

Patient Online long term conditions - Dementia

RCGP Webinar, 22nd August 2018

Dementia care with Patient Online

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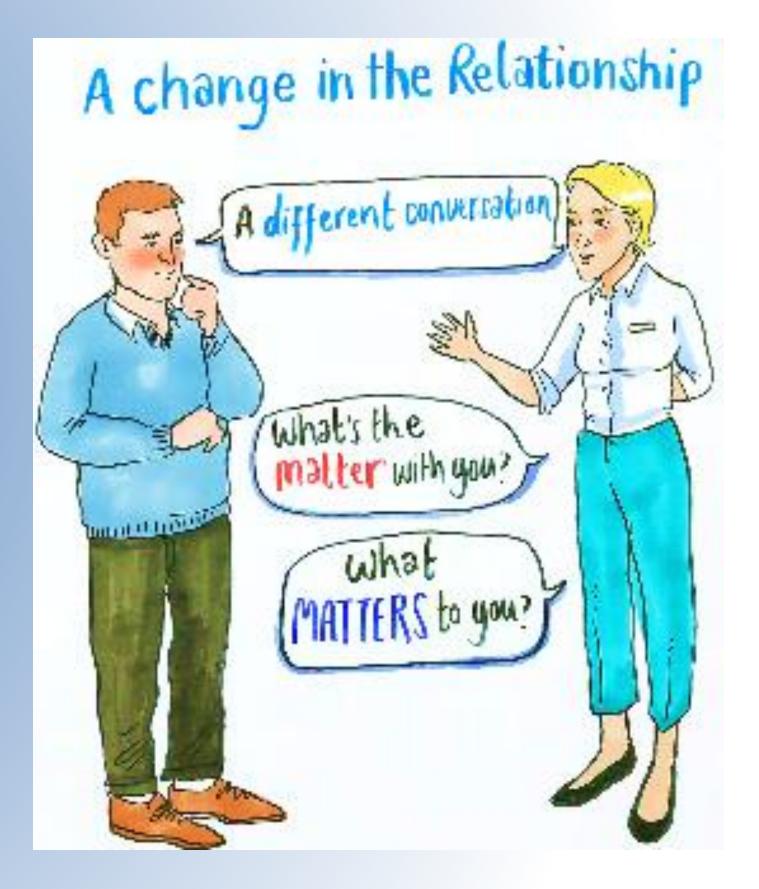
Person-centred care

"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



Learning objectives

- What are the benefits for patients and carers 1.
- What are the benefits for practices 2.
- The place of Patient Online in advance care planning for dementia 3.
- Safe and secure proxy access to patients and carers 4.
- Using Patient Online for sharing data with nursing homes 5.



Recommend Patient Online for patients with dementia

RCGP Patient Online programme

in patient care Intended for the whole practice team

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

professionals and patients



- Aim to increase awareness and confidence in using Patient Online

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

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



Webinar programme

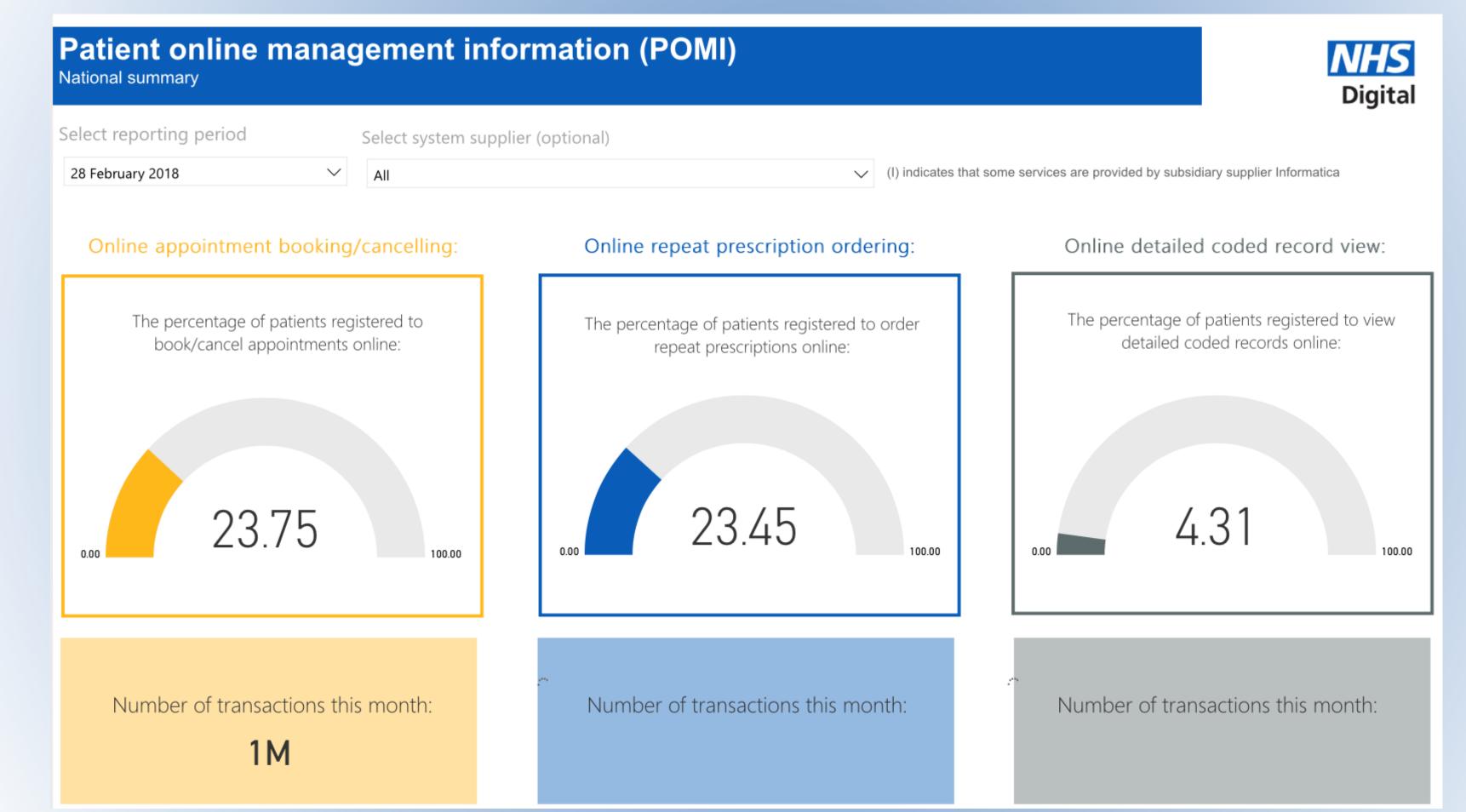
Patient Online services

- Book and cancel appointments
- Order repeat medication •
- **Detailed care record**
- Extended record access (all or part) •



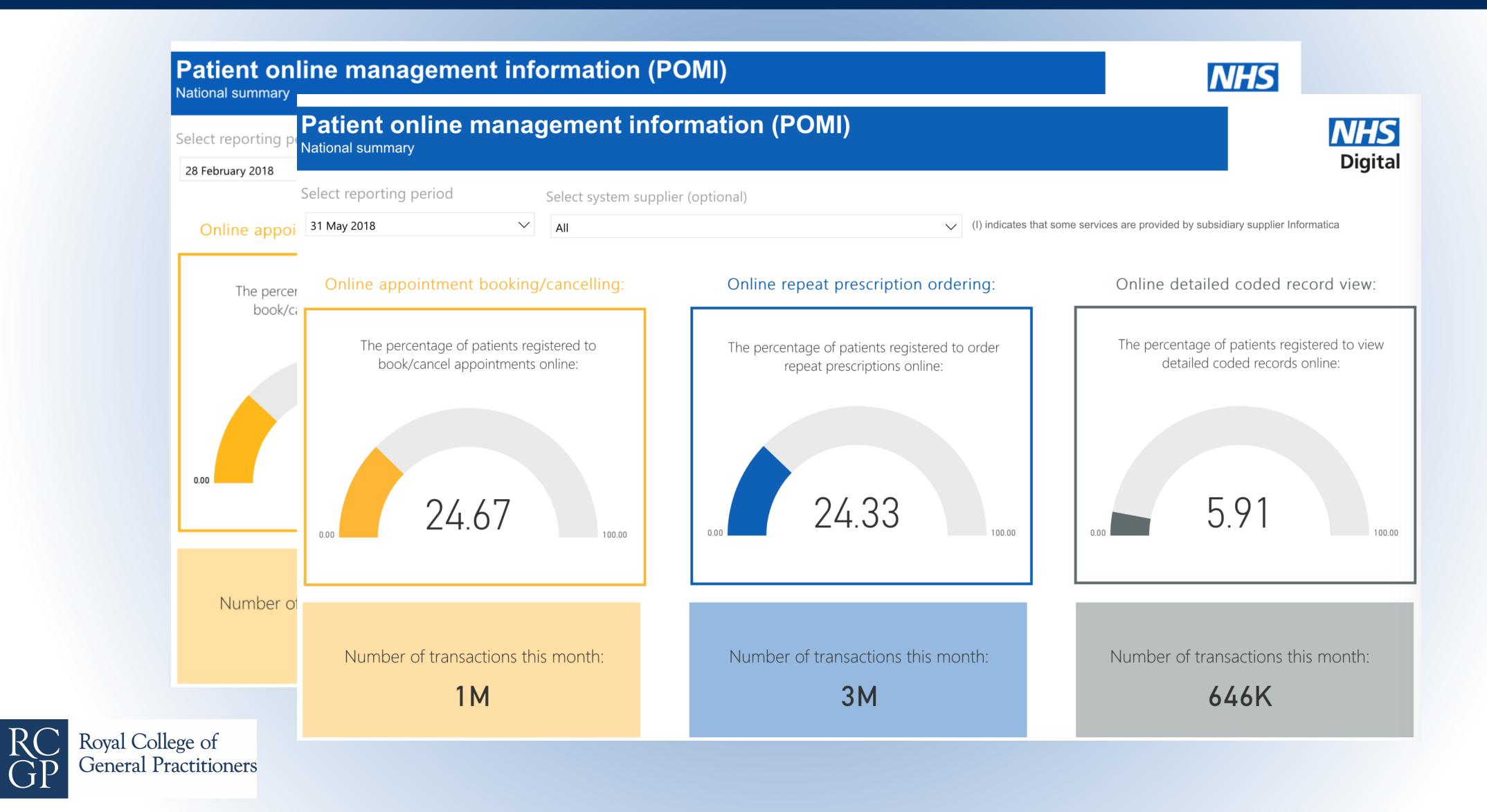


Patients registered for Patient Online

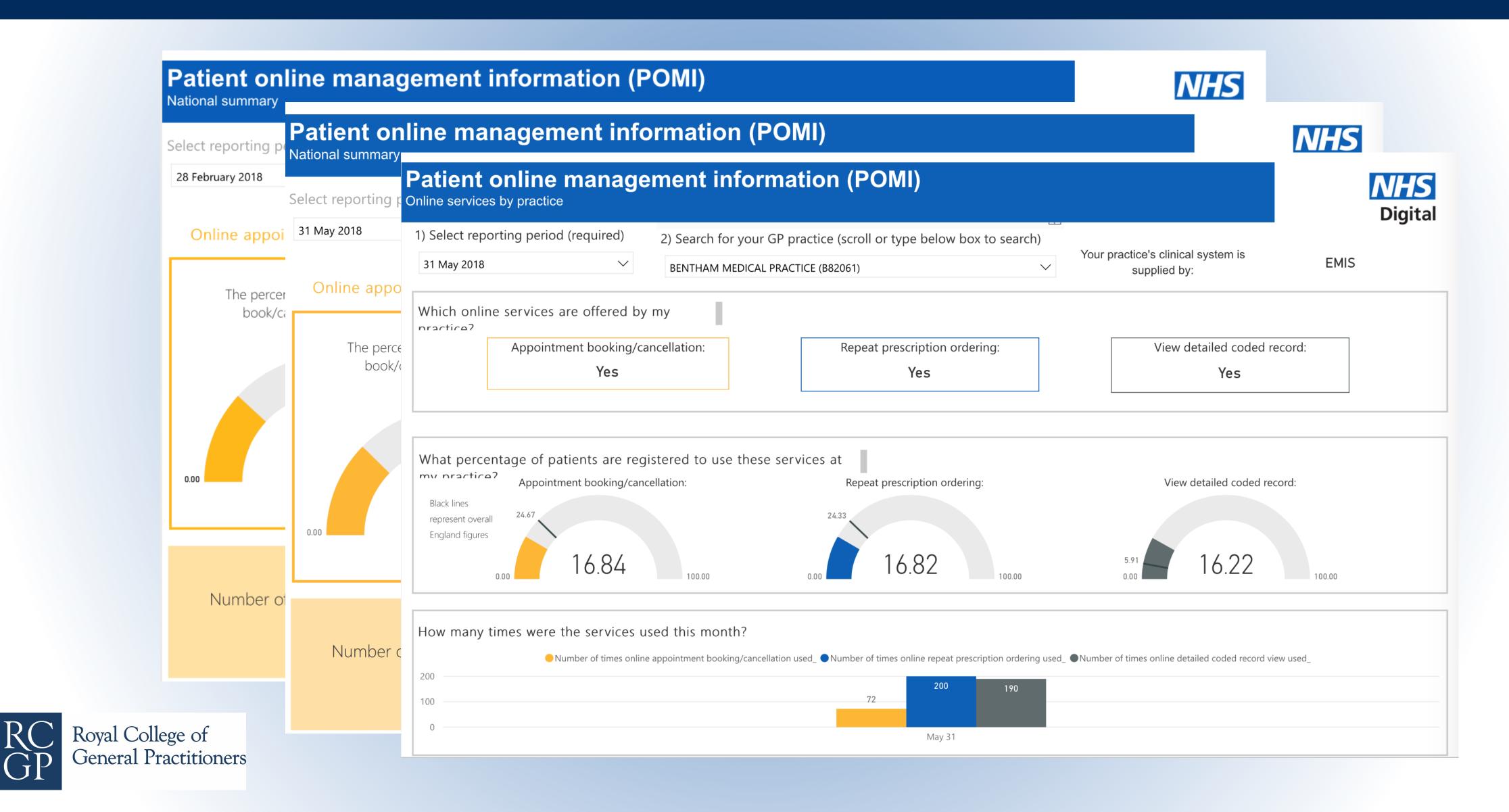




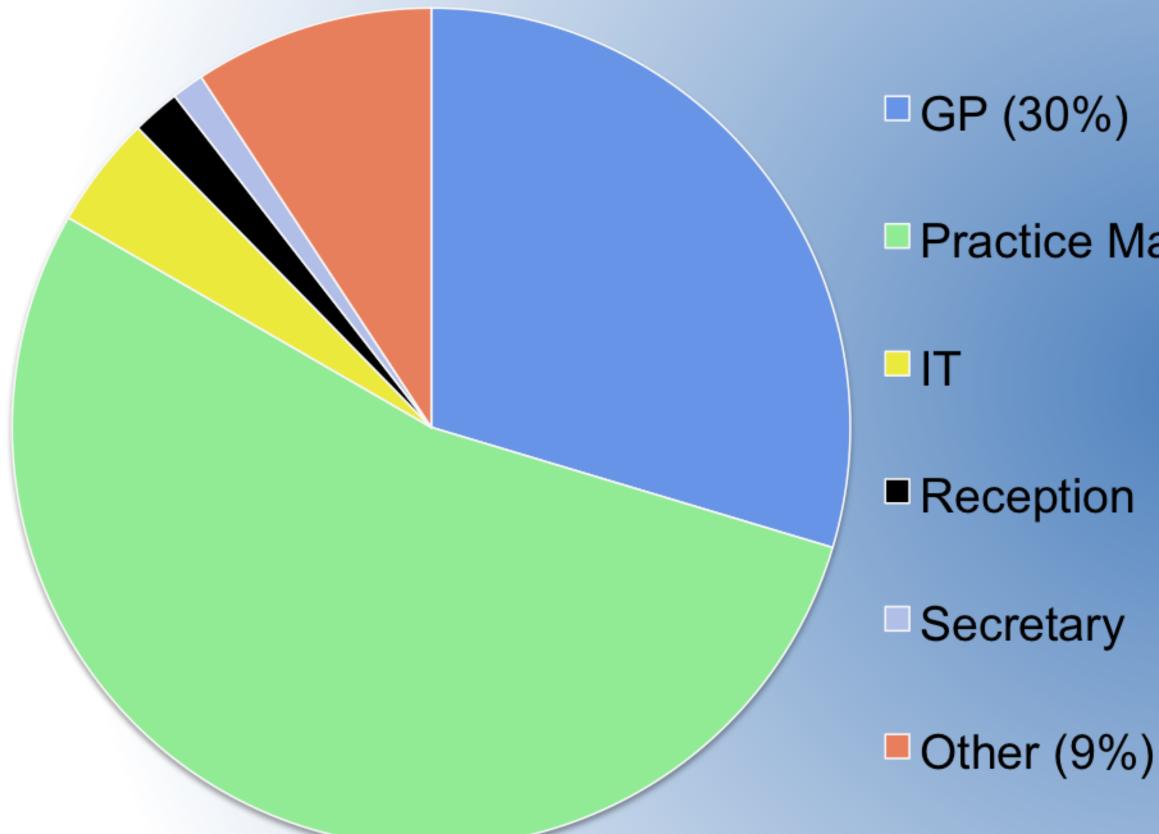
Patients registered for Patient Online



Patients registered for Patient Online



RCGP Survey, August-Sept 2016 (n=211)





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Practice Manager (54%)

Record Acess Offered n Clinical correspondence Obtailed coded record Medication, ADR and allergies 0 50 100 150 200

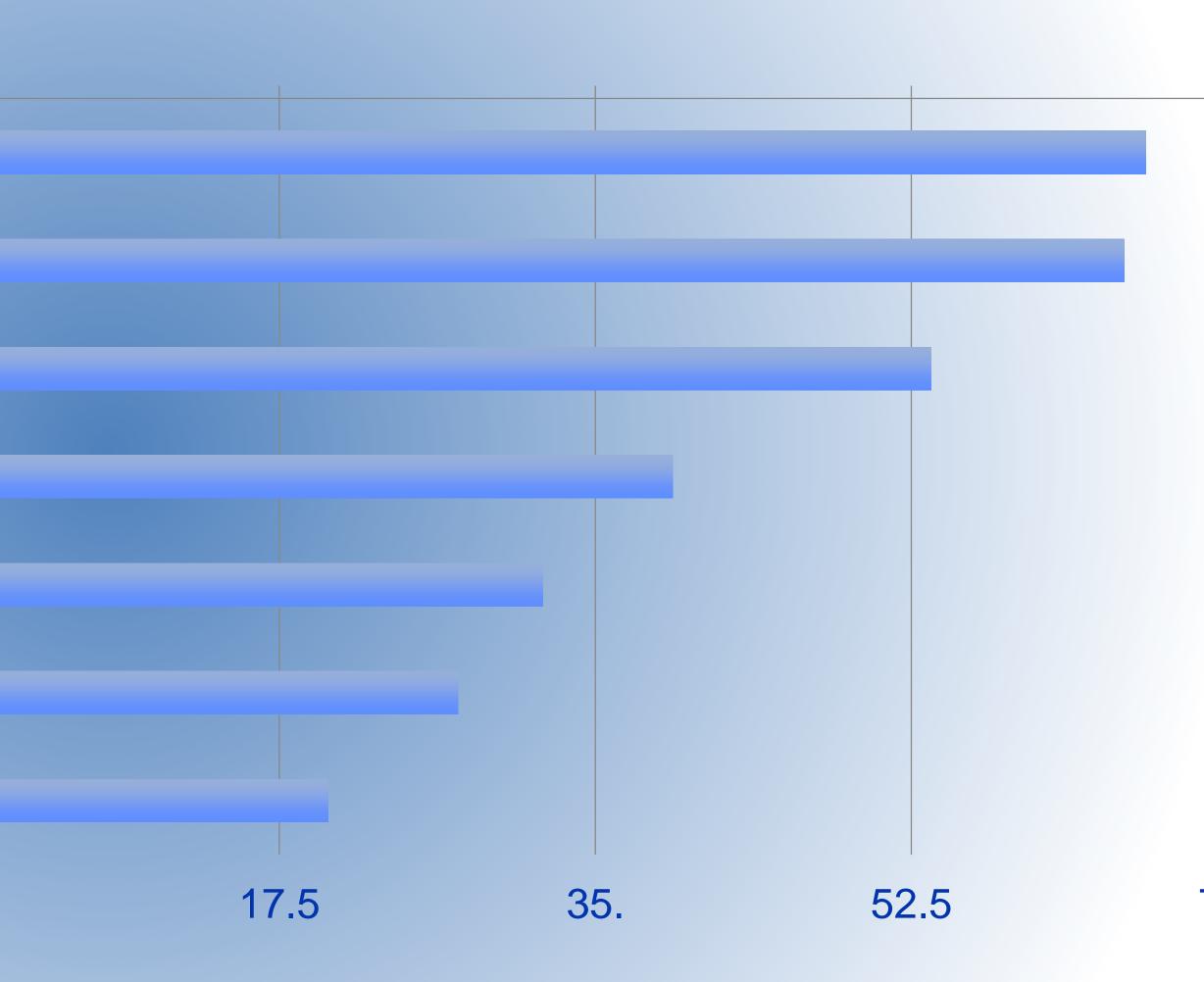


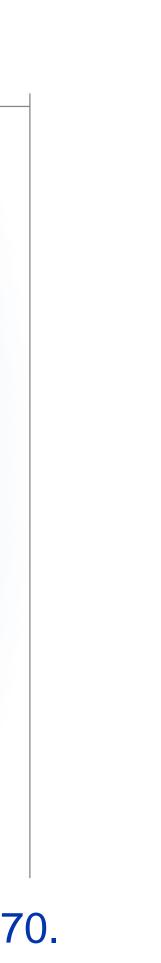
Reasons to recommended record access ... (%) n=84/211

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.





Record access application steps

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

give access to someone else unwillingly?"

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



Royal College of General Practitioners



"Do you think that you may come under pressure to

Provide log-in details and switch on access

- 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

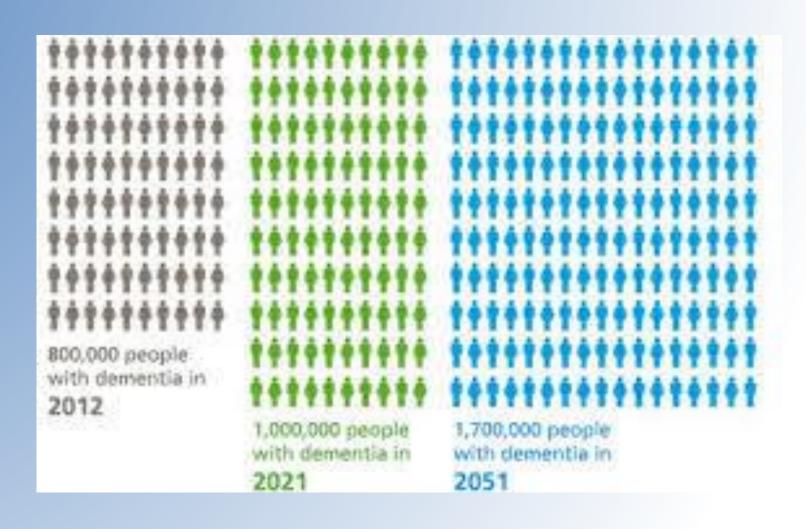
Coercion risk: Step 3 If after discussion with the patient and colleagues who know the patient and their circumstances, you believe there are good grounds for suspicion that the patient is not consenting freely, you have grounds to decline access



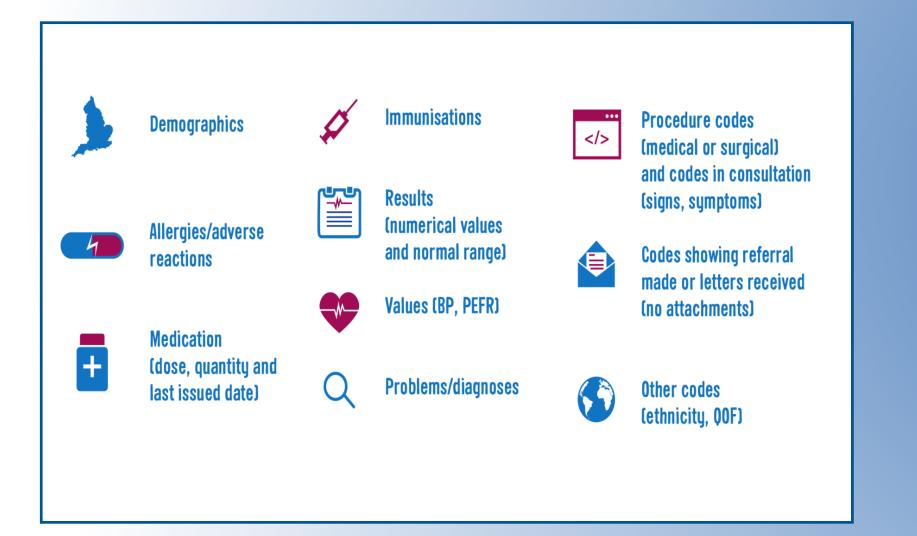
Patient Online in dementia

- 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



App Det Clin reco



- **Appointments and prescriptions**
- Detailed coded record
- Clinical correspondence and consultation records
- Complements paper care plans

Detailed coded record for dementia

Problems and diagnoses	R C
Medication	C
Advance decisions	C p
Behavioural and social record	Δ
Immunisations and allergies	Ir
Test results	\mathbf{V}
Care plan data	

- Reminder of co-morbidities and complications
- Complex polypharmacy
- Carer, nursing home, LPA, end of life preferences
- Alcohol consumption, smoking
- nfluenza, pneumoccal, shingles vaccines
- /iew latest test results...



Dementia Care Plans

- Coded data \bullet
- Medication reviews and dementia reviews \bullet
- Test results \bullet
- Legal information •
- Advanced statements/decisions \bullet
- **Carer review** lacksquare
- Additional risk factors \bullet



Dementia care planning

Diagnosis Review Medication review Evaluate risk New symptoms enquiry Individual issues Advance care planning



- Care planning
- Effective support for carers review
- Treatment of medical conditions



Therapeutic interventions

Co-morbidity review

Mental health care review

> Aids and technology



Care Planning



Collaborative Care and Support Planning

A proactive consultation model for long-term conditions



1. Describes the group of people to be involved and how they will be identified

2. Describes how they will access care and support planning

3. Describes accountability

PREPARATION

Preparation for the process

Preparation by the person

Preparation by the practitioner

CONVERSATION

The ideas and discussion at the centre of care and support planning

(What matters to the person.)

RCGP: http://www.rcgp.org.uk/clinical-and-research/resources/toolkits/collaborative-care-and-support-planningtoolkit.aspx



RECORD

The Care and Support Plan 'owned' by the person and shared access

Information for use by the person

Information for the use by the practitioner

MAKING IT HAPPEN

Co-ordination and support for actions from a variety of personal. statutory and non-statutory sources signposted during the discussion and through using personal budget

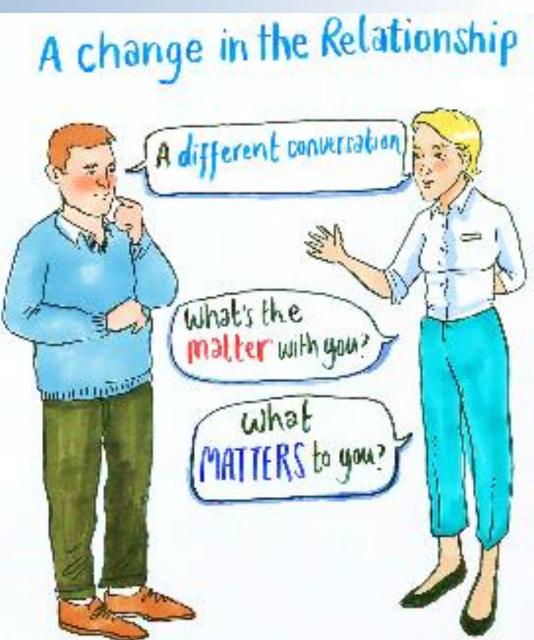
REVIEW

Regular review and plan adjustment

Patients prepare for consultations

- Online to access relevant information before the consultation. lacksquare
- Better prepared to make informed choices \bullet
- Consultations can focus on what matters \bullet
- Collaborative personalised care plan lacksquare
- 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





- Access to the patient's account for carers
- For someone acting on behalf of the patient
- Separate login credentials if possible \bullet
 - Patient consent and capacity
- Advance planning for dementia
 - Patient Online for nursing homes





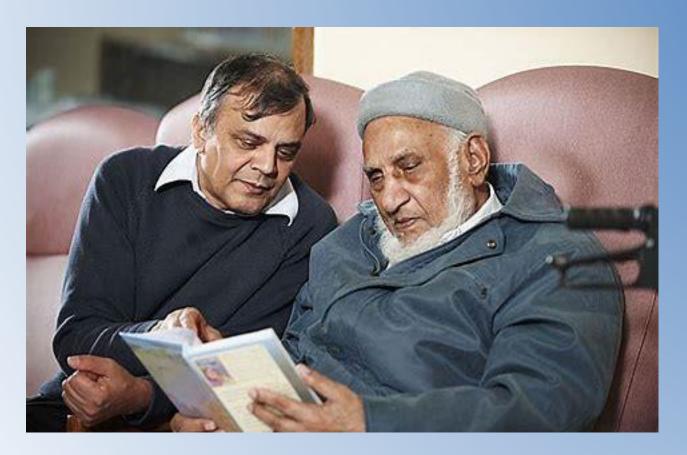
Why proxy access?

- 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

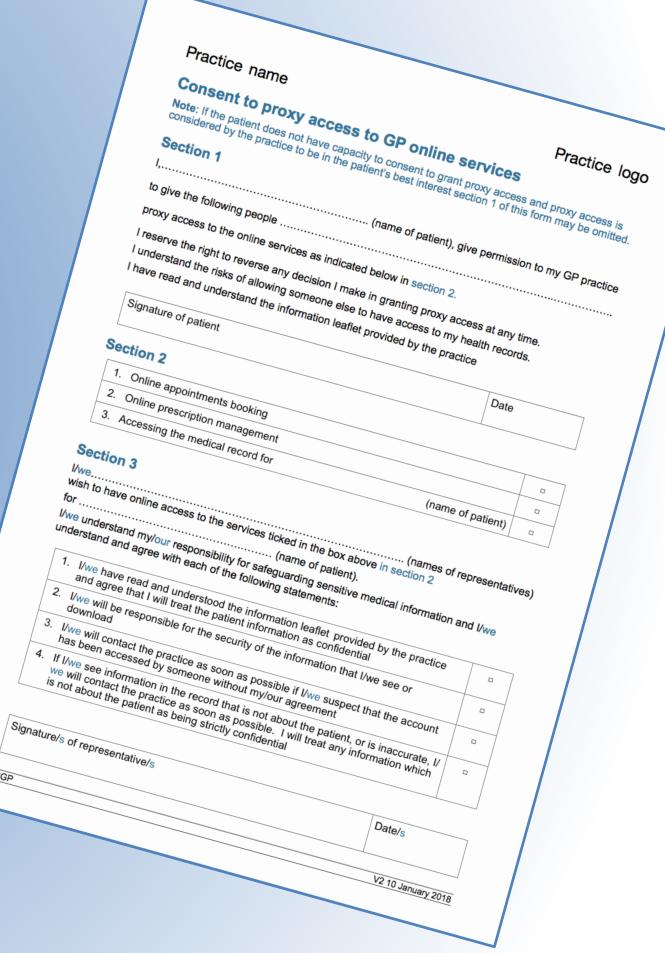


Who can have proxy access?

- Family and close friends ullet
- **Professional carers**
- With patient consent while patient has capacity lacksquare









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?

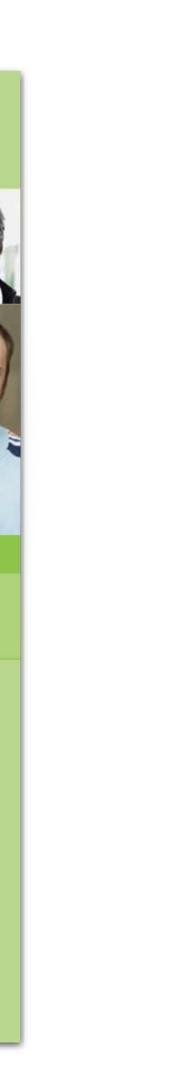




Mental Capacity Act 2005

Code of Practice

Chapters 4-8



Nursing homes

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



Legal basis GDPR and DPA 2018 Common Law



- Named health care professionals
 - Personal log in details
 - Manage access withdrawal



Chapter 6

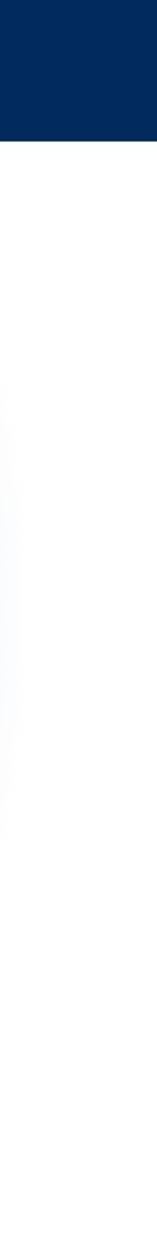


Data sharing agreements

- Agreement to cover all patients v 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 lacksquare
- Arrangements for staff changes
- Access review period







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