

RCGP Webinar, 16 May 2018

Patient Online in end of life care

End of Life Care with Patient Online



- Dr Ralph Sullivan, FRCGP, FFCI **RCGP Clinical Champion for Patient Online**
 - Dr Imran Khan, MRCGP **RCGP Clinical Support Fellow**
 - Dr Sinead Clarke, MRCGP **GP** Advisor, Macmillan Cancer Support

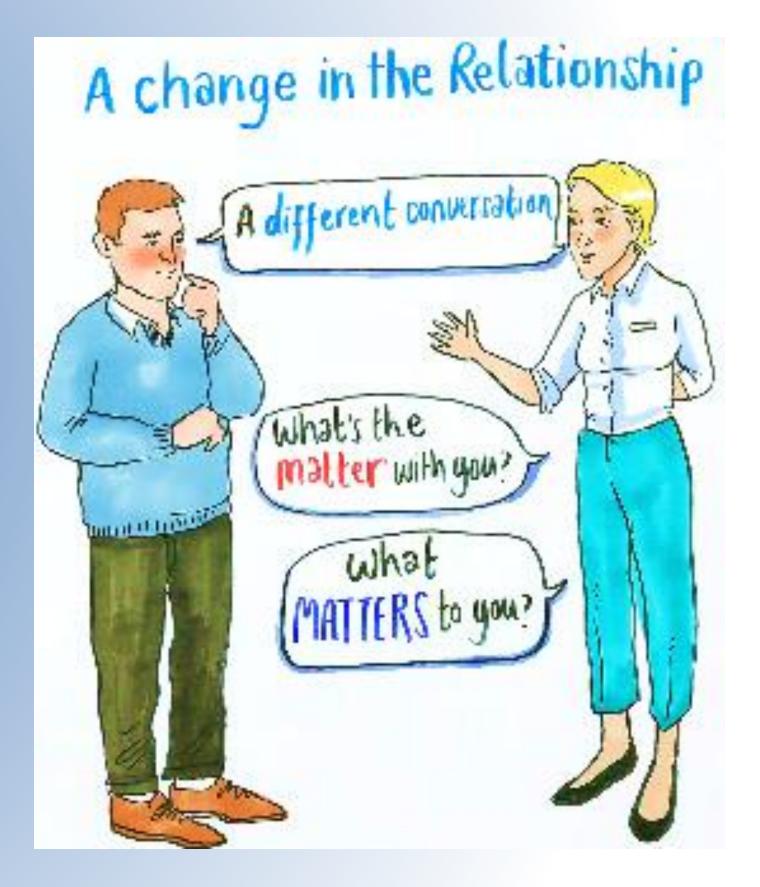
Person-Centred Care

"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."



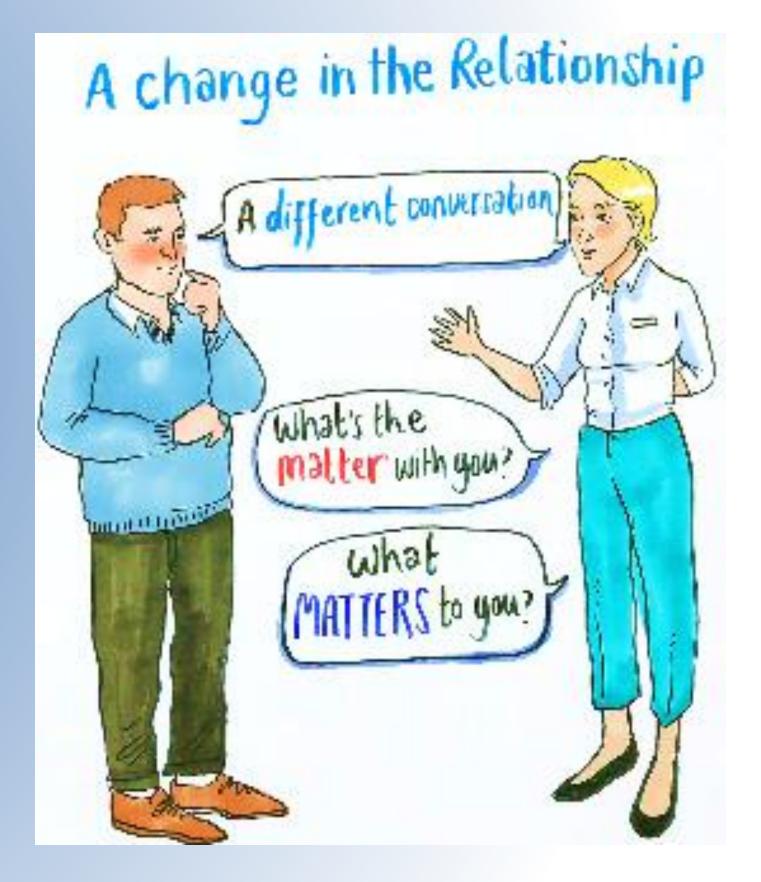
- O.C. Manchester Oct 2017



- 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



End of Life Care Learning Objectives



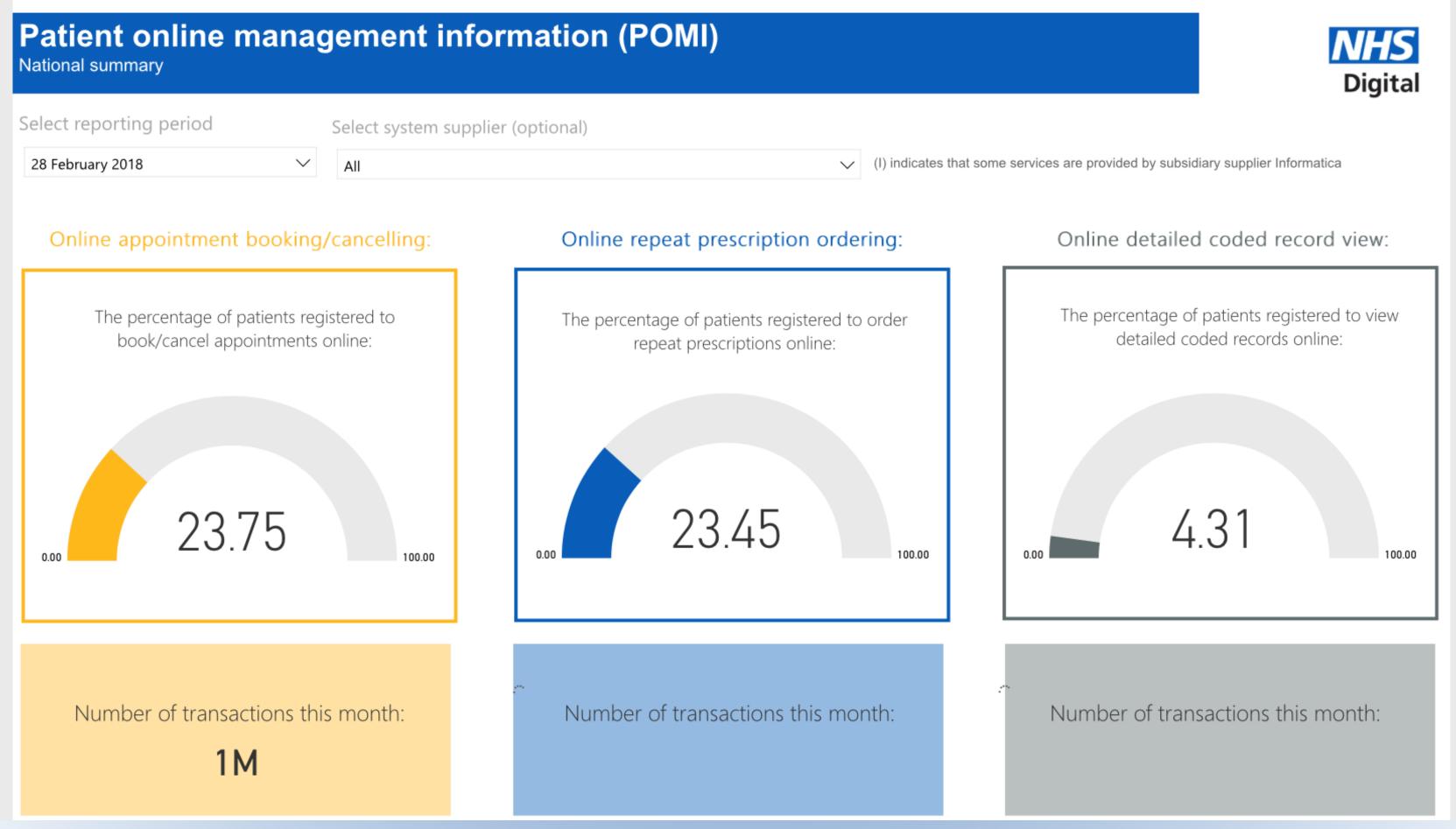
- Introduction to Patient Online for beginners 1.
- 2. Direct benefits for patients at the end of life
- 3. Person-centred care planning and collaboration
- 4. Safe and effective proxy access to Patient Online



Webinar programme

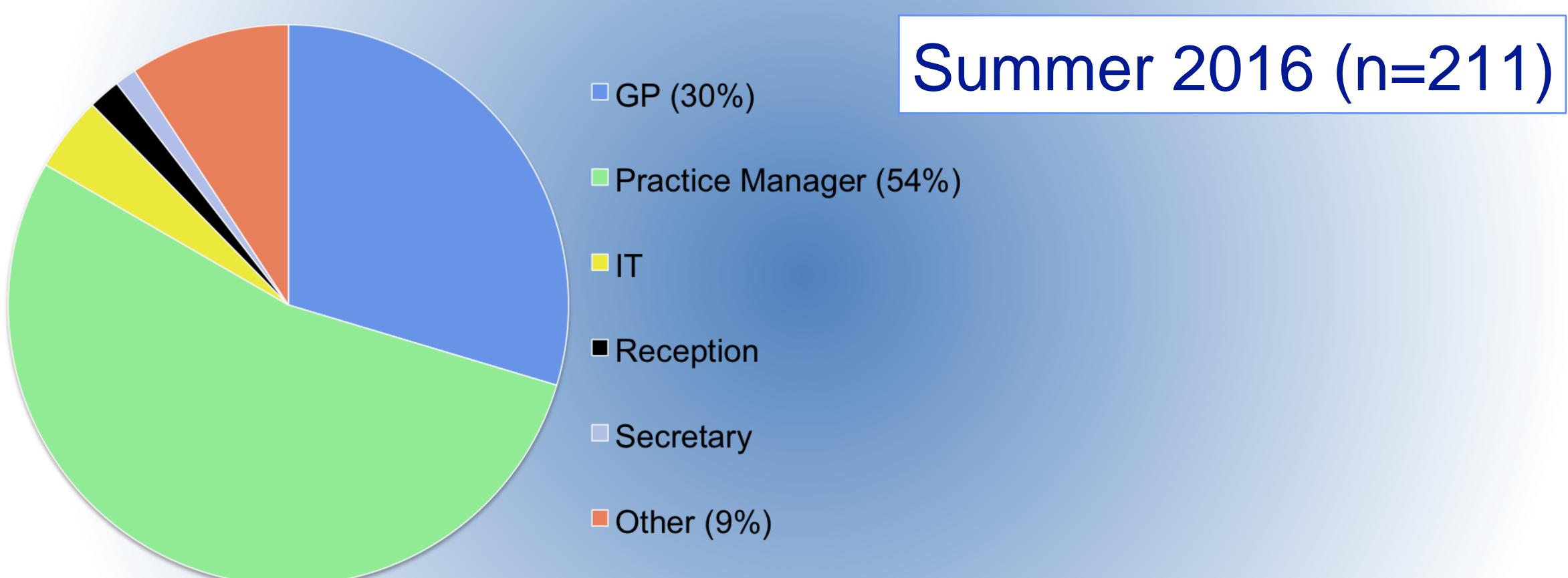
Type in your questions bottom left of screen

Patients registered for Patient Online





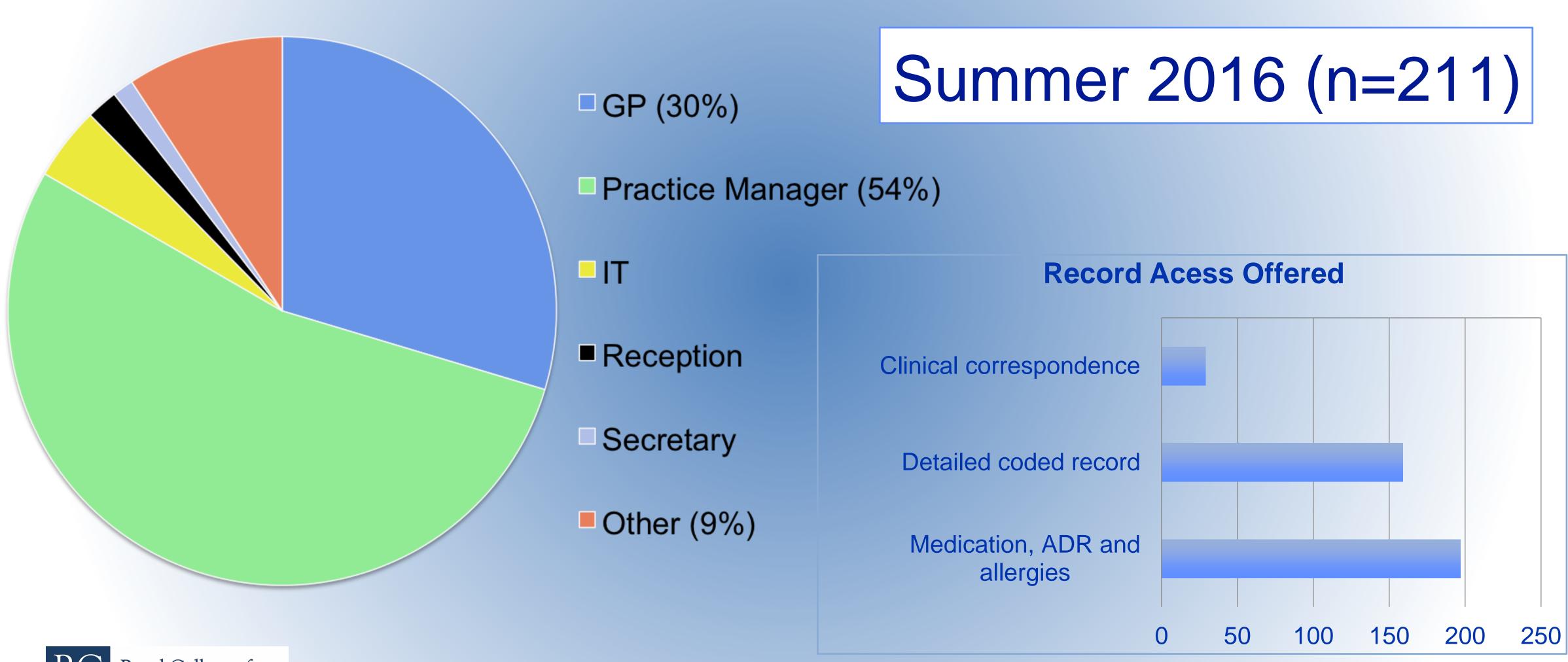
RCGP Survey: "Views on record access"







RCGP Survey: "Views on record access"





RCGP Survey: "Views on record access"

See test results

See what is in their record

Self manage long term conditions

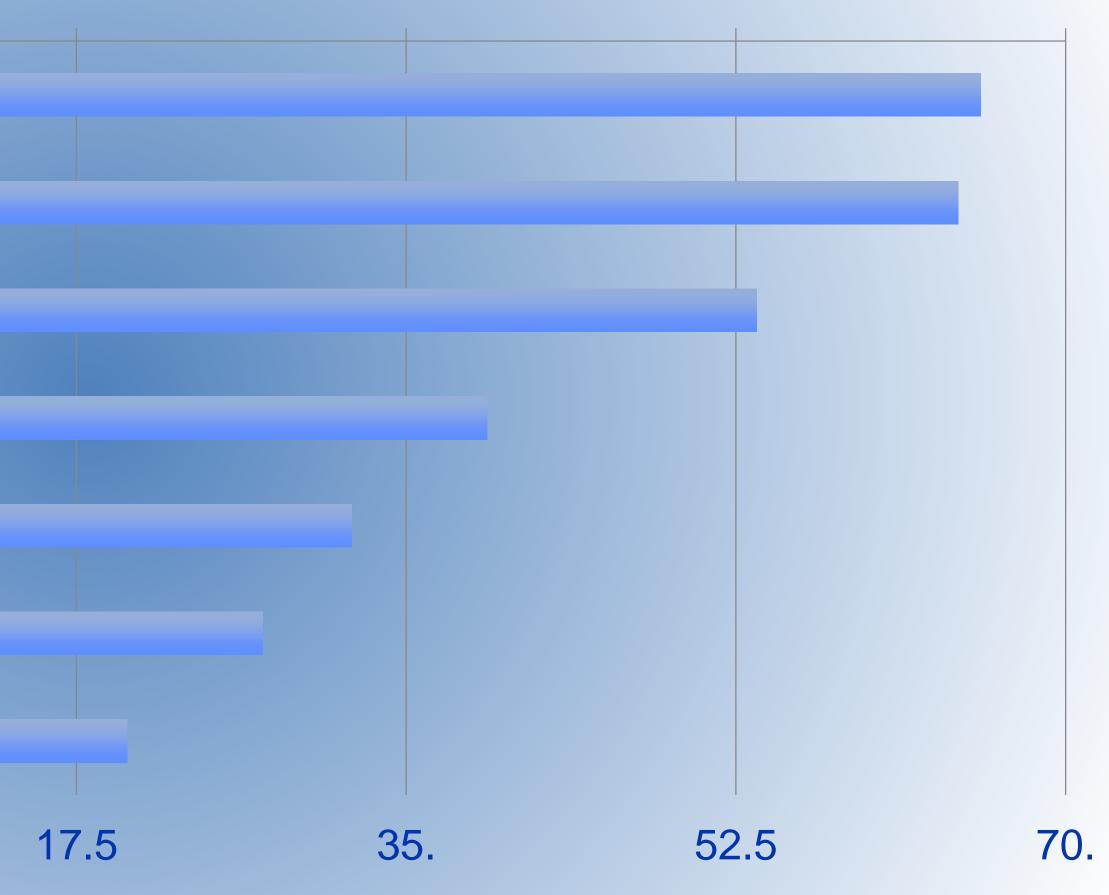
View long term condition care

Support family and carers

View clinical correspondence

Prepare for consultations

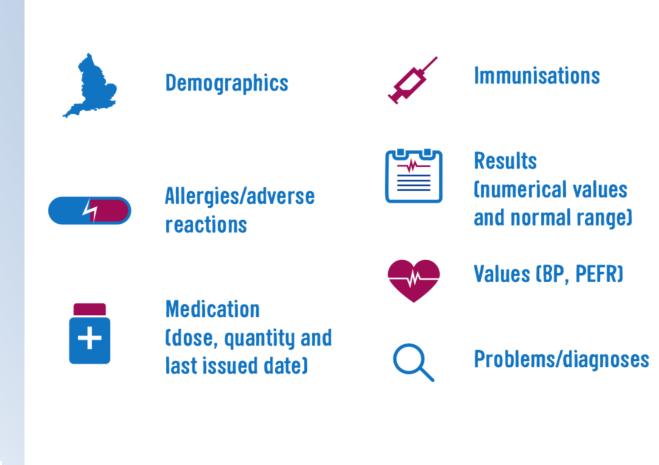
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% respondents giving each reason

Patient Online Services

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







Procedure codes (medical or surgical) and codes in consultation (signs, symptoms)



Codes showing referral made or letters received (no attachments)



Other codes (ethnicity, QOF)

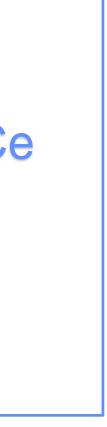
Coded information in End of Life Care

- 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



- Not for resuscitation: 1R1 Palliative care: Zv57C Preferred place of care: 8Ce Preferred place of death: 94Z Have a carer: 918F Primary contact: 918x Lasting power of attorney property and affairs: 9W4



Coded information in End of Life Care

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Royal College of General Practitioners

Online services: Data Quality Guldance for general practice

Executive summary

The quality of data in a patient's record can be assessed by the extent to which it meets the The quality or oata in a patient is record can be assessed by the externation which is means that it must be clear various purposes that the record is used for. For online services this means that it must be clear and unambiguous for the patient to understand, without displaying information that might be harmful to the patient or others or confidential information to other (third) parties. Poor data quality may be confusing and may mislead both patients and clinicians with a negative impact on the

This guidance offers recommendations on how to record and maintain data that is fit for online services. The starting point is to think of data quality in terms of five headings: Complete. Accurate, Relevant, Accessible and Timely (CARAT).

There are specific aspects of data quality that affect particular parts of the record such as problems and diagnoses, other consultation codes, summarising data and laboratory results.

Definition

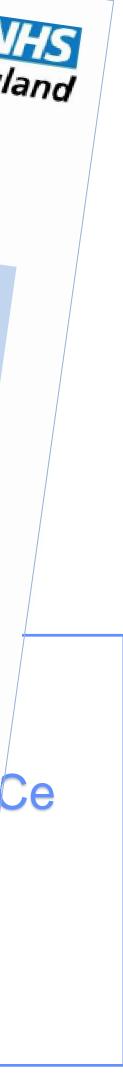
Data quality is an attribute of electronic patient records used as a measure of whether a record is fit for purpose. It can be assessed under five headings: completeness, accuracy,

Background

The quality of the data in a patient's record can only be measured by the extent to which it meets each particular purpose for which it might be used (see Box 1). The <u>GMS contract</u> and PMS arrangements for 2015–18 require practices to promote and offer their patients online access to their detailed coded record in addition to the appointments and repeat prescribing services and summary data required in 2014-15. A good quality coded patient This guidance explains how Patient Online has changed the criteria for a high quality

electronic patient record and how practices may respond to this challenge.

Primary contact: 918x

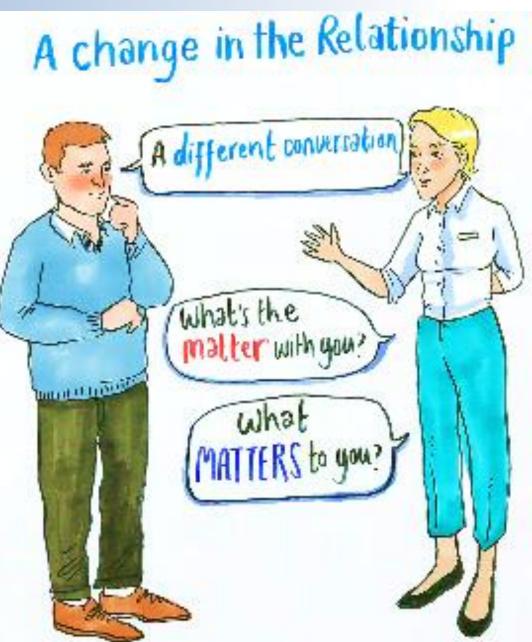


Patient Online in End of Life Care

- 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







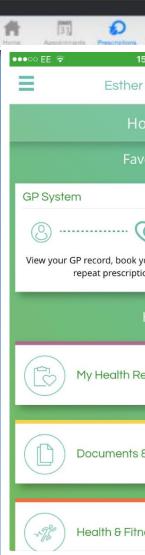
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What does good EOL Care look like?

- Coordinated and collaborative care
- lacksquareShared decision-making at the end of life
- Timely information
- Personalised care planning
- Access to the information at the point of care
- Family/Carers involved



Daffodil Standards for EOL Care

- 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 to 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





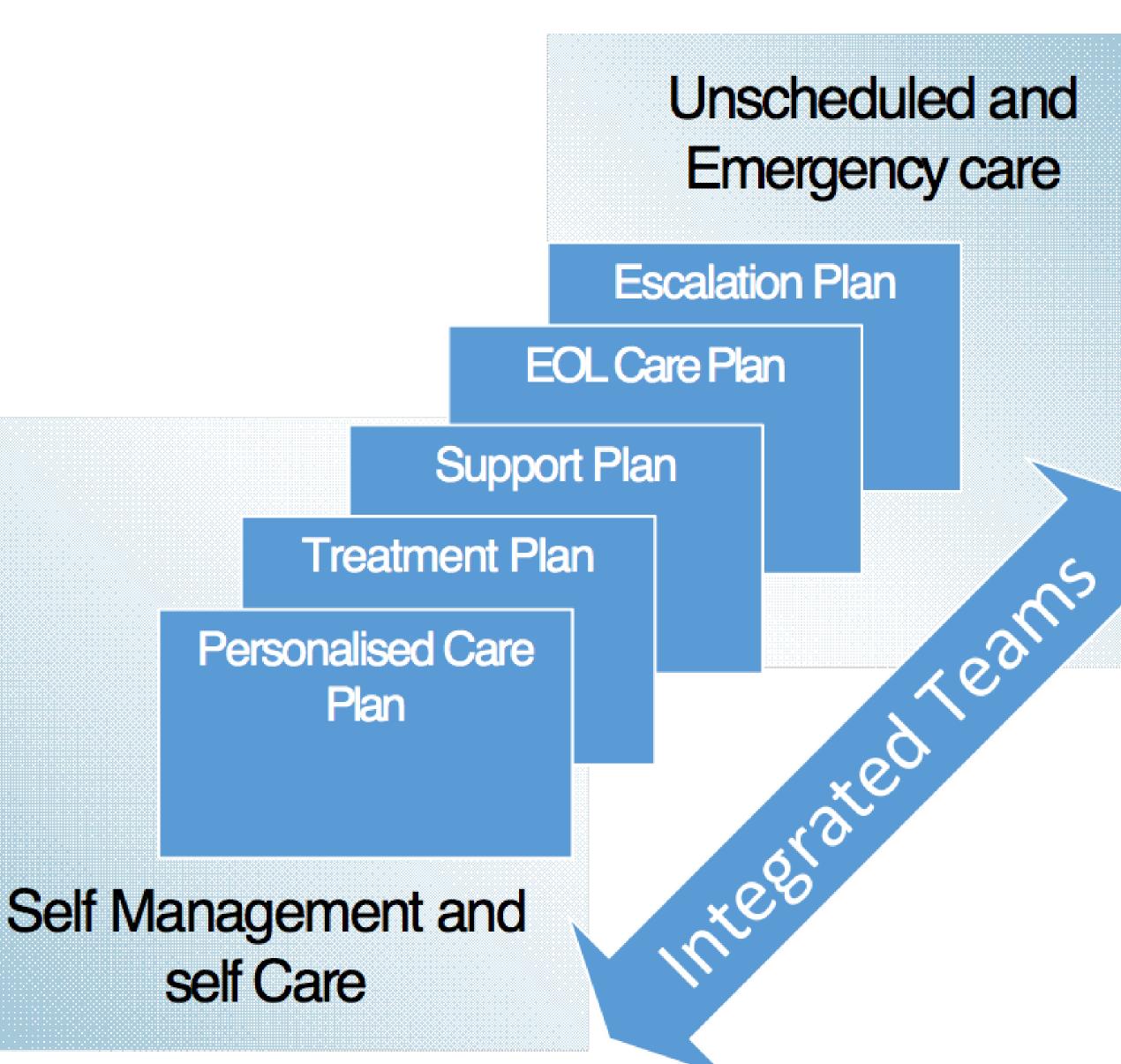
8. General Practices being hubs in Compassionate Communities



EOL Care Plans

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

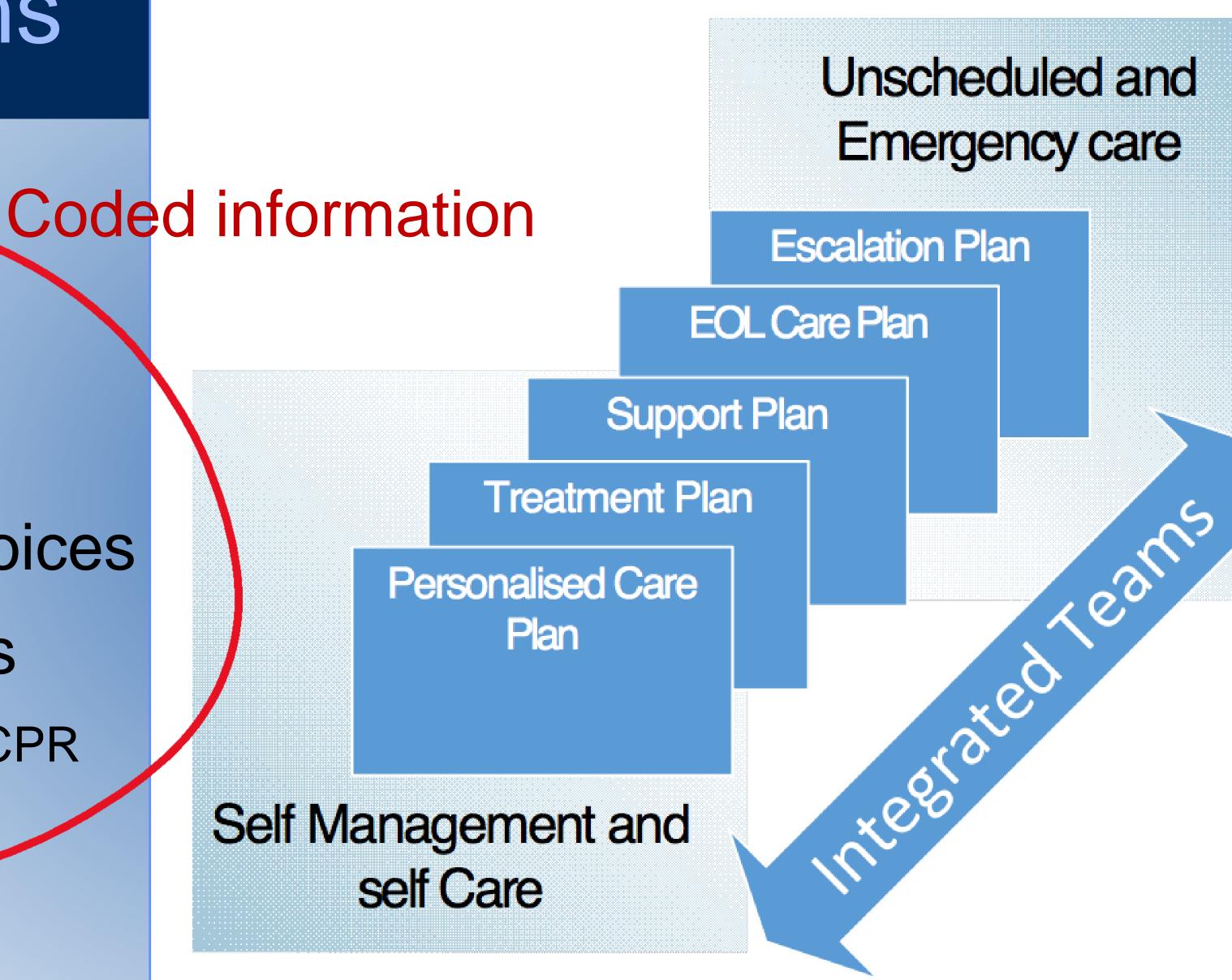




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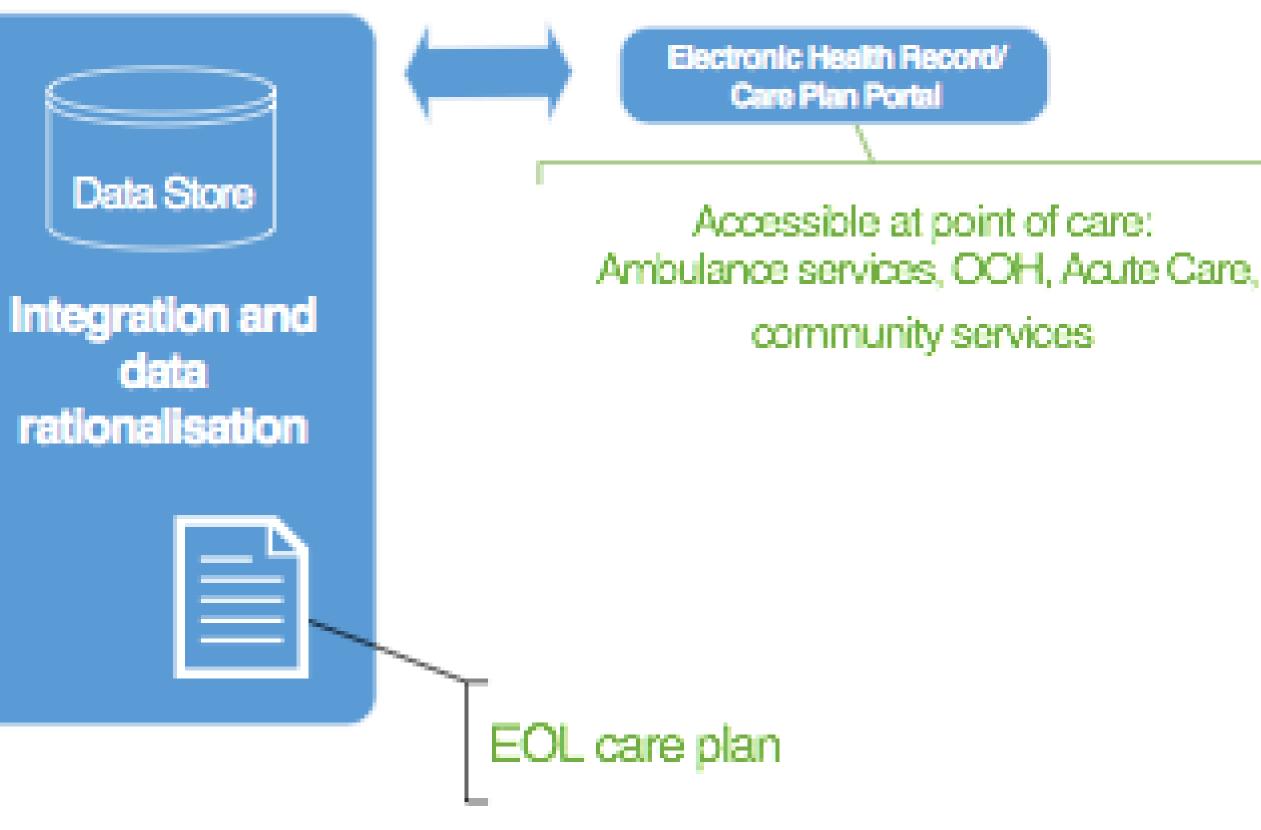
Electronic Patient Care Co-ordination Systems

Currently implemented EPaCCS System



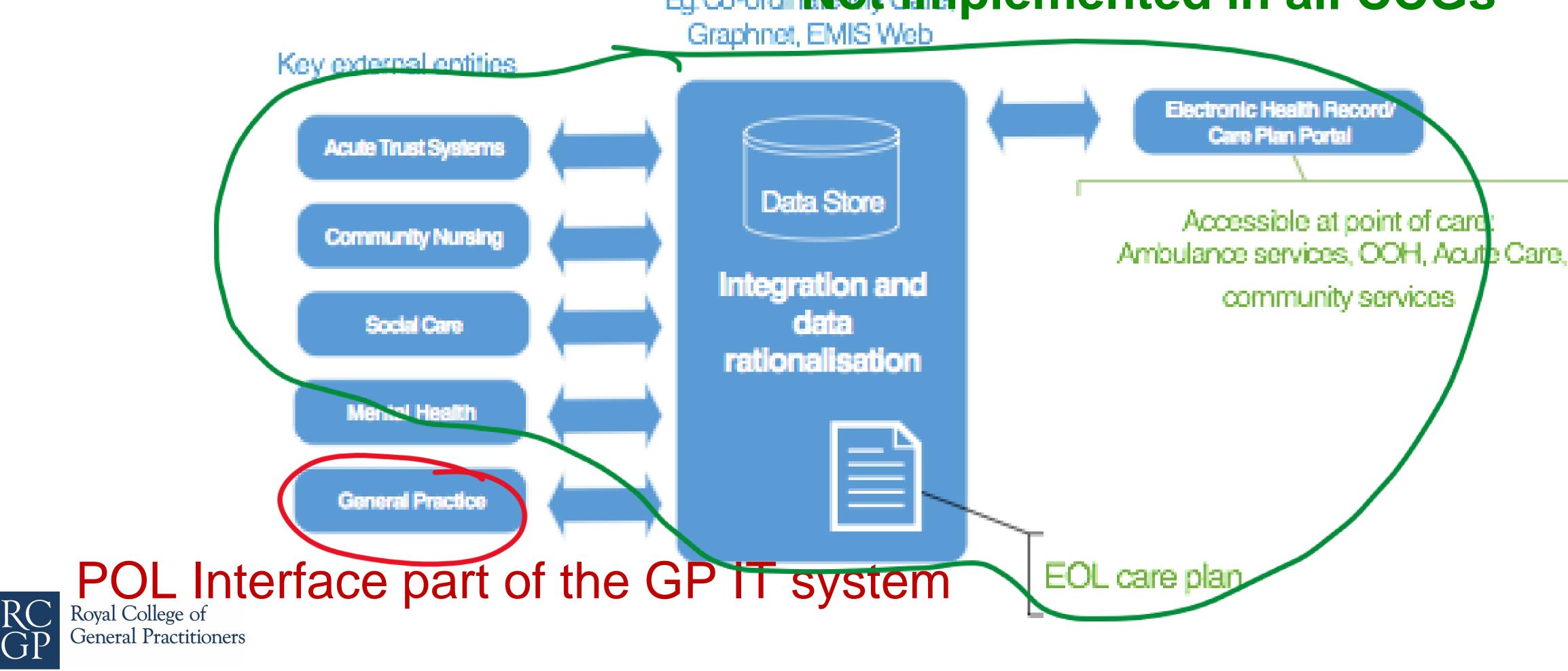






Electronic Patient Care Co-ordination Systems

Currently implemented EPaCCS System



Eq. Co-ord Not implemented in all CCGs

Pros and cons of separate EPaCCS

Benefits

Accessible by multiple agencies.

Live system across care boundaries.

Multidisciplinary access (read access or Data integration and migration issues. also able to add additional information).

Can aggregate information from across multiple specialities.

Facilitate communication across care settings.



Problems

Only a subset of the GP coded data.

Can be difficult to keep up-to-date.

Patients and carers may not have access to the information held.

Can vary considerably across localities.

Scenario A (fully operational EPaCCS)

Living with her daughter On active treatment No DNACPR



- Mrs EB is a 76yr old lady with mild COPD Recently diagnosed carcinoma bronchus

Proxy access

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



Proxy access

What is proxy access?

In the context of online services, proxy access means access to online services by somebody acting on behalf of a patient, for example the patient's parent or carer. To obtain proxy access a person must be registered for online access at the practice where the patient they are acting for is registered.

Patients may choose to use online services such as appointment booking, ordering repeat prescriptions or access to their records. They may choose to share their account credentials with family, friends and carers (including a care home) but as part of their access application they must be advised of the risks associated with doing this. Proxy access is the recommended alternative to sharing login details.

See below for guidance for general practice on when proxy access might be enabled, levels of access and when it is not advisable; as well as guidance on enabling proxy access in regard to children and young people, including stages of access. Also see below for a patient information leaflet and example consent form.

Proxy access - guidance for general practice:

- Proxy access guidance for general practice: PDF
- Proxy access on behalf of children and young people guidance: PDF

Proxy access - supporting material:

- NHS England patient information leaflets
- Consent to proxy access to GP online services form: Word | PDF

"Proxy access", Children and young people's access" and "Protecting patients and practices" eLearning – available here (free registration/ login required)

RCGP Patient Online Toolkit

http://elearning.rcgp.org.uk/patientonline





Prompt to practice/other HCP to update record

Error identified or update required

Iterative feedback from POL

Patient or Proxy Views coded data/plan via POL



Scenario A (y operational EPaCCS)

GP Consultation

Update or Review Care plan or coded data



Prompt to practice/other HCP to update record

Error identified or update required

Iterative feedback from POL

Patient or Proxy Views coded data/plan via POL



Scenario A (y operational EPaCCS)

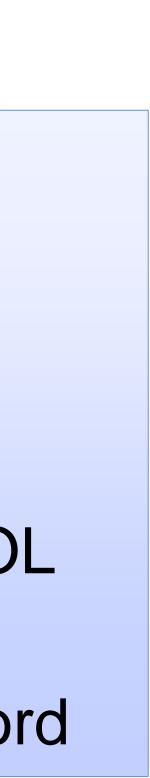
GP Consultation

Update or Review Care plan or coded data

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

EPaCCS



Scenario A (Fully operational EPaCCS)

Six months later No further active treatment **DNACPR** completed **Discharged from hospital**



Pleural effusion, hospitalised, metastatic disease

Prompt to practice/other HCP to update record

Error identified or update required

Iterative feedback from POL

Patient or Proxy Views coded data/plan via POL



Scenario A (y operational EPaCCS)

GP Consultation

Update or Review Care plan or coded data

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

EPaCCS



Scenario A (Fully operational EPaCCS)

Mrs EB's condition deteriorates views GP record online She notices that her mother is still for full escalation of care, which is not wanted



- Her daughter orders repeat prescriptions and
- She is pleased to see the DNACPR is recorded

Prompt to practice/other HCP to update record

Error identified or update required

Iterative feedback from POL

Patient or Proxy Views coded data/plan via POL



Scenario A (y operational EPaCCS)

GP Consultation

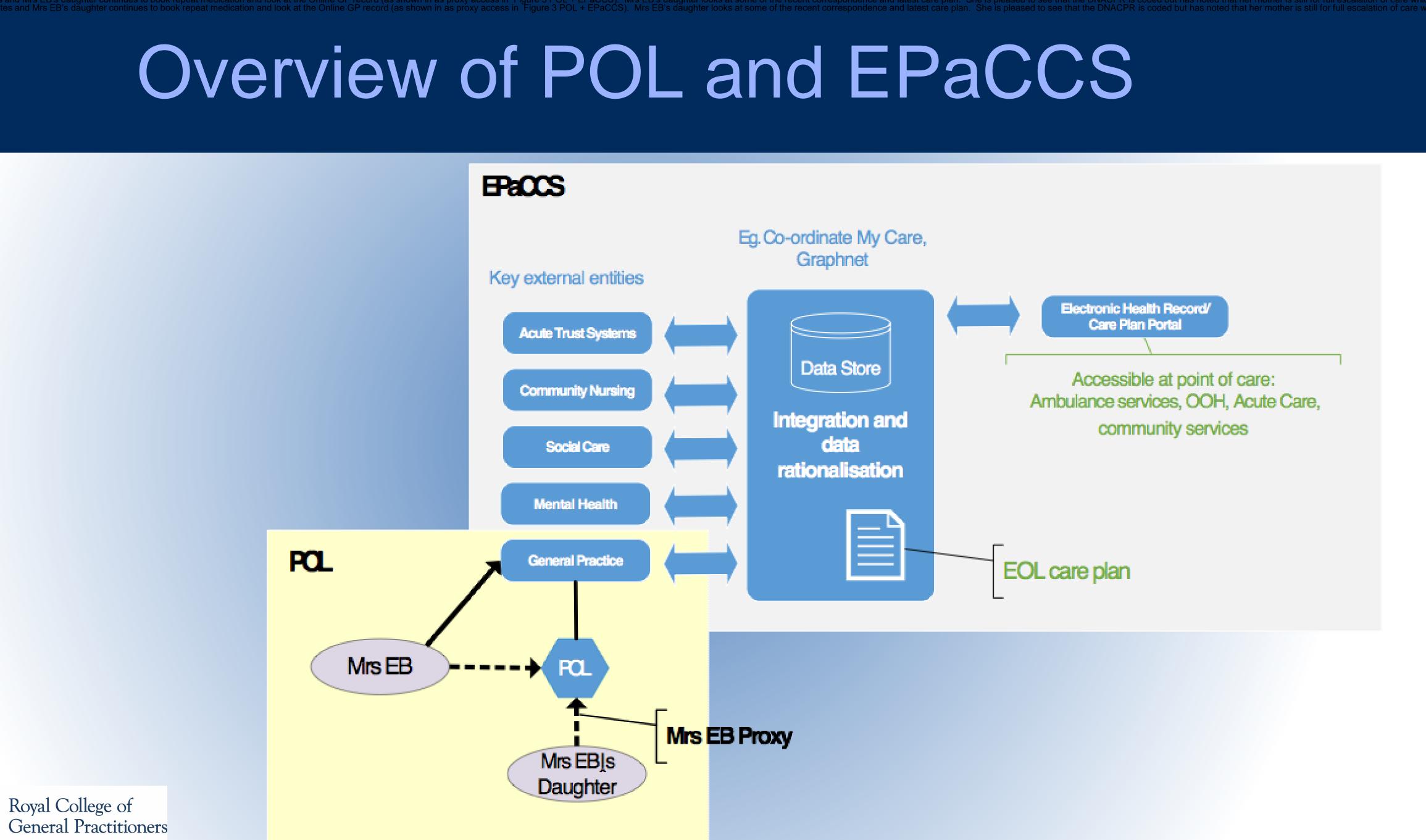
Update or Review Care plan or coded data

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





Scenario B (without operational EPaCCS)

Living with her daughter On active treatment No DNACPR



- Mrs EB is a 76yr old lady with mild COPD Recently diagnosed carcinoma bronchus

Scenario B (without operational EPaCCS) For Sold And to

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Prompt to practice/other HCP to update record

Error identified or update required

Iterative feedback from POL



Patient or Proxy Views coded data/plan via POL

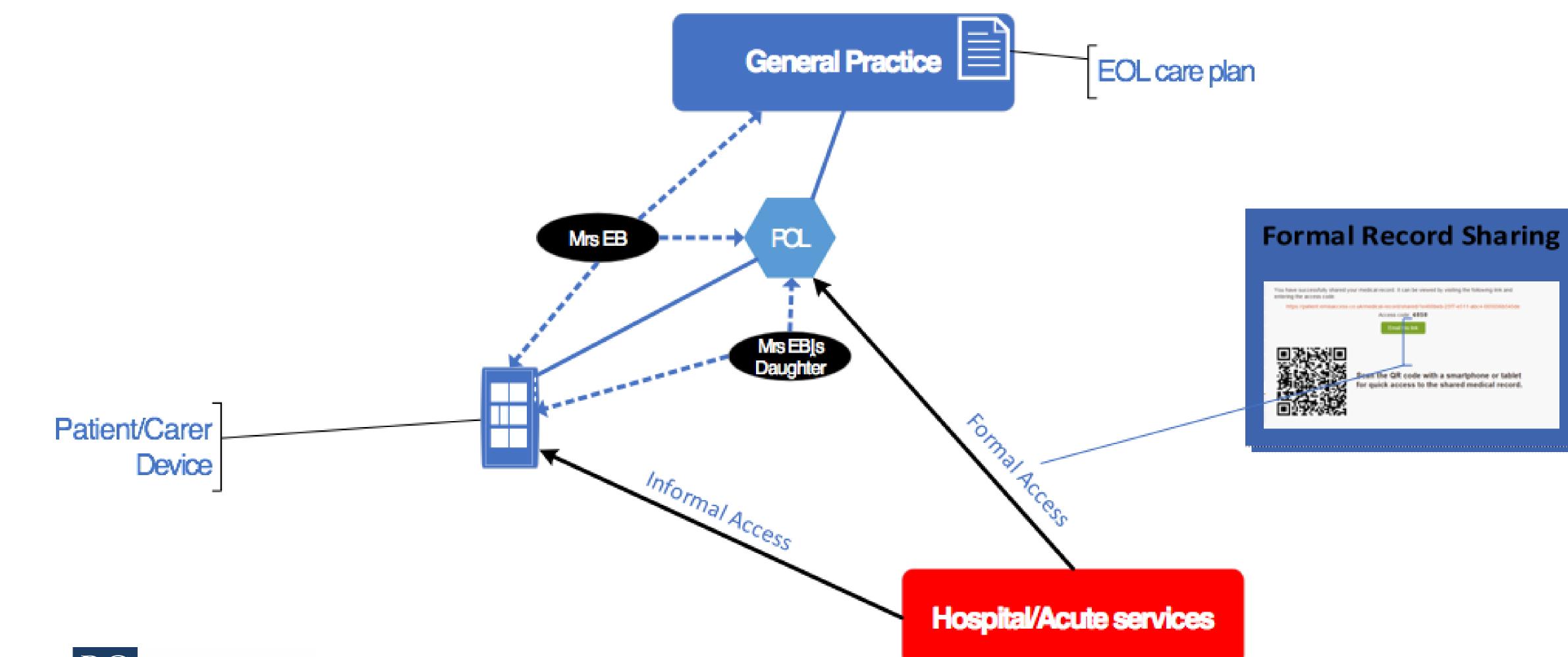
GP Consultation

Update or Review Care plan or coded data

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 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 fully 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 fully 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 fully 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 fully 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 fully 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 fully access in Figure 3 POL + EPaCCS).

Patient Online HCP Access







Section 1 RS Closing summary (in 2 mins)



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





- 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



Summary

