consent
- Level of access required
- Patient safety
- Capacity implications

RCGP Patient Online Toolkit
http://elearning.rcgp.org.uk/patientonline
Scenario A (fully operational EPaCCS)

Prompt to practice/other HCP to update record

Error identified or update required

Patient or Proxy Views coded data/plan via POL

Update or Review Care plan or coded data

Iterative feedback from POL

GP Consultation

EPaCCS
Mrs EB
1. GP produces care plan
2. Coded data updated
3. (EPaCCS updated)
4. Prompted to consider POL and proxy access
5. Patient/Proxy Views record
Scenario A (Fully operational EPaCCS)

Six months later

Pleural effusion, hospitalised, metastatic disease
No further active treatment
DNACPR completed
Discharged from hospital
Mrs EB
1. DNACPR is required following hospital stay
2. Prompts contact with practice to update preference
3. Contact made with practice
4. DNACPR coded, record updated
Mrs EB’s condition deteriorates
Her daughter orders repeat prescriptions and views GP record online
She is pleased to see the DNACPR is recorded
She notices that her mother is still for full escalation of care, which is not wanted
Scenario A (fully operational EPaCCS)

Prompt to practice/other HCP to update record

Error identified or update required

Patient or Proxy Views coded data/plan via POL

Iterative feedback from POL

GP Consultation

Update or Review Care plan or coded data

EPaCCS

Mrs EB

1. Proxy views care plan
2. Prompts contact with practice to update preference
3. Contact made with practice by telephone or F2F
4. Preference for care escalation coded, record updated
Mrs EB's condition slowly deteriorates and Mrs EB's daughter continues to book repeat medication and look at the Online GP record (as shown in as proxy access in Figure 3 POL + EPaCCS). Mrs EB's daughter looks at some of the 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.
Mrs EB is a 76yr old lady with mild COPD
Recently diagnosed carcinoma bronchus
Living with her daughter
On active treatment
No DNACPR
Scenario B (without operational EPaCCS)

Coded information is not transferred to an external system.
Mrs EB's condition slowly deteriorates and Mrs EB's daughter continues to book repeat medication and look at the Online GP record (as shown in proxy access in Figure 3 POL + EPaCCS). Mrs EB’s daughter looks at some of the 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.
Section 1 RS Closing summary (in 2 mins)
Mrs EB's condition slowly deteriorates and Mrs EB's daughter continues to book repeat medication and look at the Online GP record (as shown in as proxy access in Figure 3 POL + EPaCCS). Mrs EB's daughter looks at some of the 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.

What is coming next?

- Guidance documents on End of Life Care
- Information about Patient Online for carers/proxies
- Clinical scenarios in long-term conditions
- Podcasts and other upcoming webinars
- Other collaborative work
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Summary

- Patient Online can play an important role in EOLC
- Coded information enables person-centred care
- Feedback empowers patients and improves record accuracy
- Complements EPaCCS systems
- Reflects the patients own GP record