



Royal College of  
General Practitioners

# Patient Online

*in end of life care*

RCGP Webinar, 16 May 2018

# 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

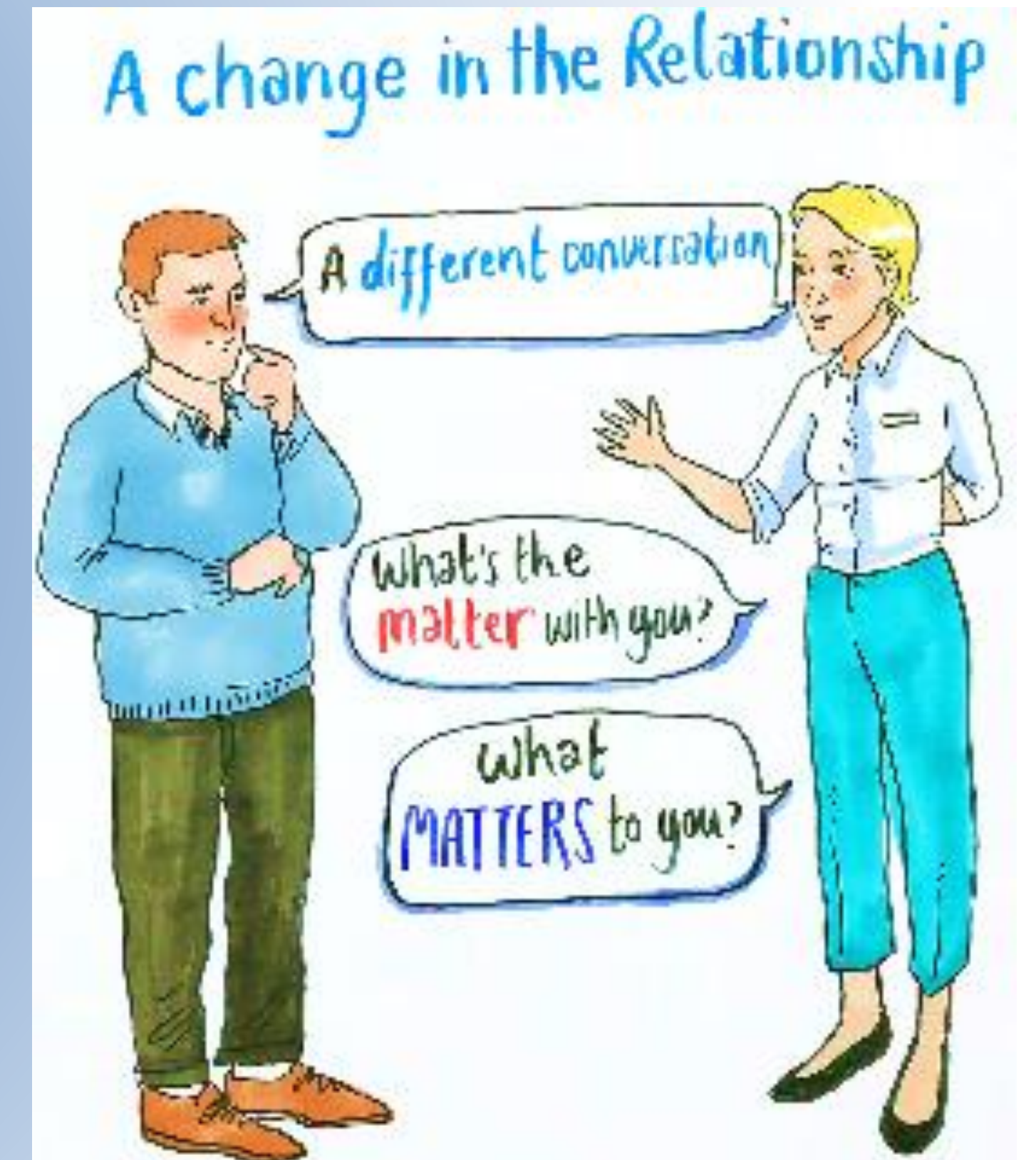
Dr Sinead Clarke, MRCGP  
GP Advisor, Macmillan Cancer Support

# 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.**

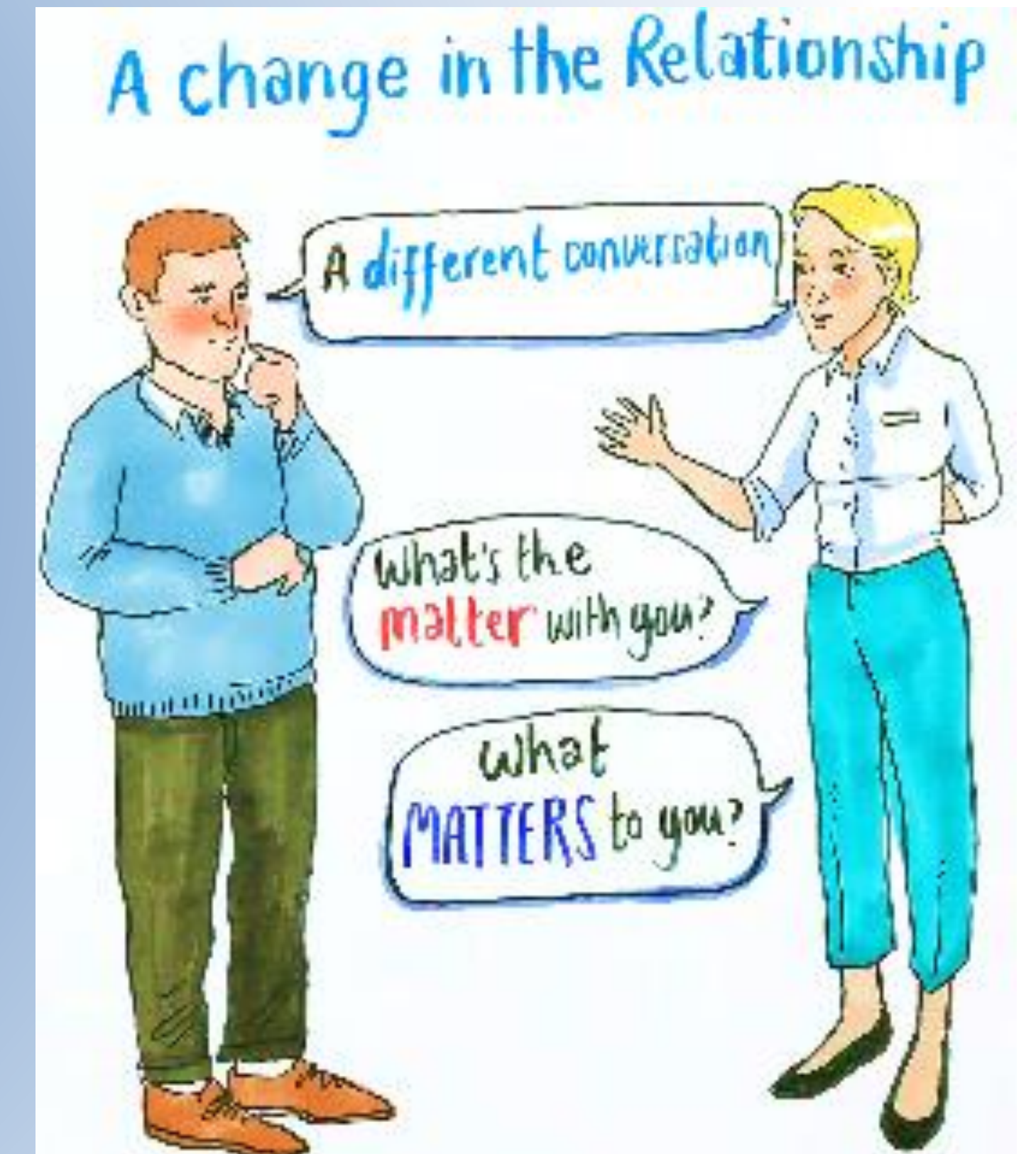
Access to my medical data ... in short I am no longer a passenger, I am now very much **part of the management team** for the effective treatment of my condition.”

*O.C. Manchester Oct 2017*



# 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

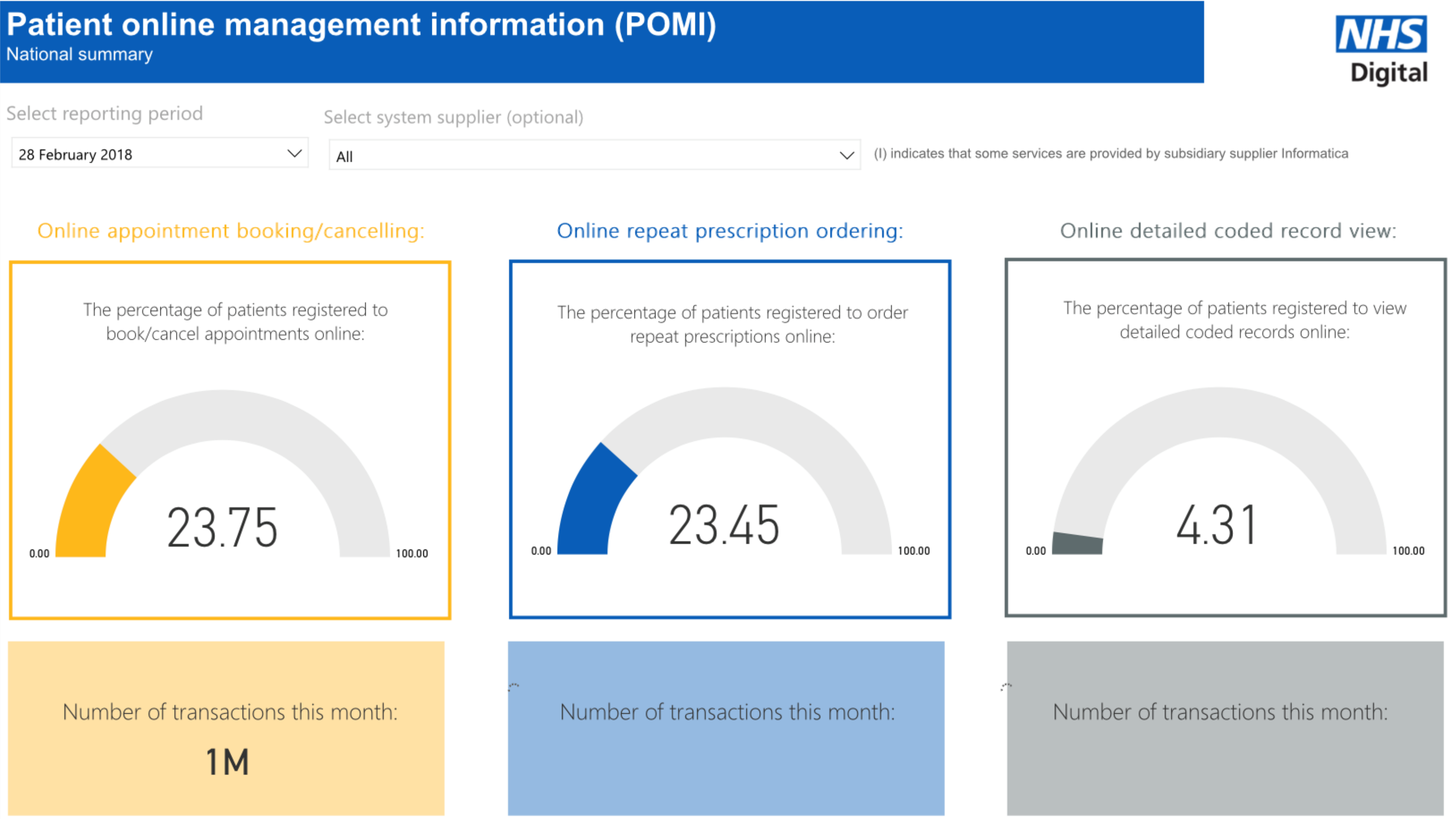


# Webinar programme

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

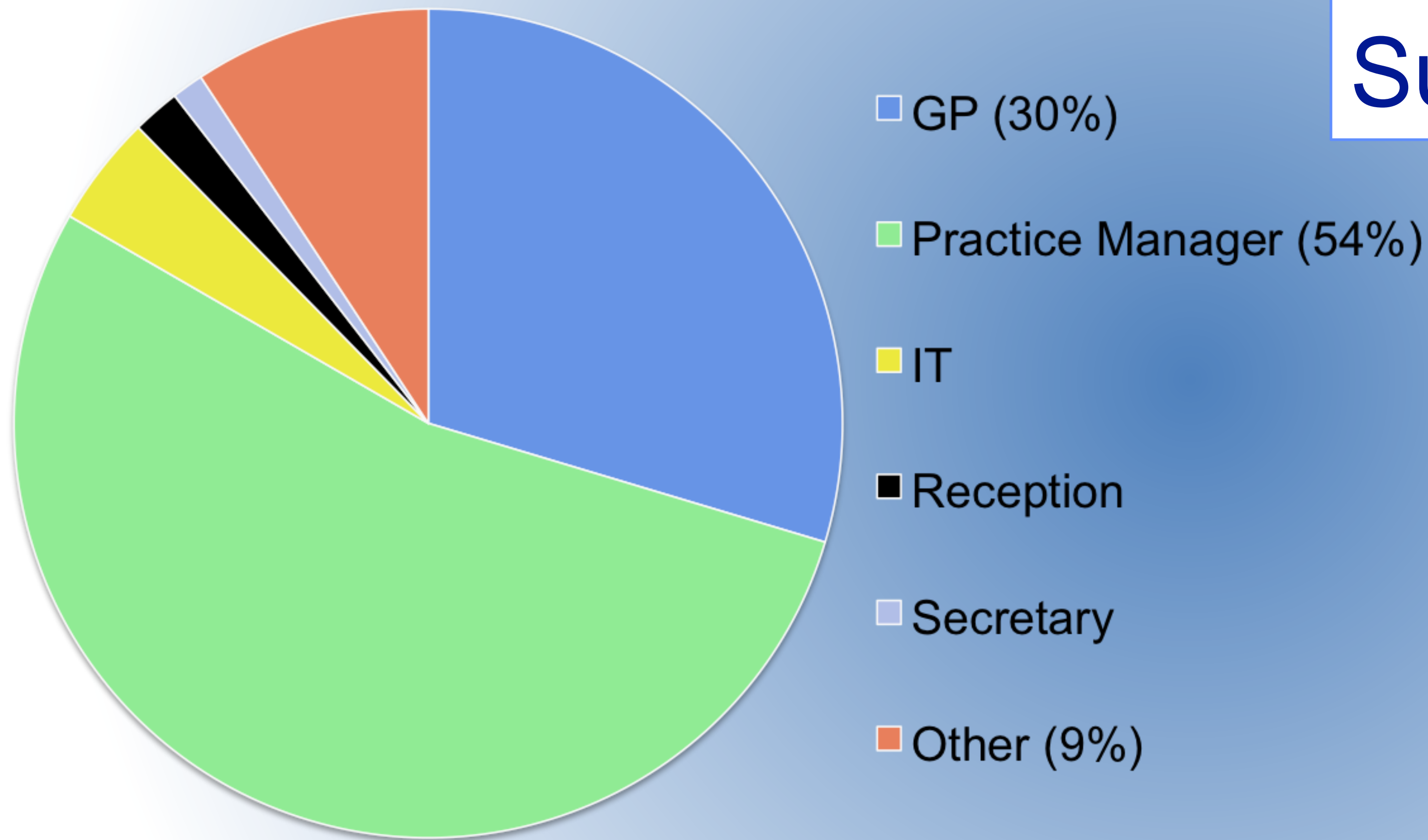
Type in your questions bottom left of screen

# Patients registered for Patient Online



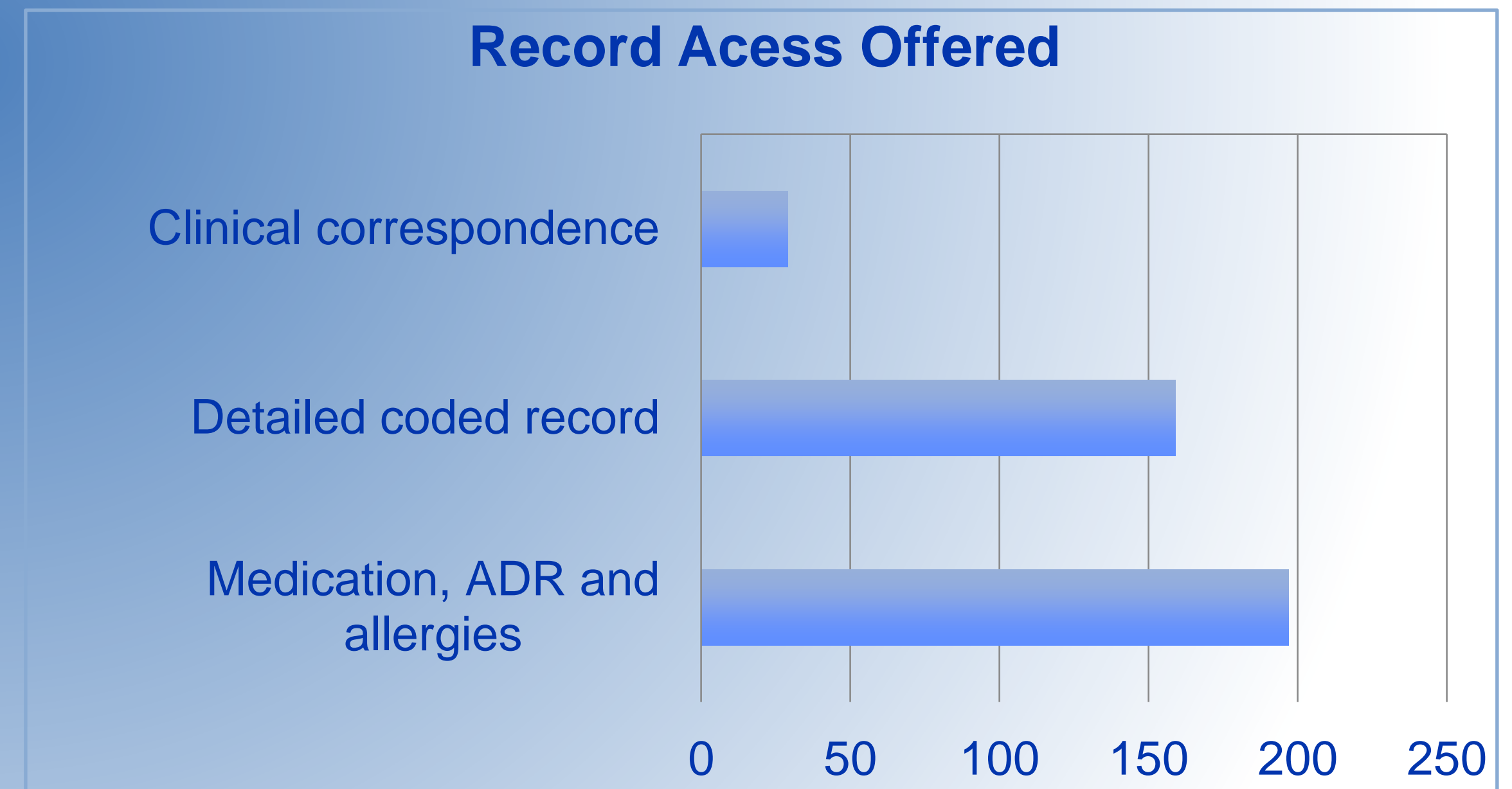
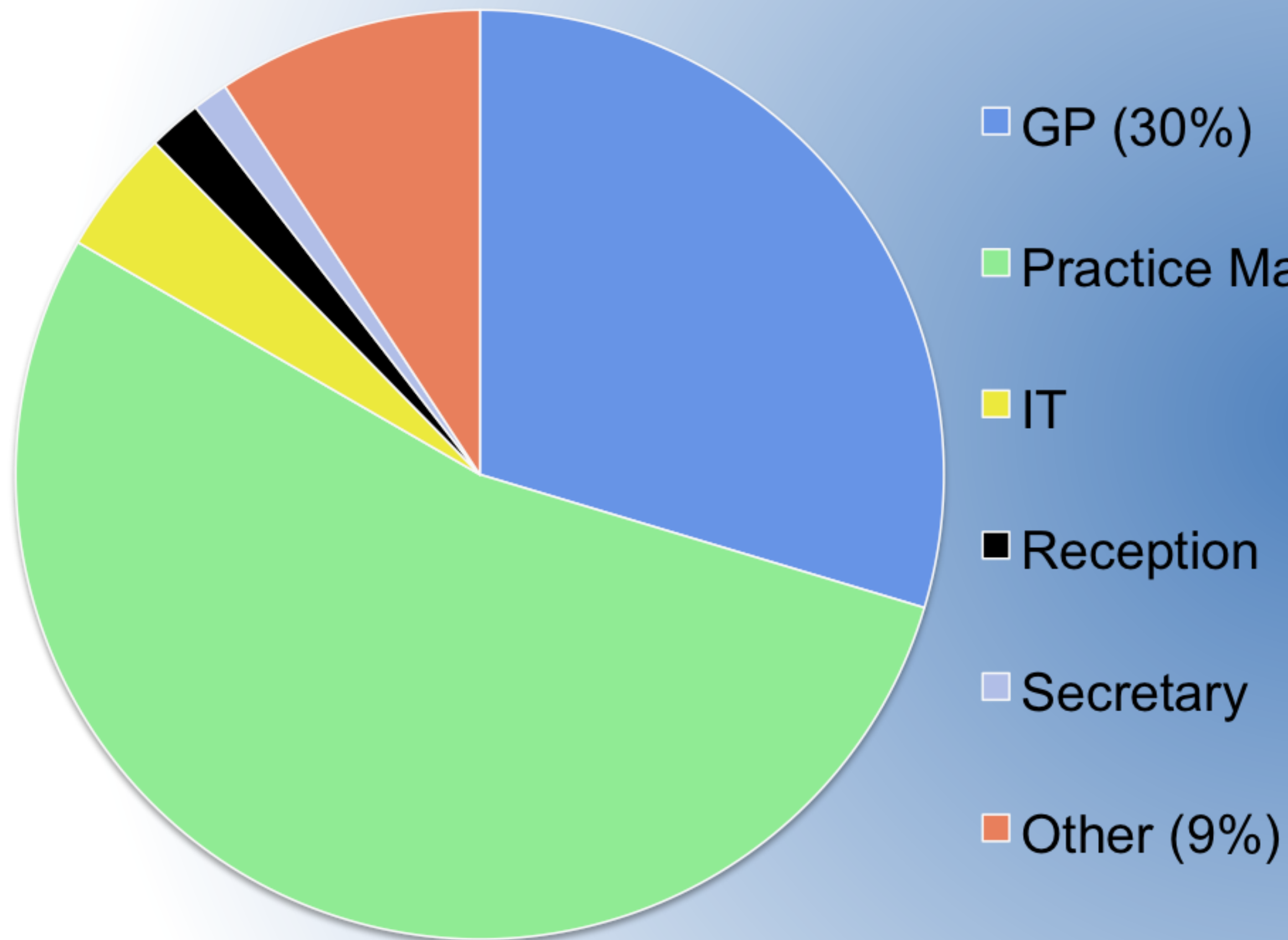
# RCGP Survey: “Views on record access”

Summer 2016 (n=211)



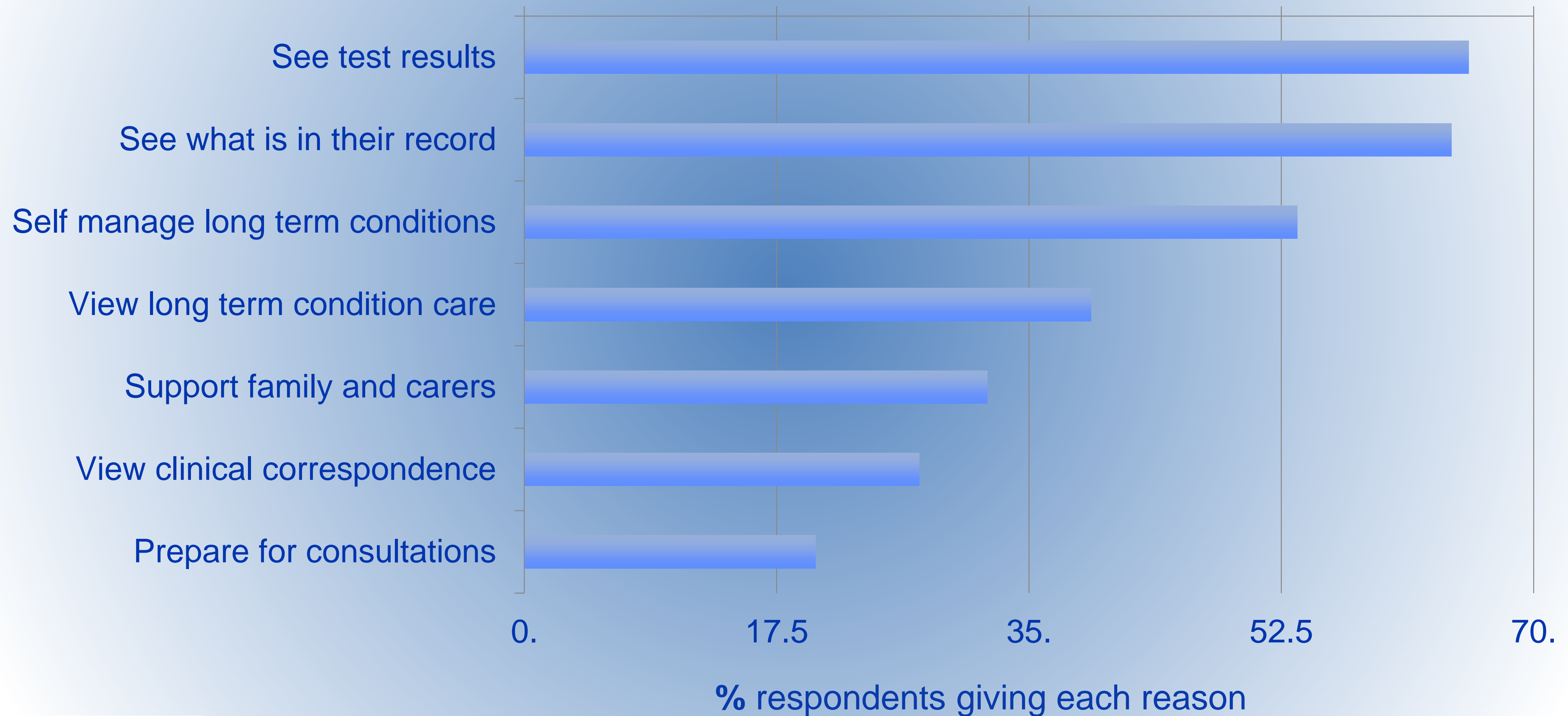
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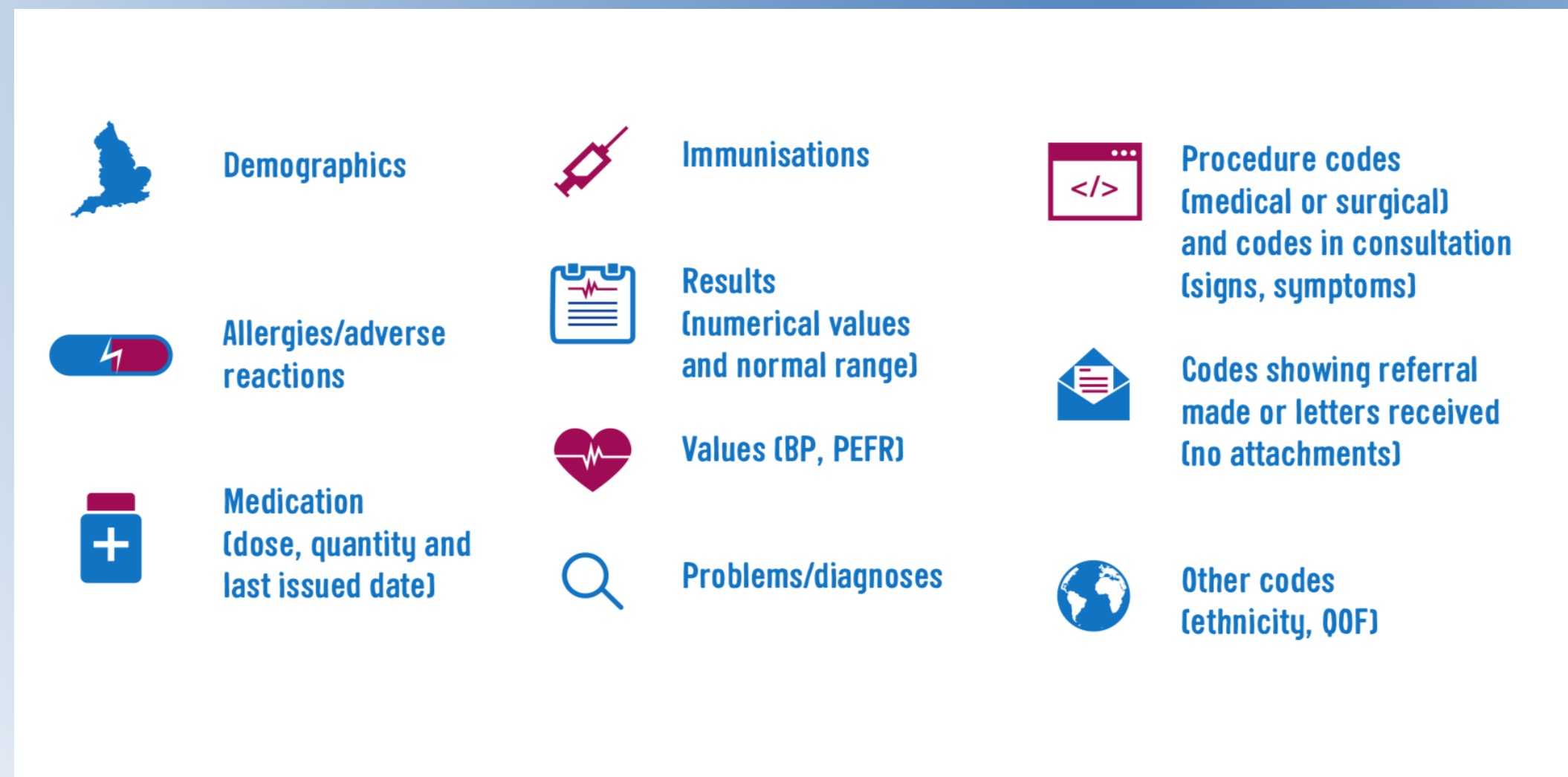


# RCGP Survey: “Views on record access”



# Patient Online Services

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



# 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

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#### Executive summary

The quality of data in a patient's record can be assessed by the extent to which it meets the 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 patient's health care and safety.

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, relevance, accessibility and timeliness (CARAT).

#### 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 GMS contract and PMS arrangements for 2015-16 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 record must be fit for this new purpose.

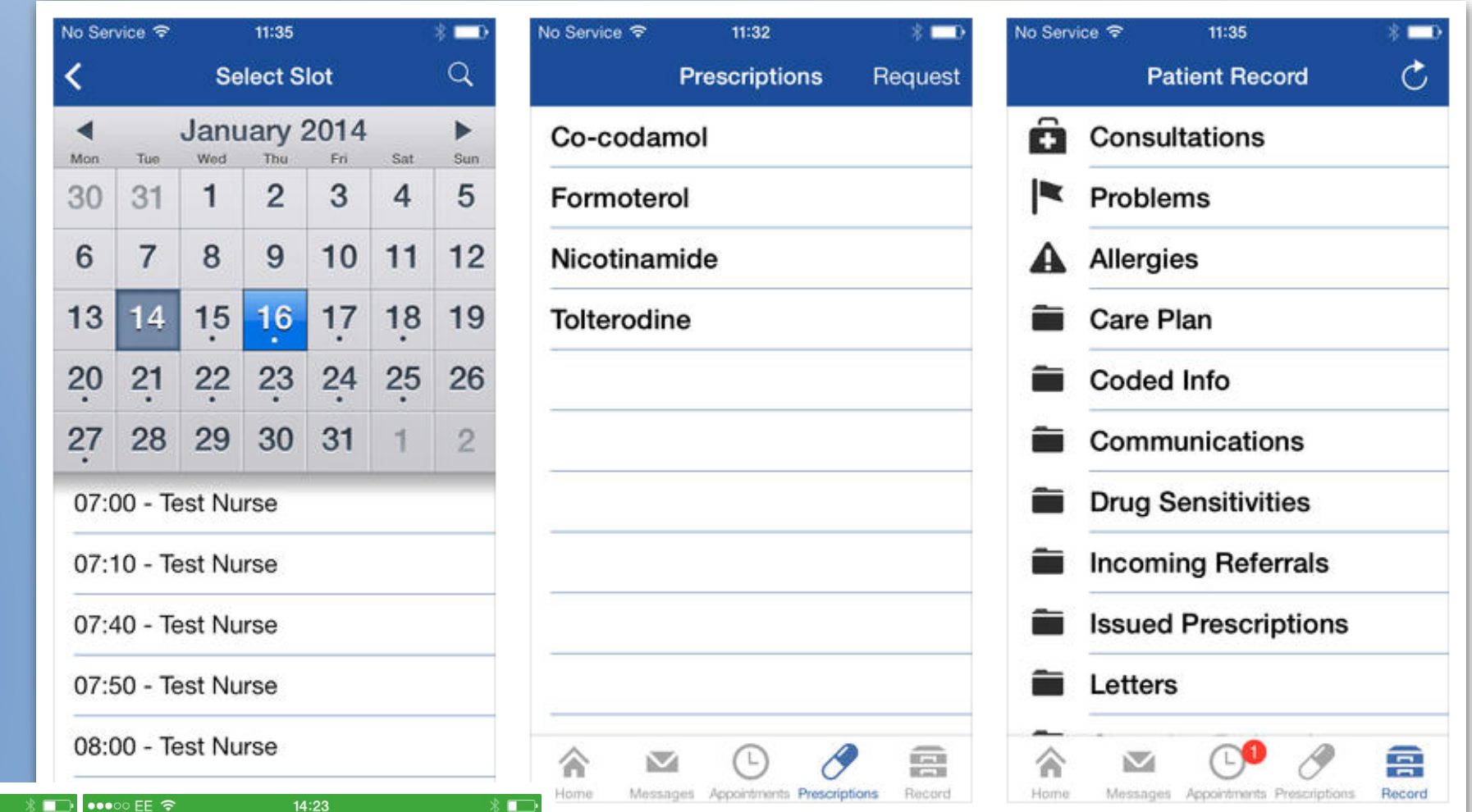
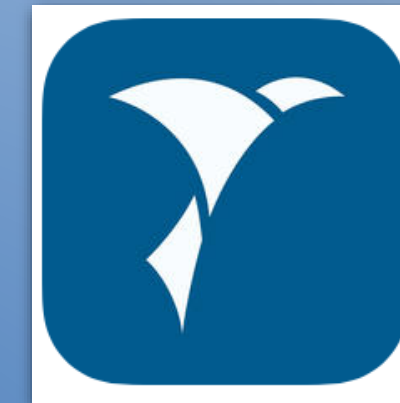
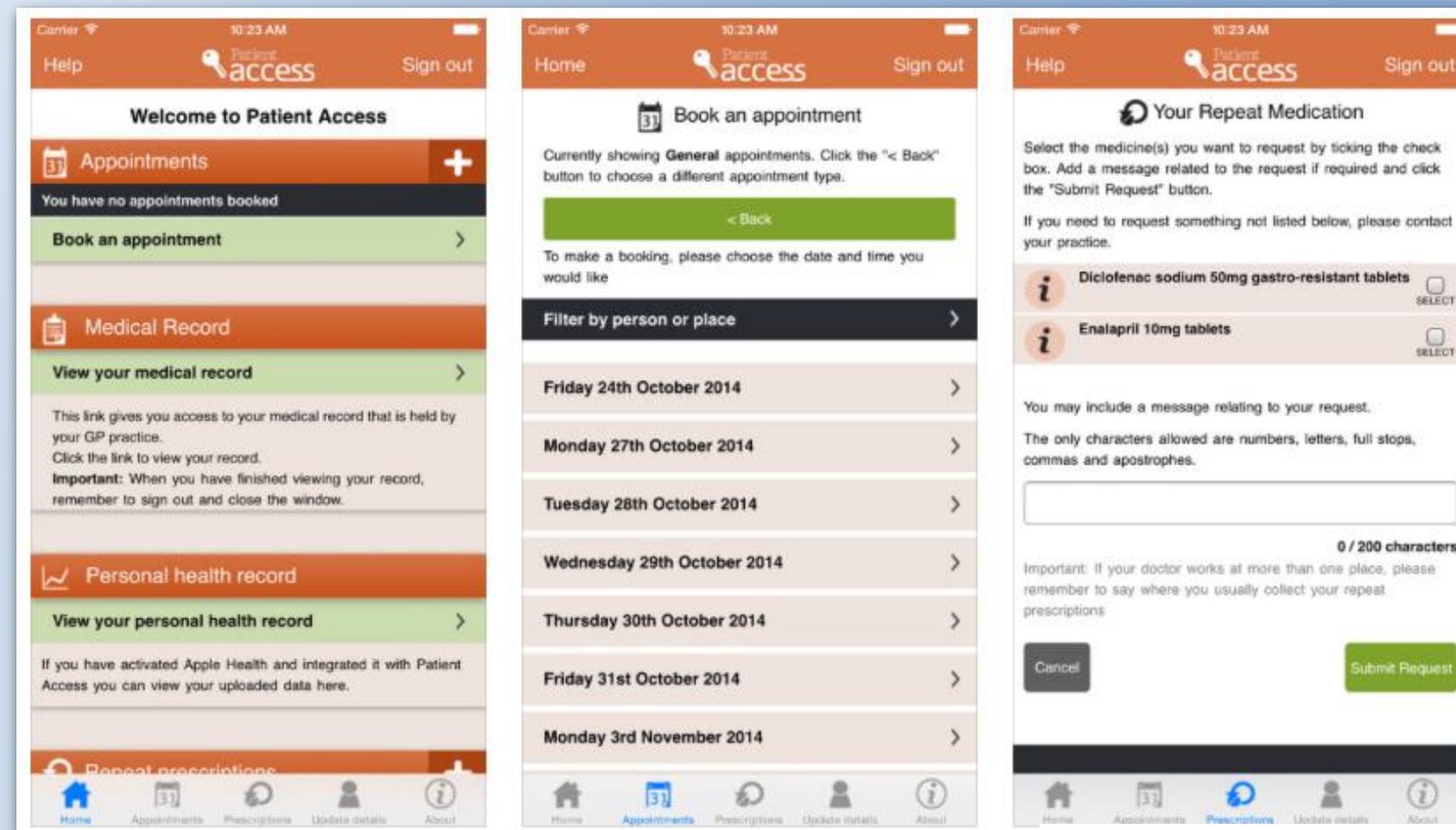
This guidance explains how Patient Online has changed the criteria for a high quality electronic patient record and how practices may respond to this challenge.

# 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



# 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

# 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

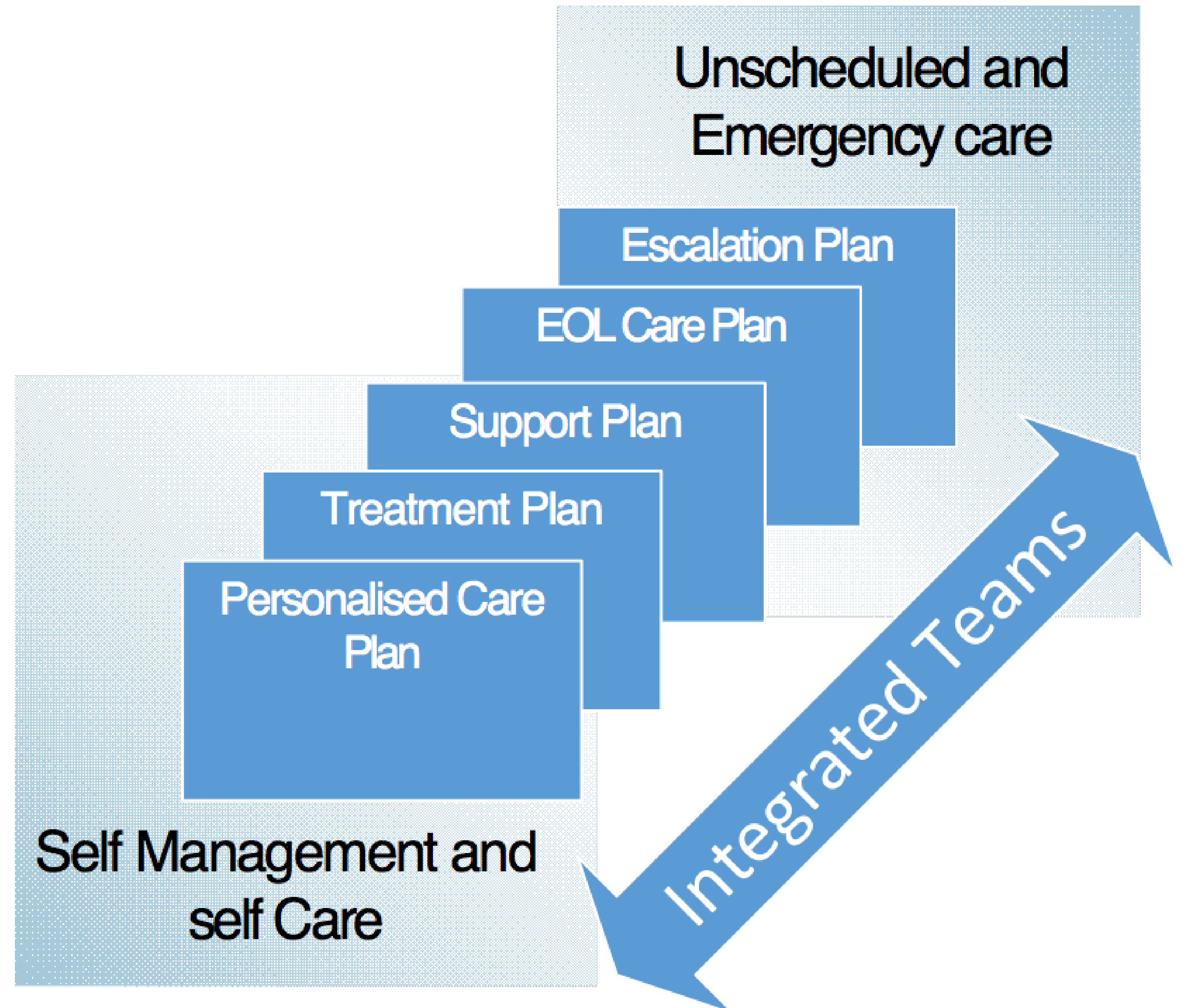
Patient Online can be used to inform to patients and empower them to be more involved in their own care and care planning

4. Seamless, planned, coordinated care
5. Assessment of unique needs of the patient
6. Quality care during the last days of life
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# EOL Care Plans

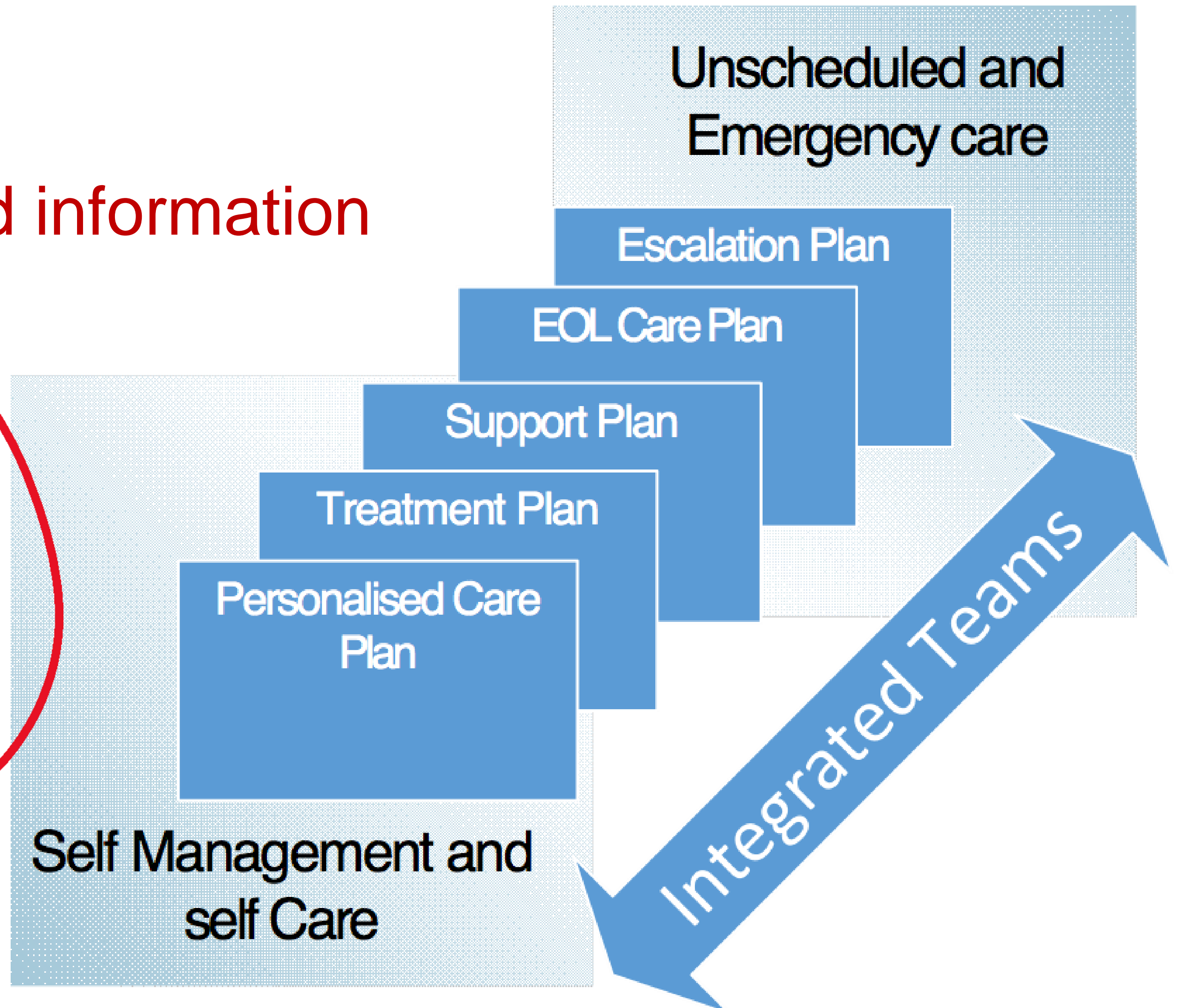
- Personal details
- Carer information.
- Care preferences/choices
- Future care decisions  
e.g. escalation levels, DNACPR



# EOL Care Plans

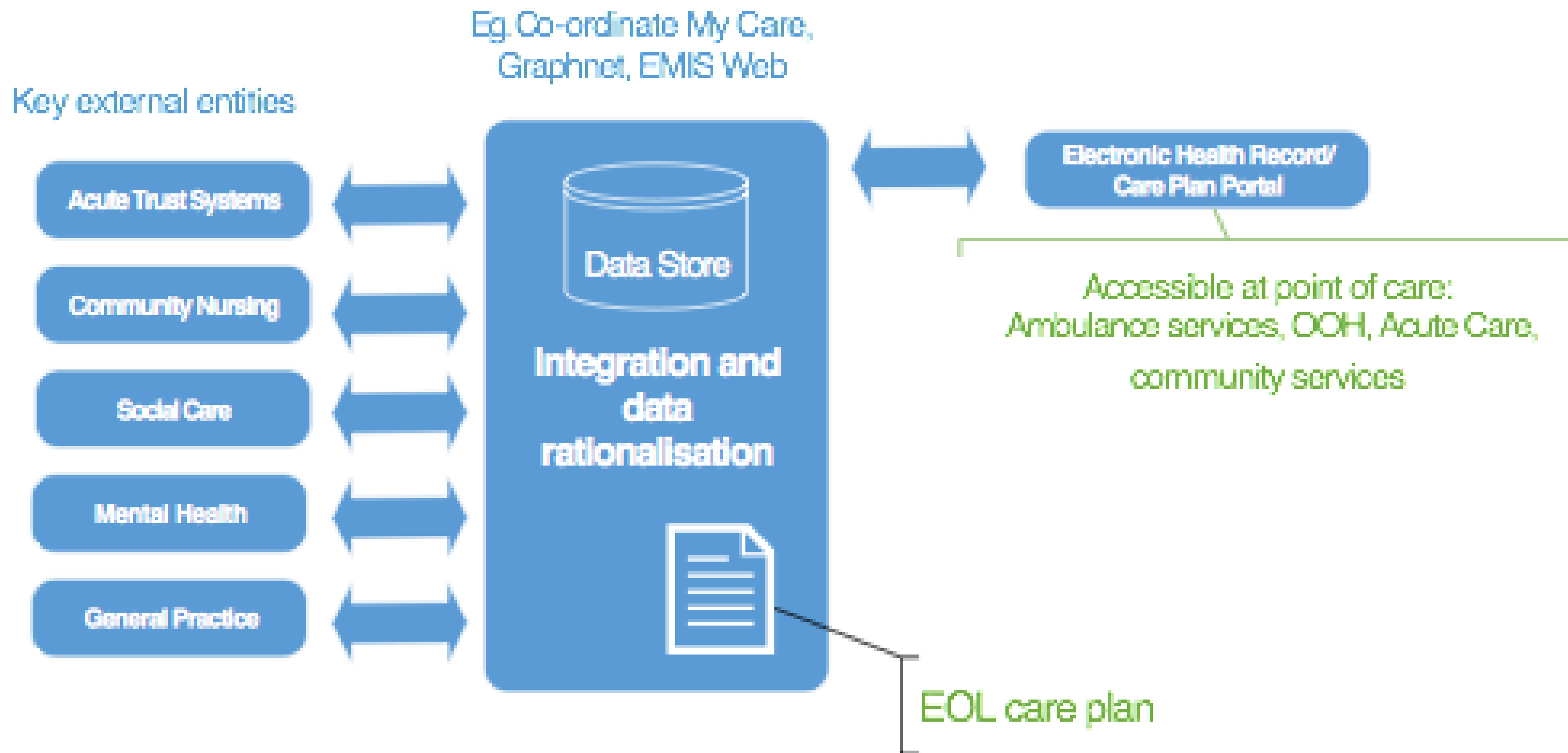
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Coded information



# Electronic Patient Care Co-ordination Systems

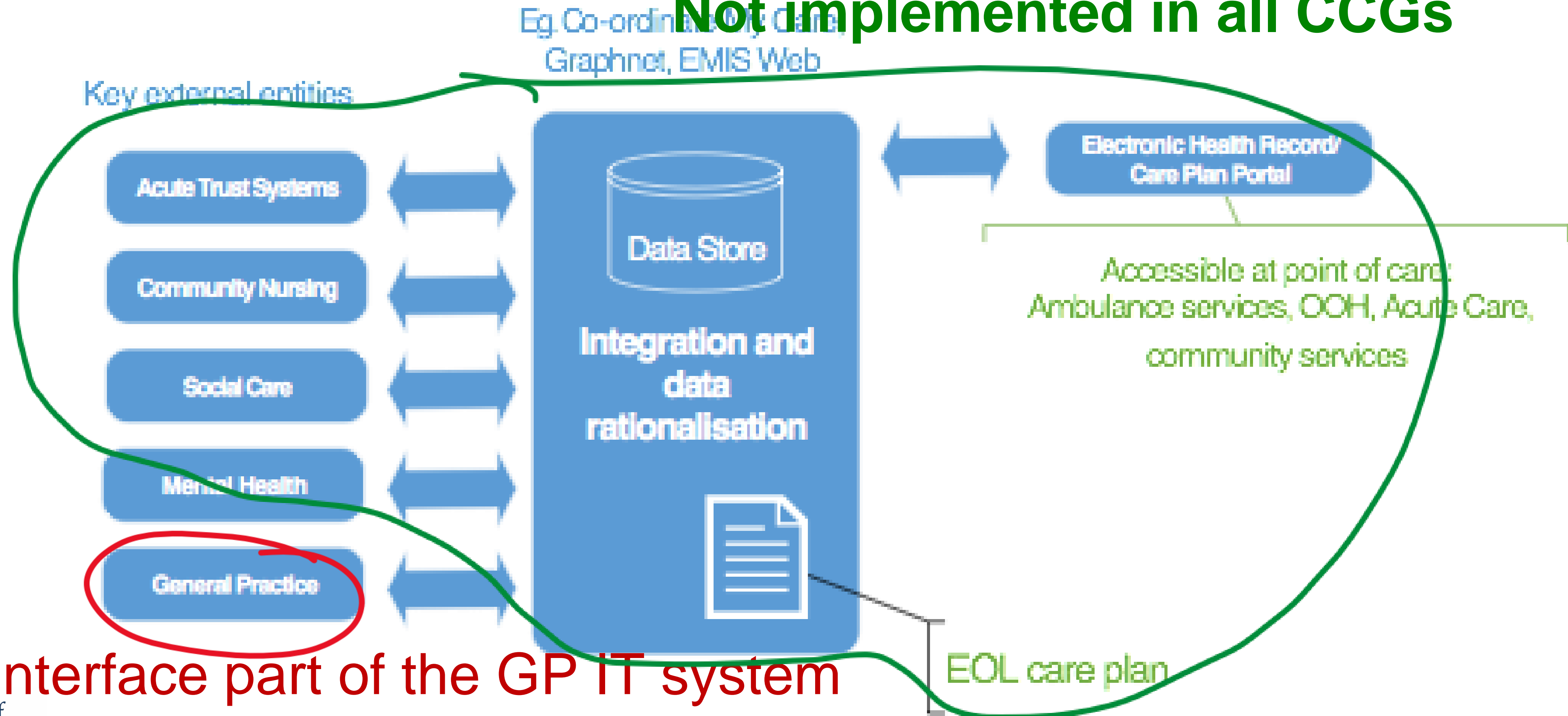
## Currently implemented EPaCCS System



# Electronic Patient Care Co-ordination Systems

Currently implemented EPaCCS System

**Not implemented in all CCGs**



**POL Interface part of the GP IT system**

# Pros and cons of separate EPaCCS

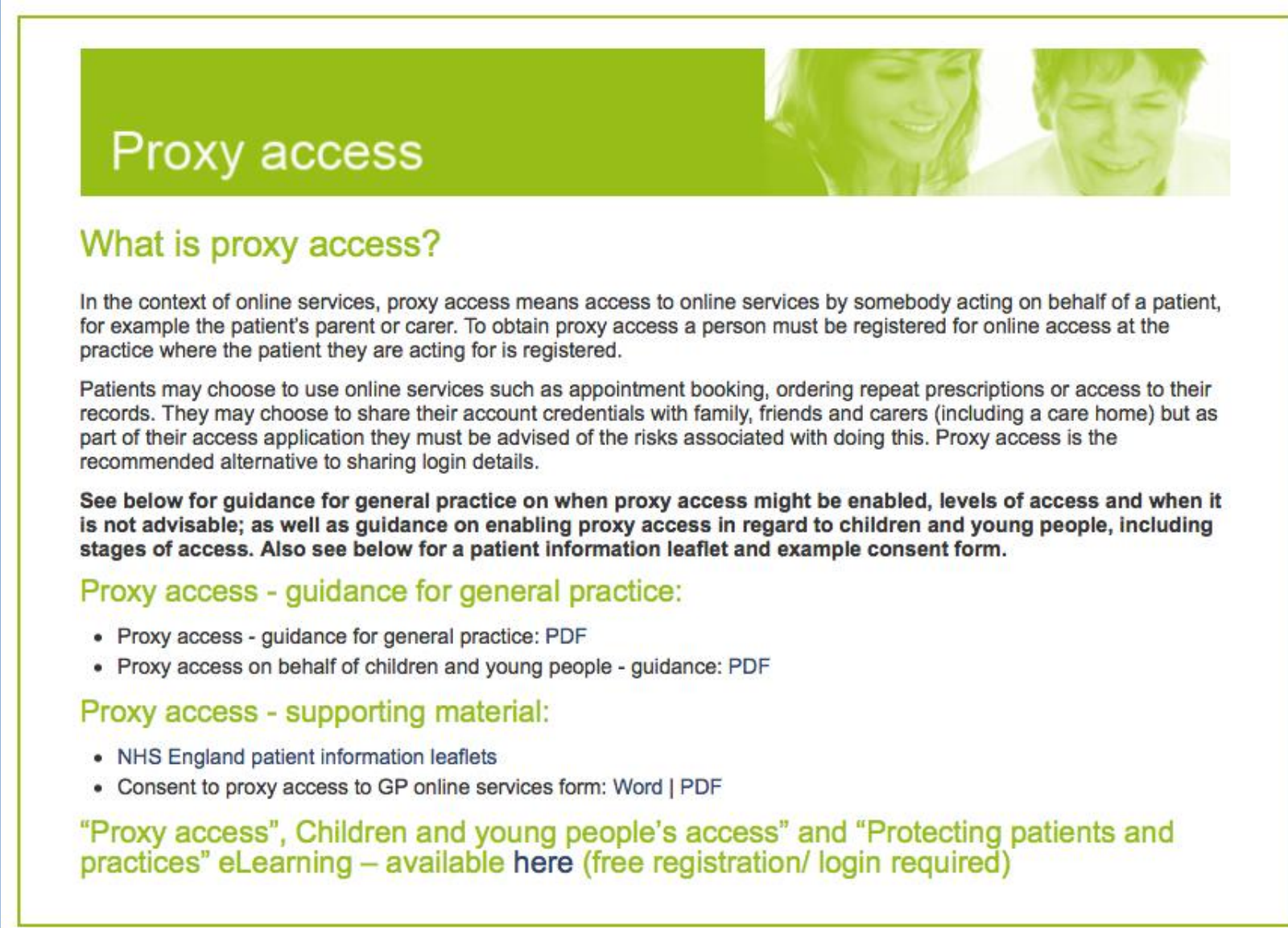
Benefits	Problems
Accessible by multiple agencies.	Only a subset of the GP coded data.
Live system across care boundaries.	Can be difficult to keep up-to-date.
Multidisciplinary access (read access or also able to add additional information).	Data integration and migration issues.
Can aggregate information from across multiple specialities.	Patients and carers may not have access to the information held.
Facilitate communication across care settings.	Can vary considerably across localities.

# 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



**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

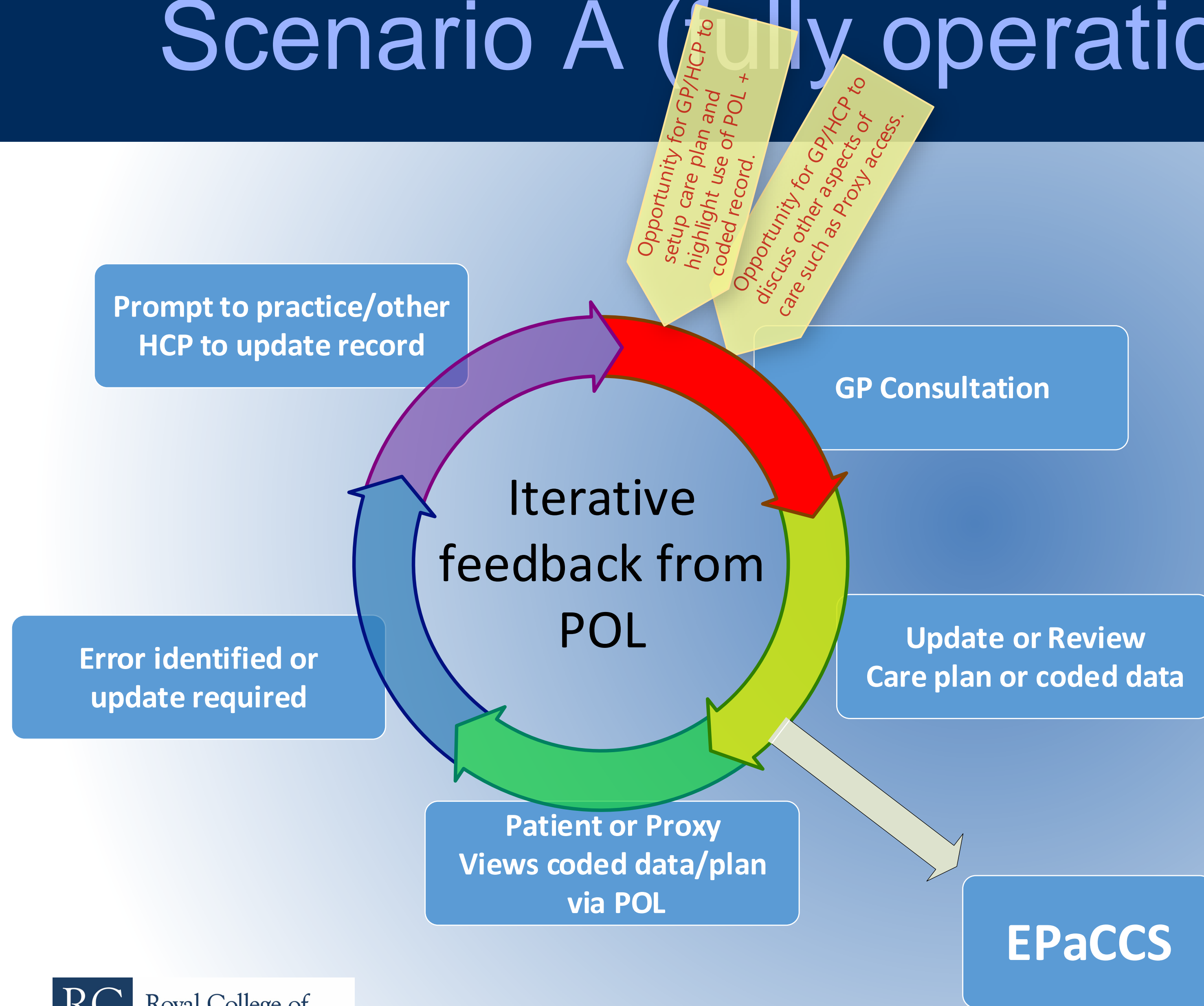
"Proxy access", Children and young people's access" and "Protecting patients and practices" eLearning – available [here](#) (free registration/ login required)

RCGP Patient Online Toolkit

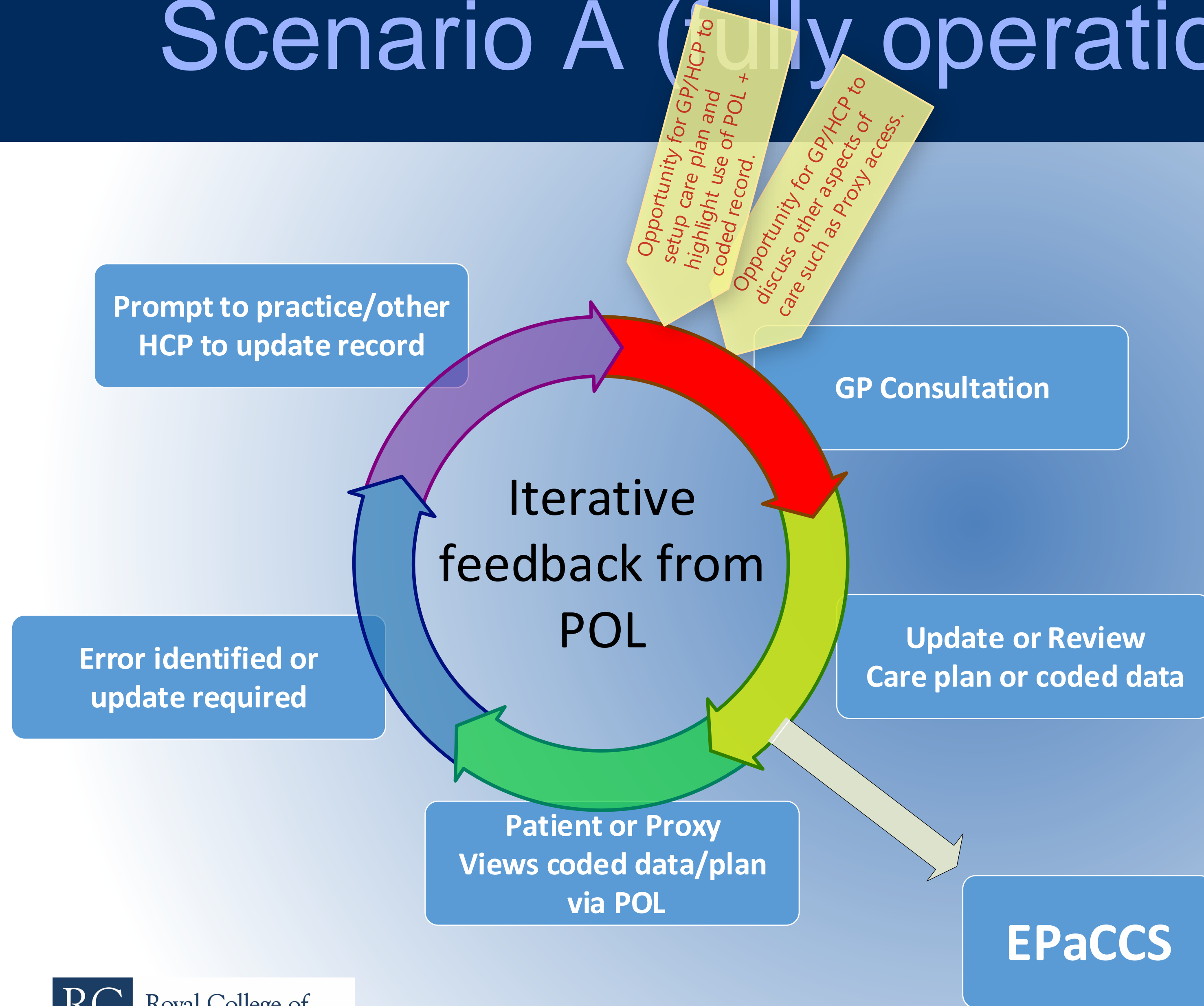
<http://elearning.rcgp.org.uk/patientonline>



# Scenario A (Fully operational EPaCCS)



# Scenario A (Fully operational 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

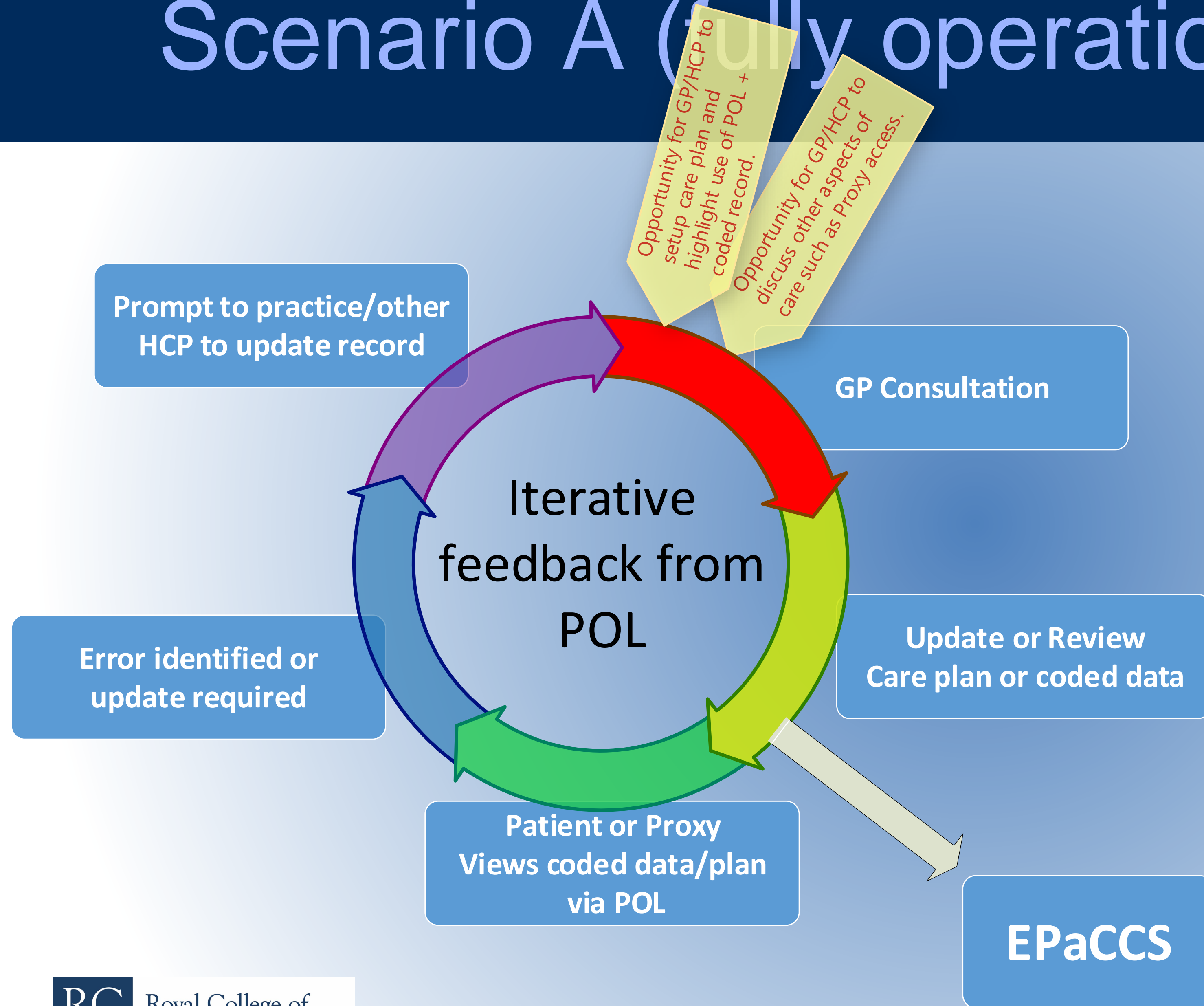
Pleural effusion, hospitalised, metastatic disease

No further active treatment

DNACPR completed

Discharged from hospital

# Scenario A (Fully operational EPaCCS)



## 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

# Scenario A (Fully operational EPaCCS)

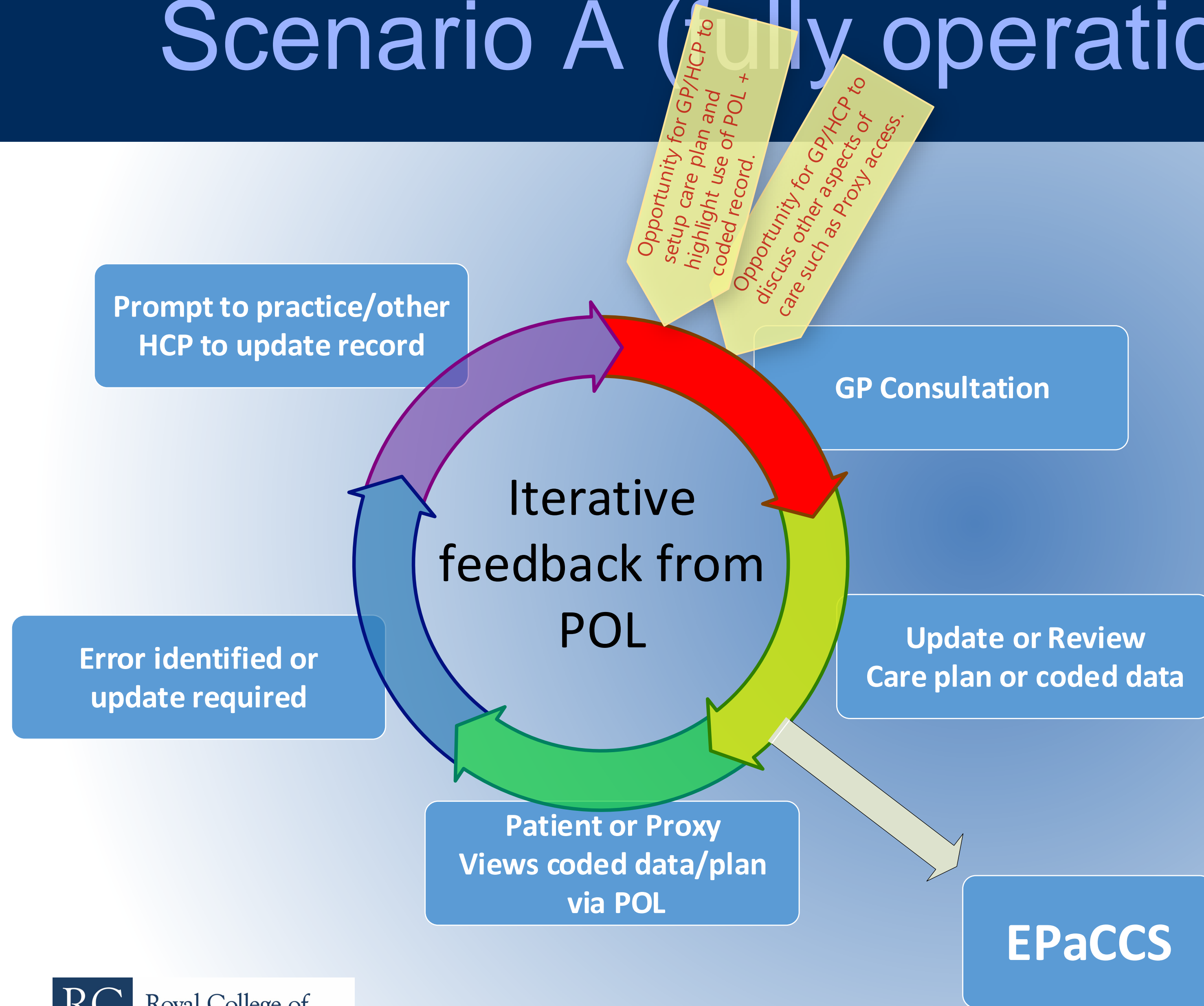
**Mrs EB's condition deteriorates**

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

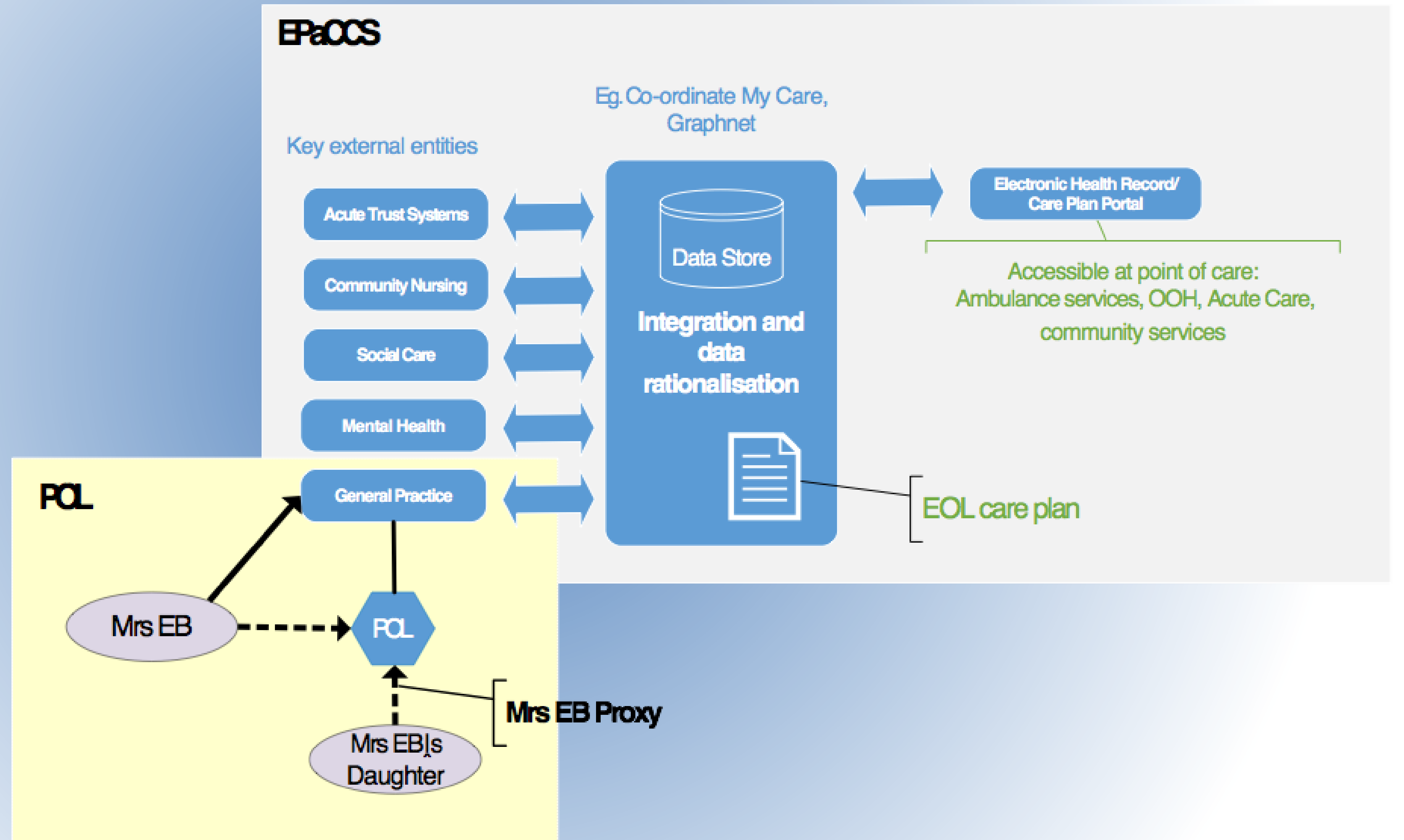
# Scenario A (Fully operational EPaCCS)



## 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

# Overview of POL and EPaCCS

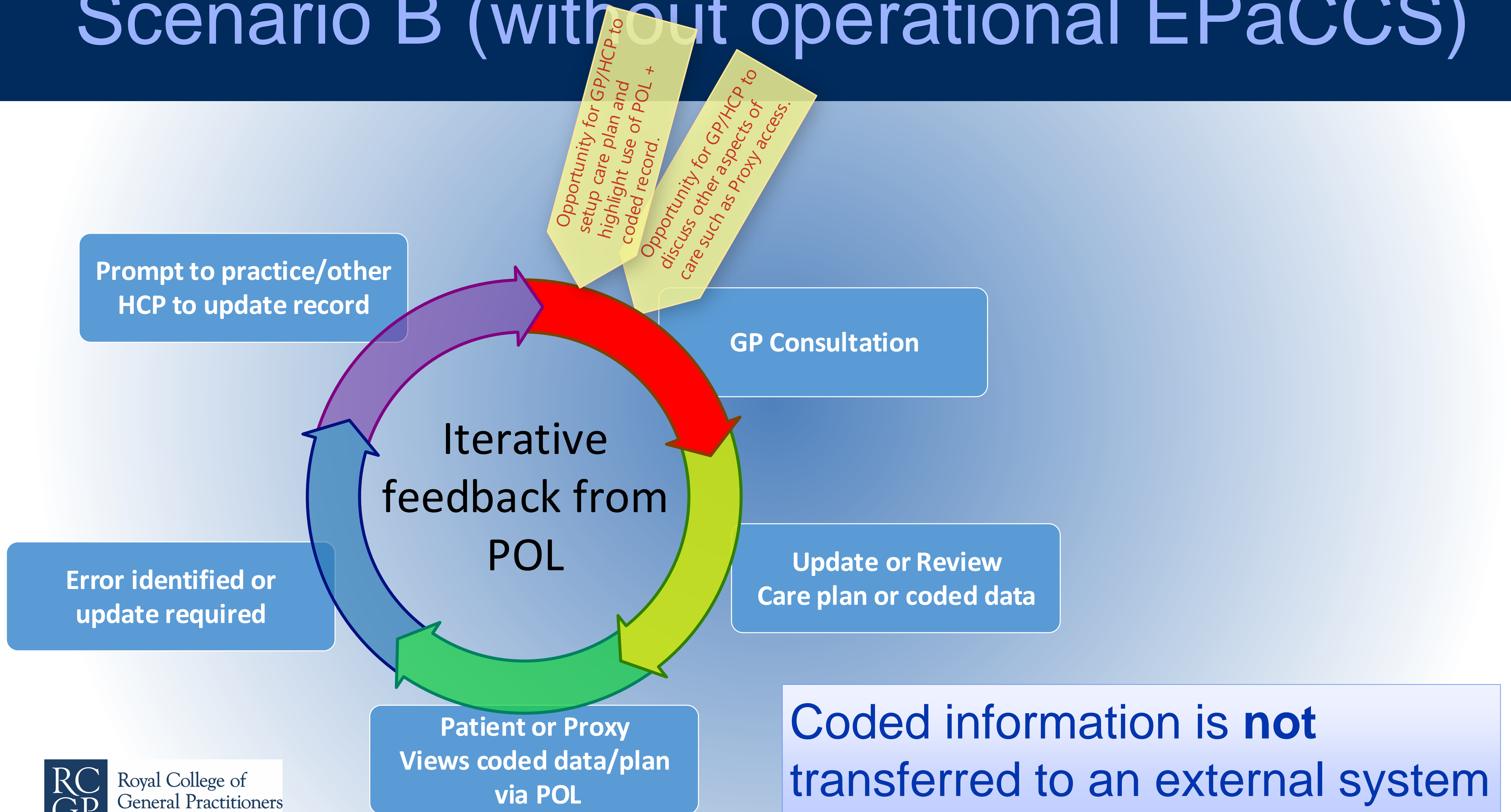


# Scenario B (without operational EPaCCS)

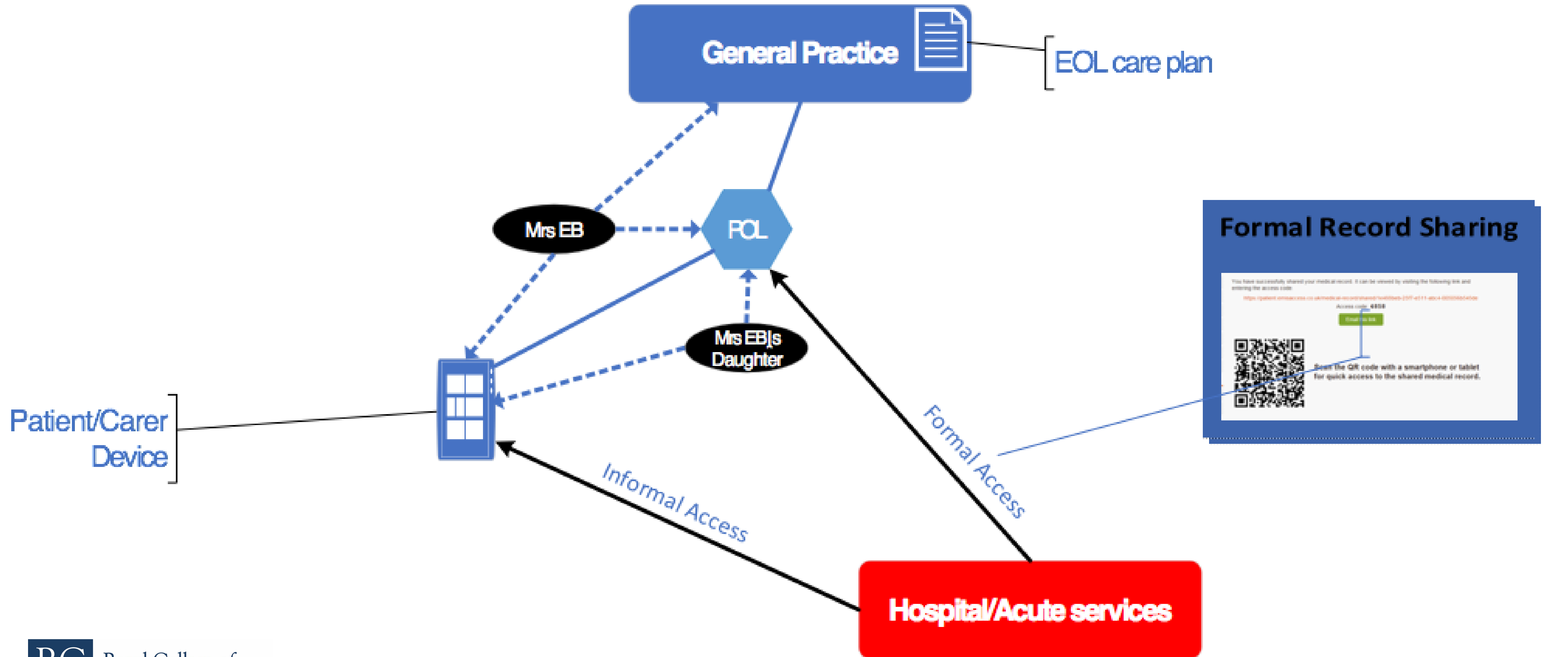
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No DNACPR



# Scenario B (without operational 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

# 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