COMMIT/

Beyond the Dutch EPD

Towards physician-controlled decentralized medical record exchange

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History and context

Early developments: GPs and computer hobbyists in the '80s

' 90s Erasmus University (Rotterdam) – EDIFACT / MEDEUR (Johan vd Lei)

OZIS – regional pharmacist rings and GP rings for information exchange – MEDEUR over mail

MEDEUR used for many types of message: specialist, medication etc.

Healthcare Reform

~ 2000 new health agenda: 'market reform' for healthcare emerges

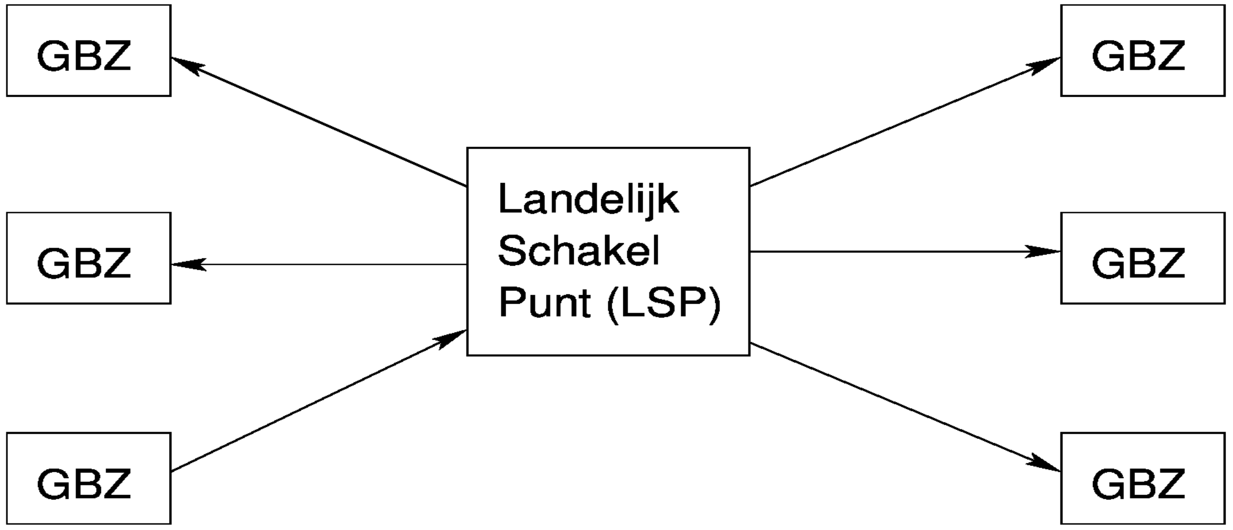
~ 2003, work on switching point commences

~ 2005 pharmacy market 'liberated' – (pharmacist no longer dossier-keeper)

~ 2008: “opt-out” letter for switching point (before law!)

~ 2010/11: law proposal 31466: opt out rejected!

Dutch switching point



Centralized registry *and* access control (RBAC)
UZI smartcards (no patient cards),

Hospital specialisation: LSP ensures access to records when patient moves (or is directed) to another hospital. The argument for *pull* at its core.

Advantages touted

- Always up-to-date record access
- Ease of use
- Emergencies
- Logging available to patients
- Avoid telling same (patient) story twice
- Patients would be able to view own records (still does not work)

Risks perceived

- Risks of attack: (breach of switching point core) and/or at the endpoints
- Decrease of autonomy (Gps)
- Snooping, feature creep: future access by …?
- ***Motion after senate rejected law:***
  - - Stop gov't involvement
  - - Strengthen regional systems (security)

Do not underestimate…

- Convenant between nearly all health and patient organizations and ICT vendors
- Payed by health insurers (~25MEuro/yr)
- Doctors (must) ask patient consent, %..
- OZIS “phased out”

2014: court case GPs (VPH, ~10%) Medical secrecy at its core:

- central vs discretionary control
- overly broad (general?) consent

Claims rejected, now w/supreme court

Government has no formal role, but...

- law proposal 33509: patient rights for health exchange (in senate now)
  - “specified consent”
  - consent can be **shared and 'observed'** through health exchange system

- effectively could be large “green button”

Amsterdam Initiative

LHV
Huisartsenkring
Amsterdam/Almere

GP Huisartsen Kring Amsterdam (HKA)

- critical since ~2008

- voted against restart in LHV, 2013

- wanted “small” (specific) opt-in variant

+ asked UvA to think about regional alternative (now in pilot phase)

Ideas for alternative

Decentralized control: healthcare professional decides (with patient),

only share data when needed (mimic push communication in terms of control)

No data (transport) visible “outside” practice

“Small” specific consent, if needed

GP at the center

GP post considered most important application for now

Considerations

Need to solve problem for GPs now..

..as 'privacy by design' as possible

But needs to also cover more cases towards the future, cover 'LSP cases' (e.g., pharmacists, emergencies) to make impact – and help healthcare

Whitebox

Small computer (ARM-based board, running Linux) in GP practice

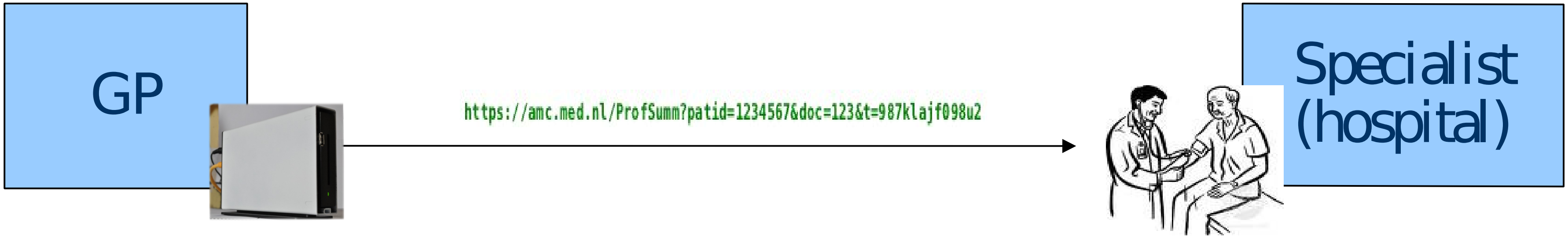
Whitebox generates URL + registers policy

per document / patient

- issue URL to GP post automatically (default)

- have user (or GP system) disseminate URL manually, e.g., to authorize Pharmacist or hospital

Alternative: decentral control



GP

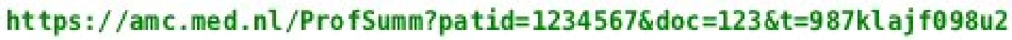
https://amc.med.nl/ProfSumm?patid=1234567&doc=123&t=987klajf098u2

Specialist (hospital)

- Capability encoded as URL: locator and authorization token at once
- Identity based capability: coupled to key (healthcare smartcard , pre- or late binding)

- Policy at the source enforces access rights
- Whitebox coupled to GP system internally

URL / capability



https://amc.med.nl/ProfSumm?patid=1234567&doc=123&t=987klajf098u2

URL encodes access rights:

https://amc.med.nl/.../RO=y/

Readonly, read-write/append

https://amc.med.nl/.../copyable=y/

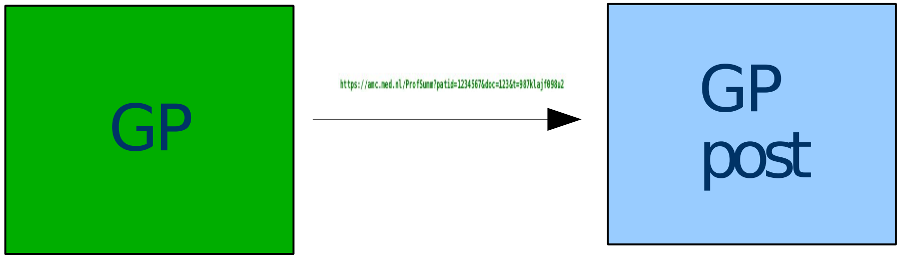
Copyable is right to autorize (make copy of URL for) other healthcare professional

Usage (example) 1

GP

GP post

Usage (example) 1



GP

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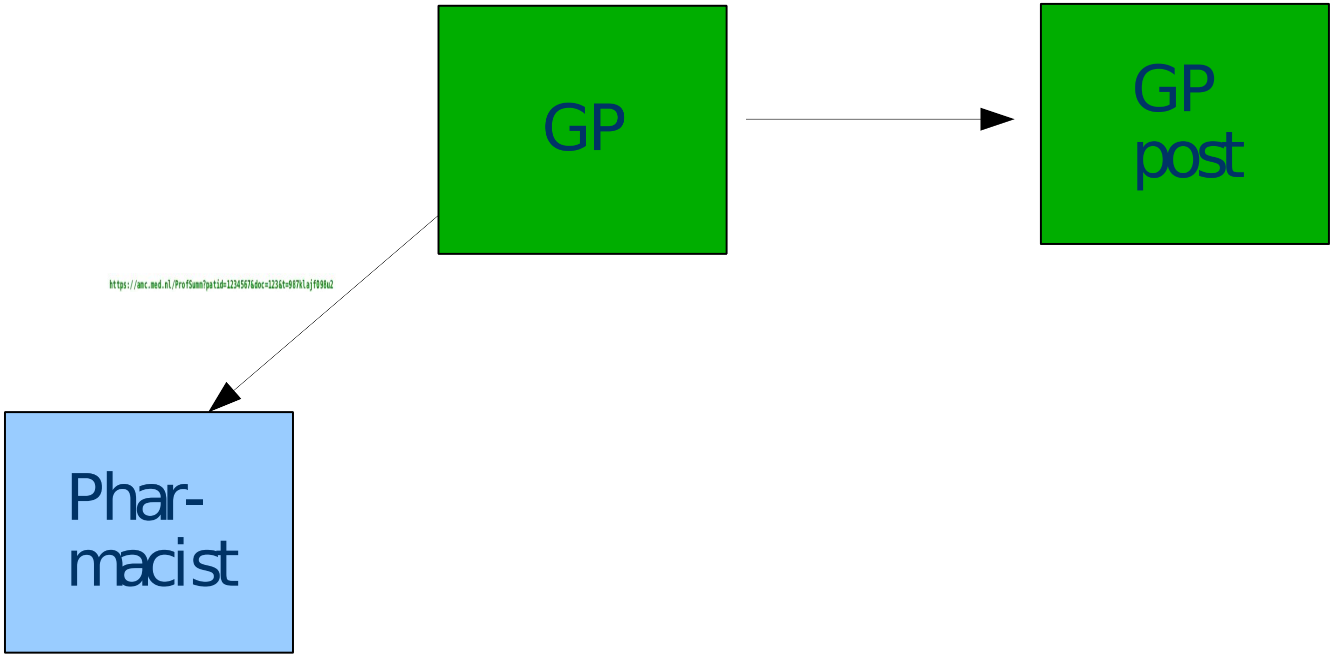
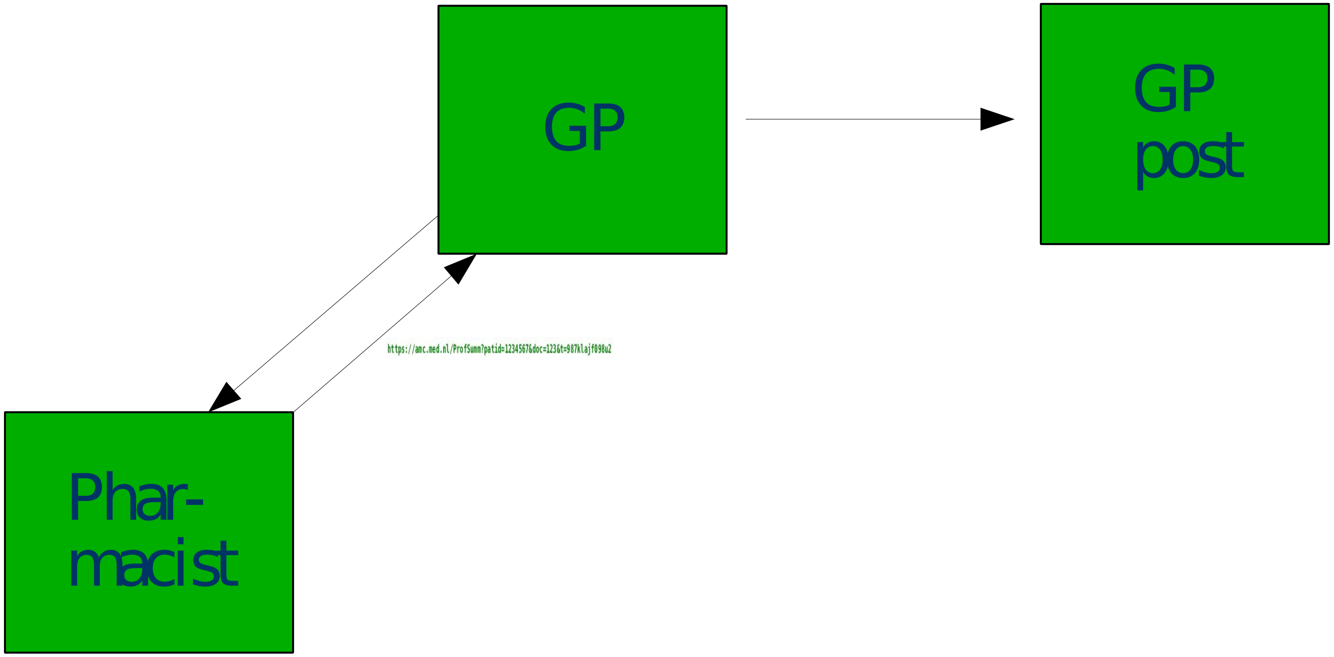
GP post

Usage (example) 2



GP
GP post
https://amc.med.nl/ProfSumm?patid=1234567&doc=123&t=987klajf098u2
Phar-macist

Usage (example) 2



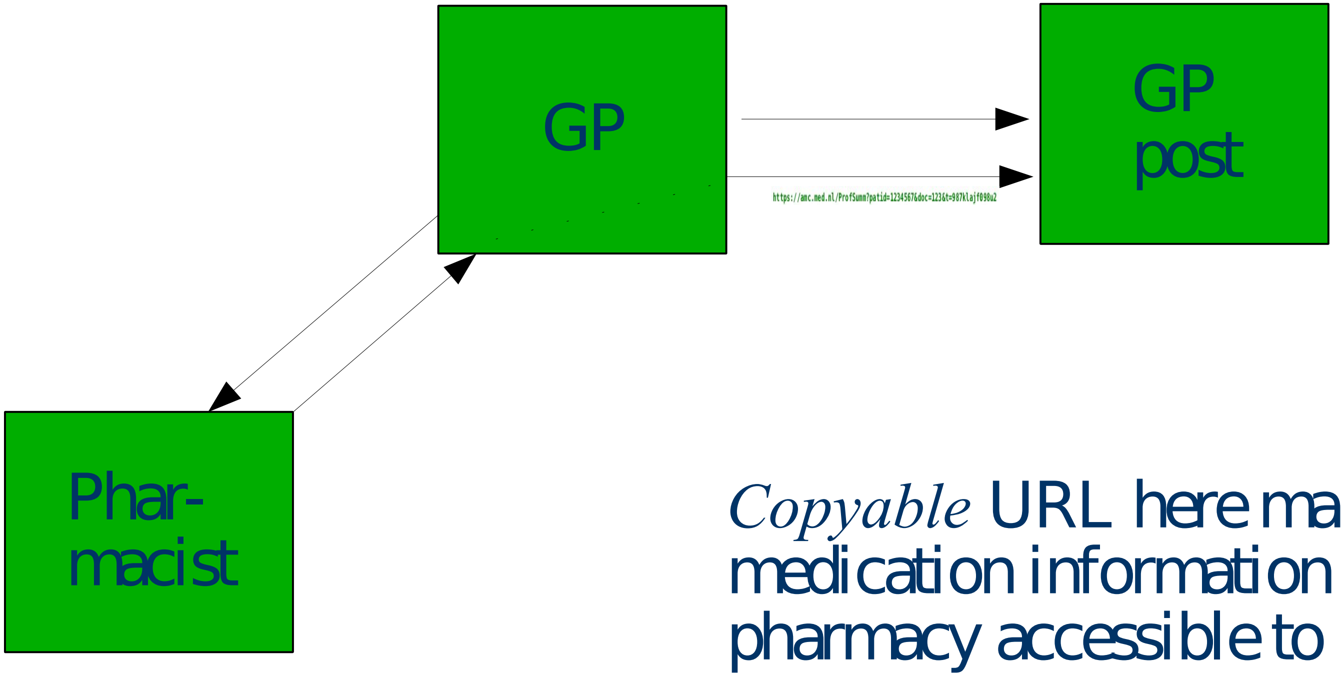
GP

GP post

Phar-
macist

https://amc.med.nl/ProfSumm?patid=1234567&doc=123&t=987klajf098u2

Usage (example) 2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Phar-
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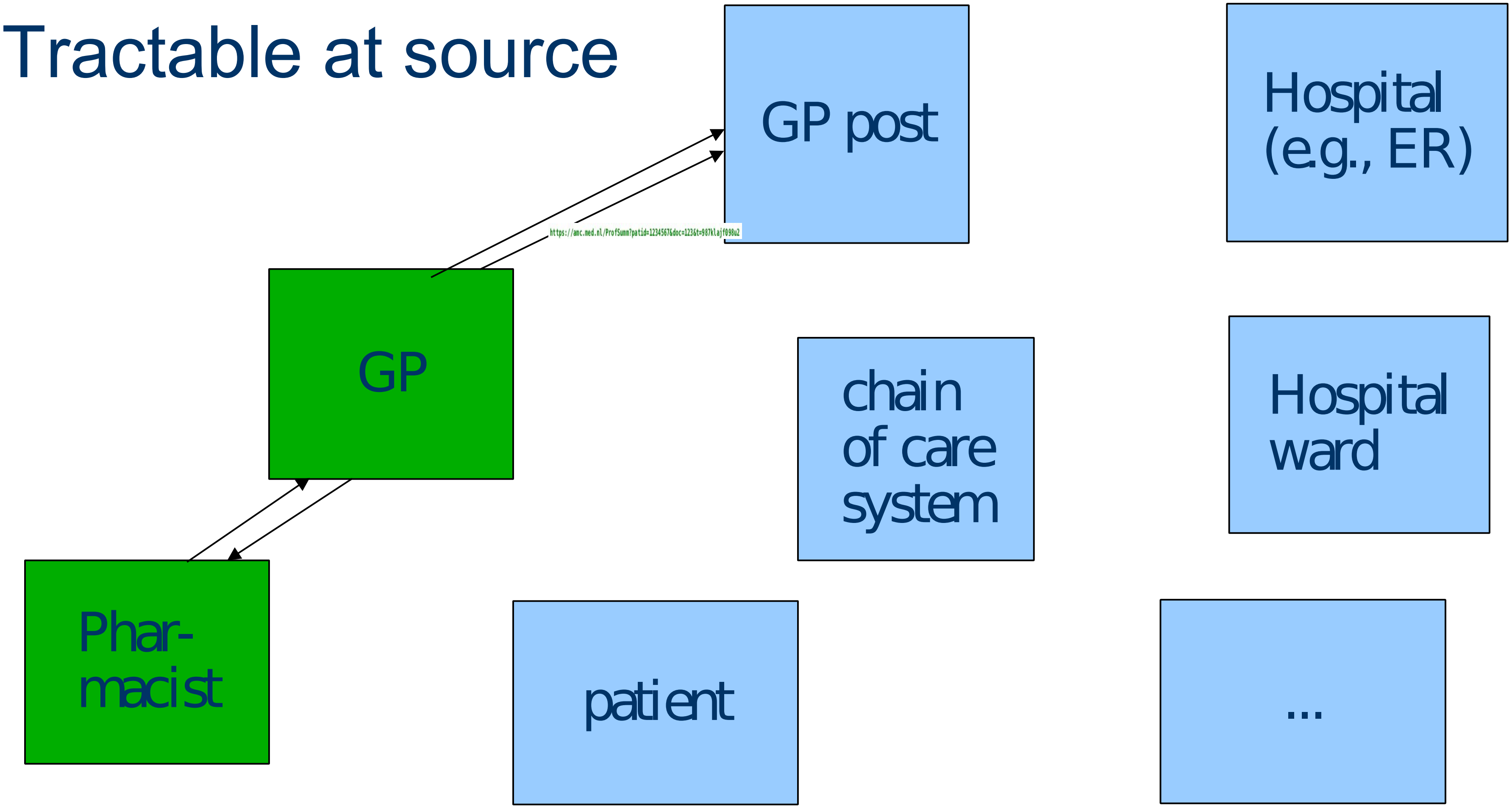
Copyable URL here makes medication information from pharmacy accessible to GP post, *besides* GP summary

Chain authorization

- Always someone (current capability holder) responsible for authorization
- Tractable at source



GP post

Hospital (e.g., ER)

https://amc.med.nl/ProfSumm?patid=1234567&doc=123&t=987klajf098u2

GP

chain of care system

Hospital ward

Phar-macist

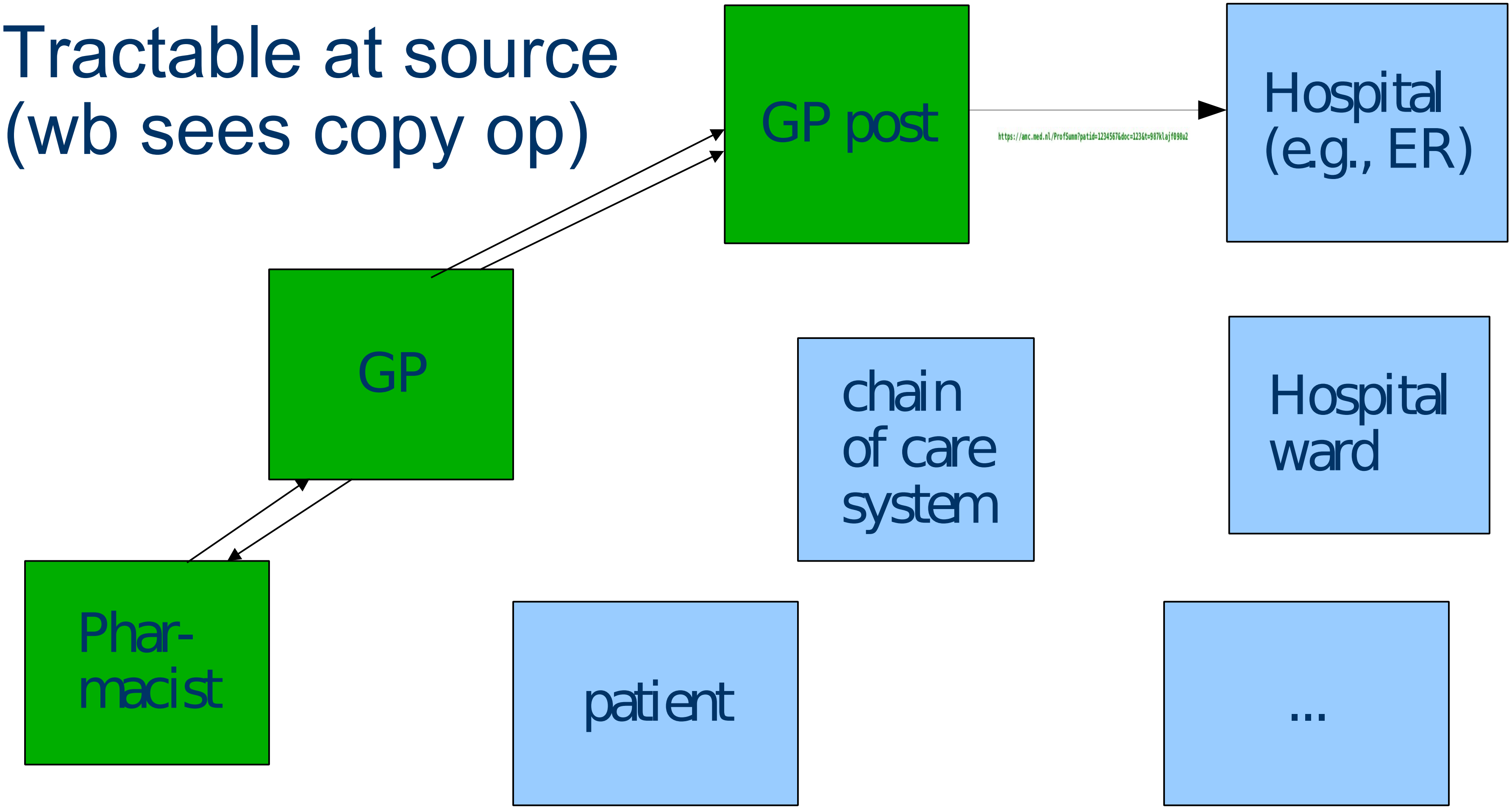
patient

...

Chain authorization

Always someone (current capability holder) responsible for authorization

Tractable at source (wb sees copy op)



GP post

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Hospital (e.g., ER)

GP

chain of care system

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patient

...

Chain authorization

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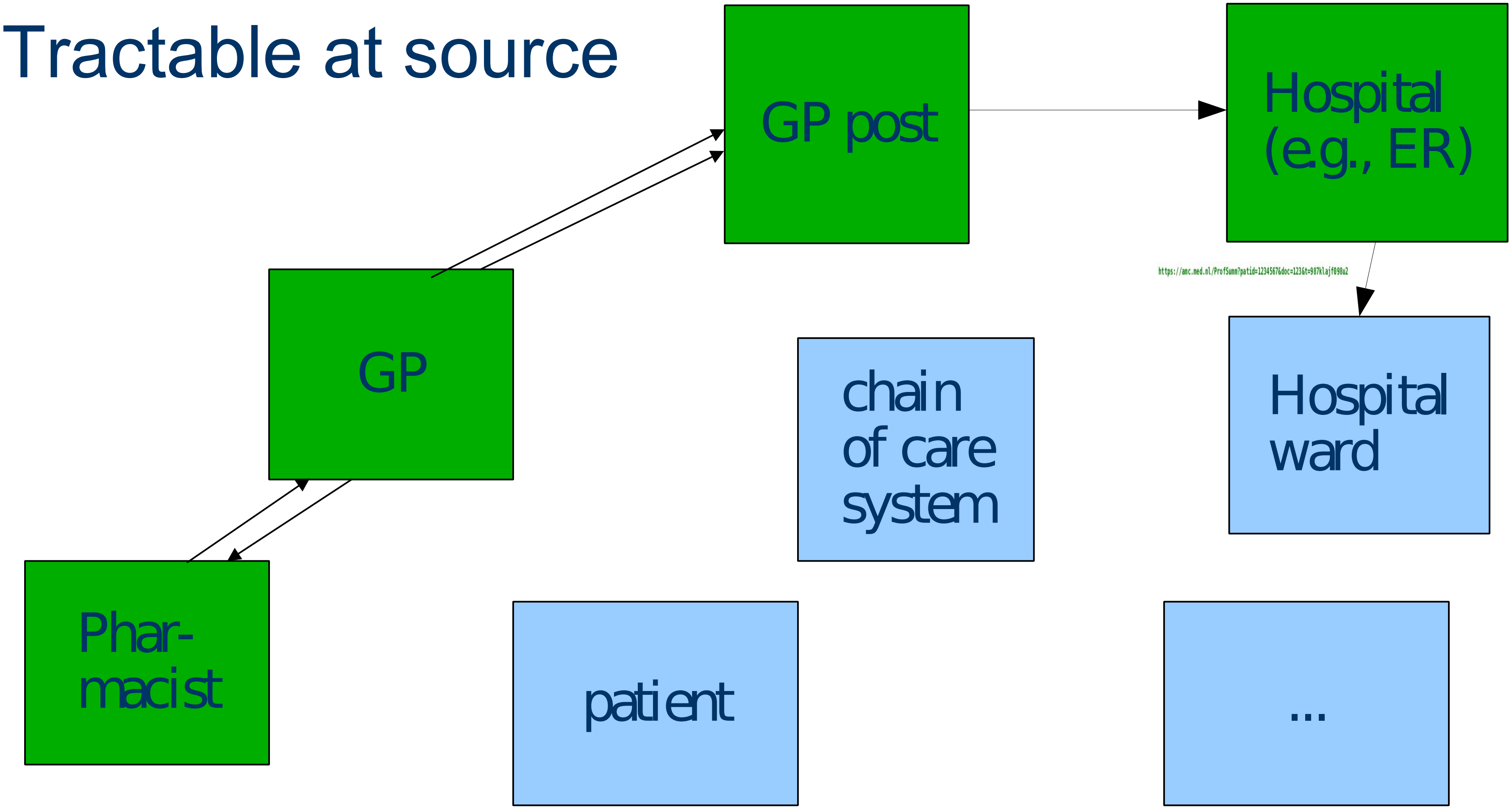

GP post

Hospital (e.g., ER)

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GP

chain of care system

Hospital ward

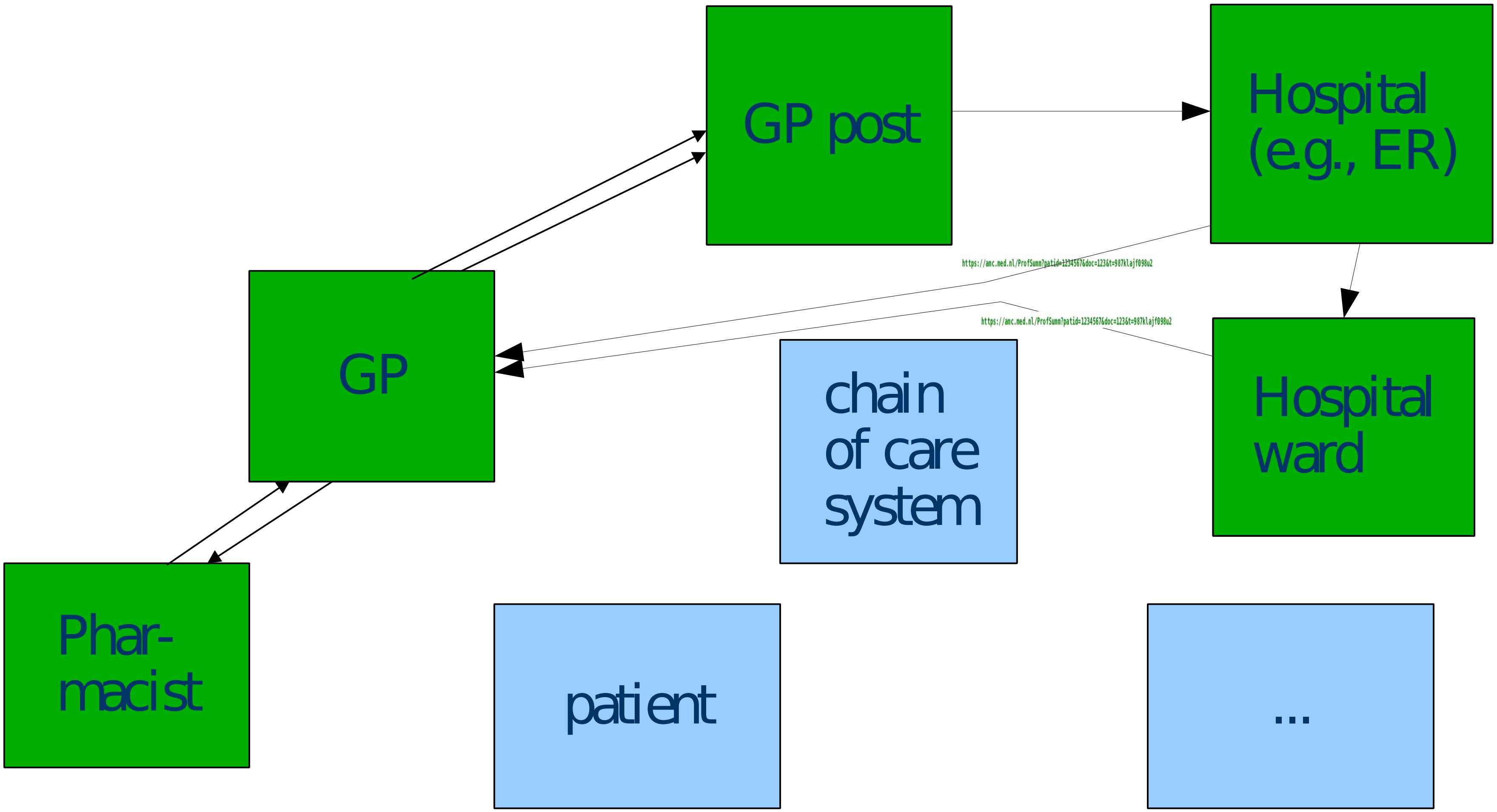
Phar-macist

patient

...

Chain authorization

Push “backlinks” back to source (i.e., GP)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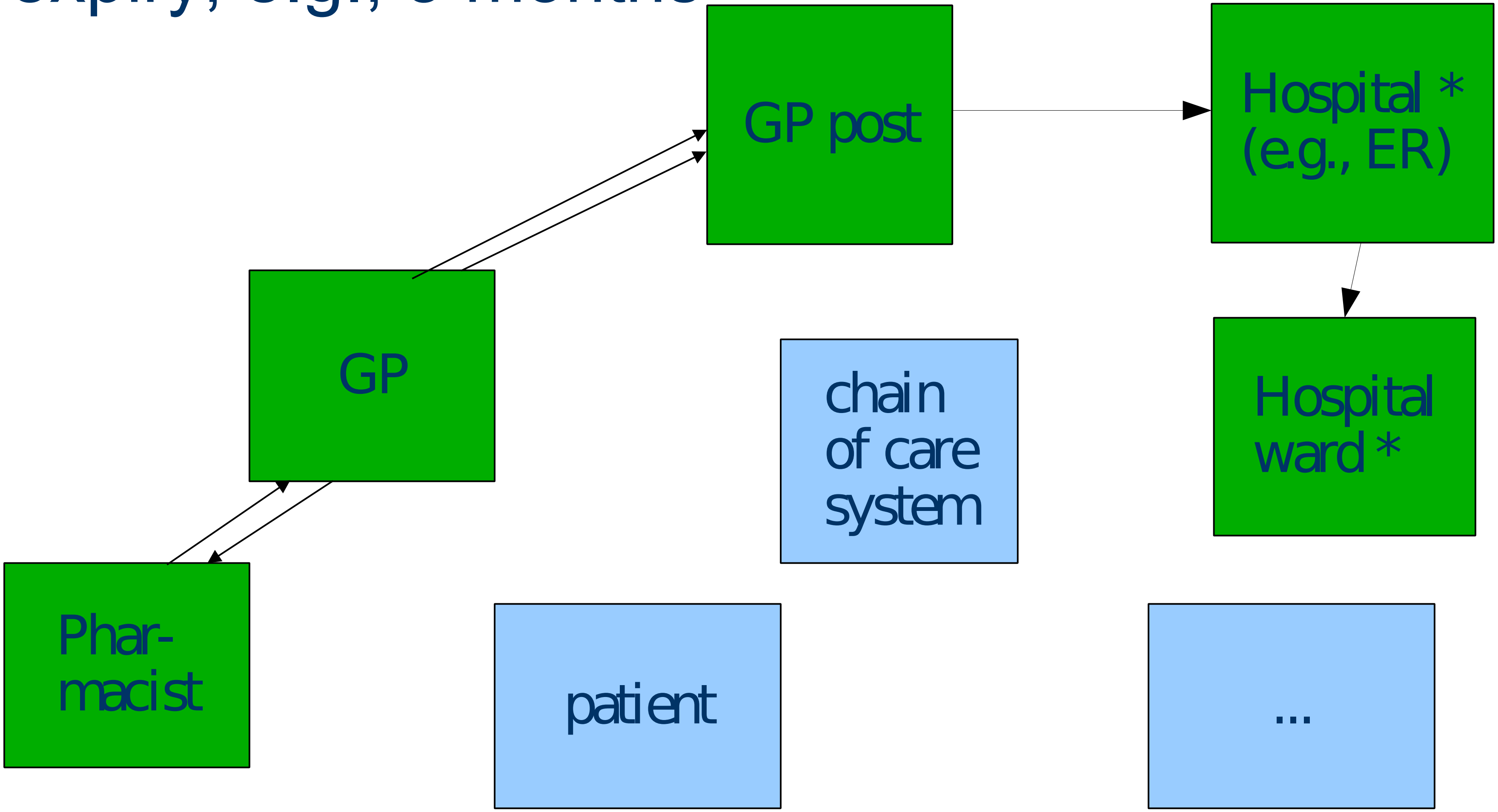
GP
chain of care system
Hospital ward
Phar-macist
patient
...

Network of access ..

… around the patient

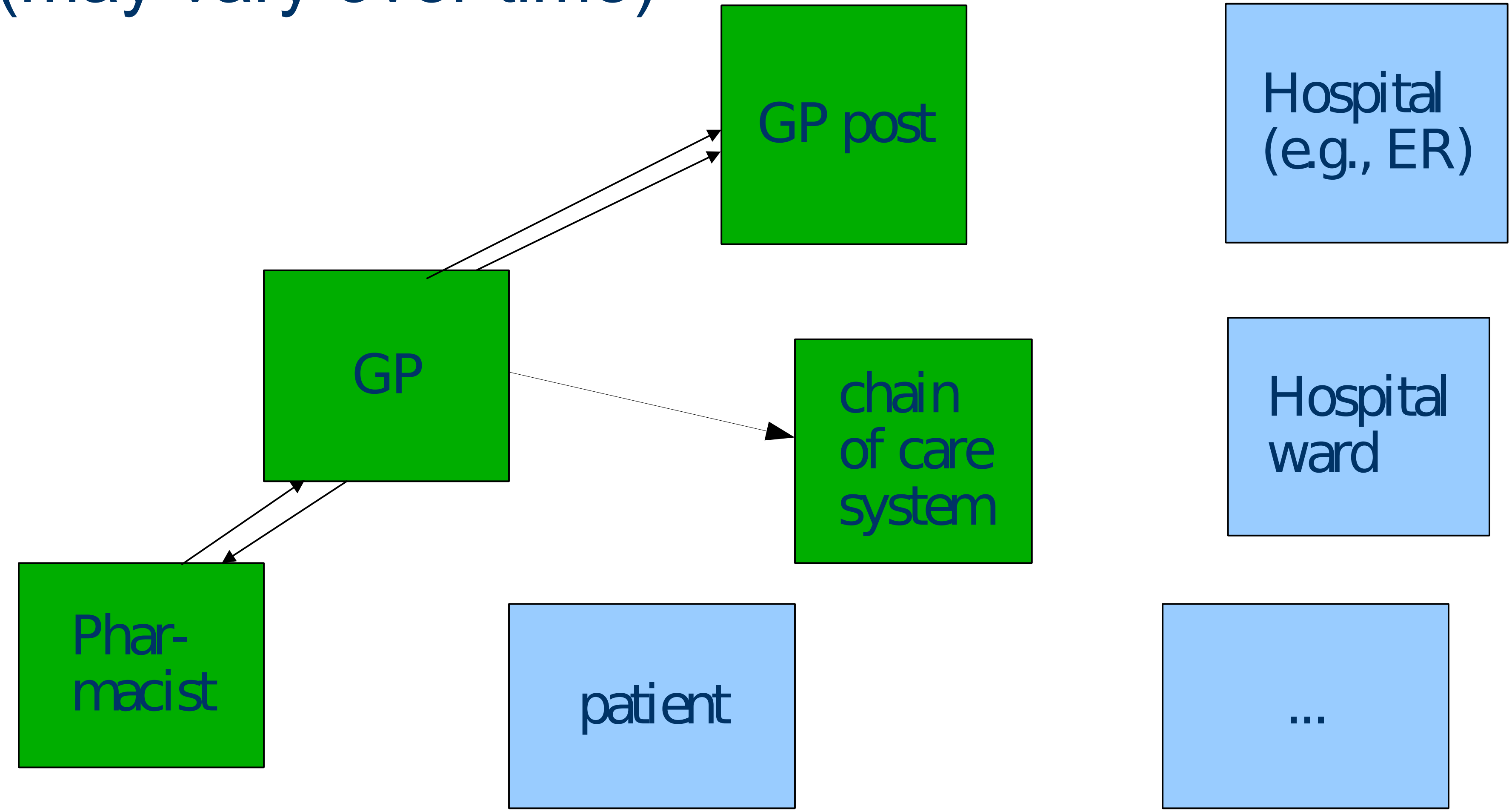
*expiry, e.g., 3 months



Network of access ..

… around the patient

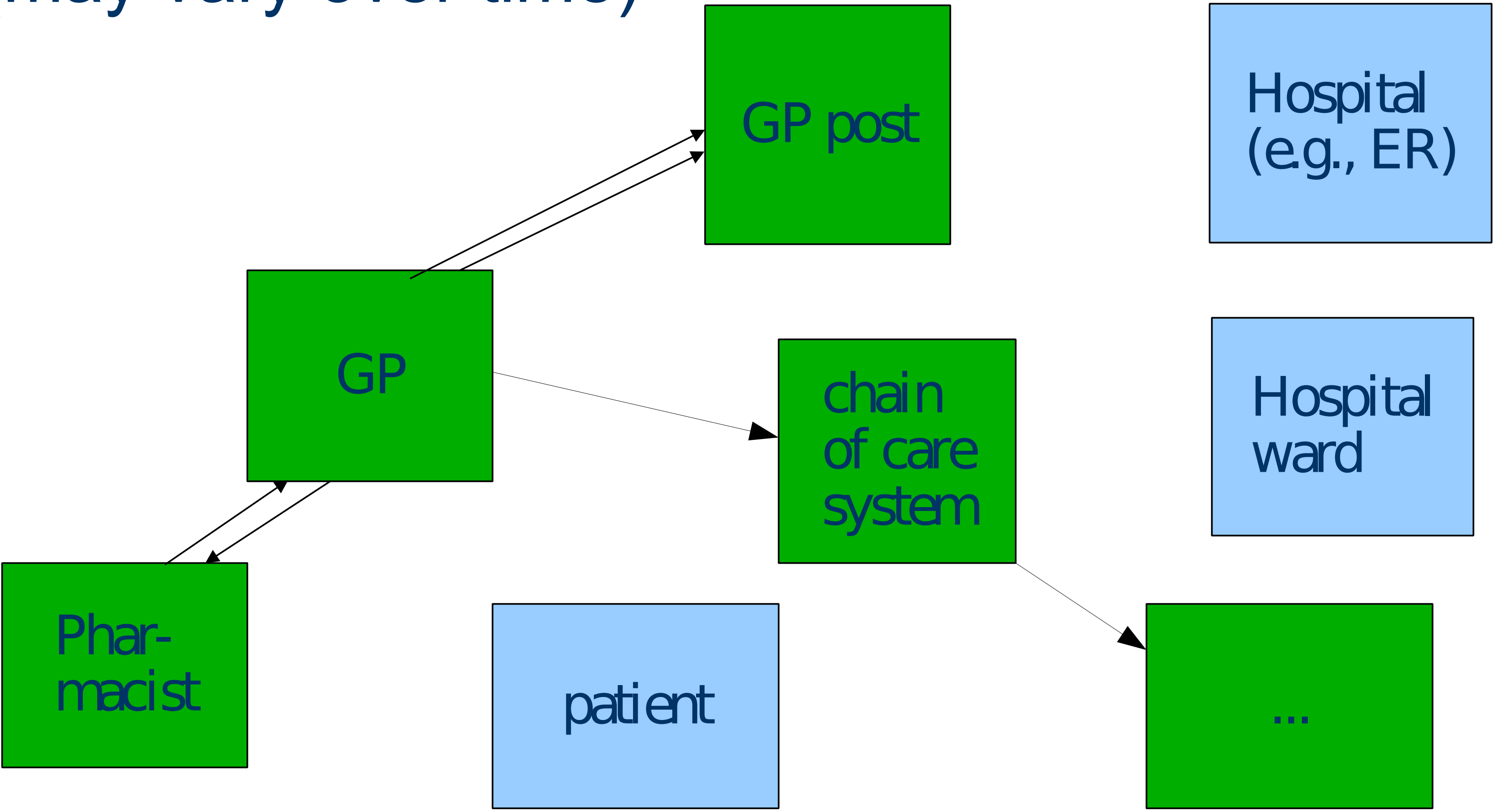
(may vary over time)



Network of access ..

… around the patient

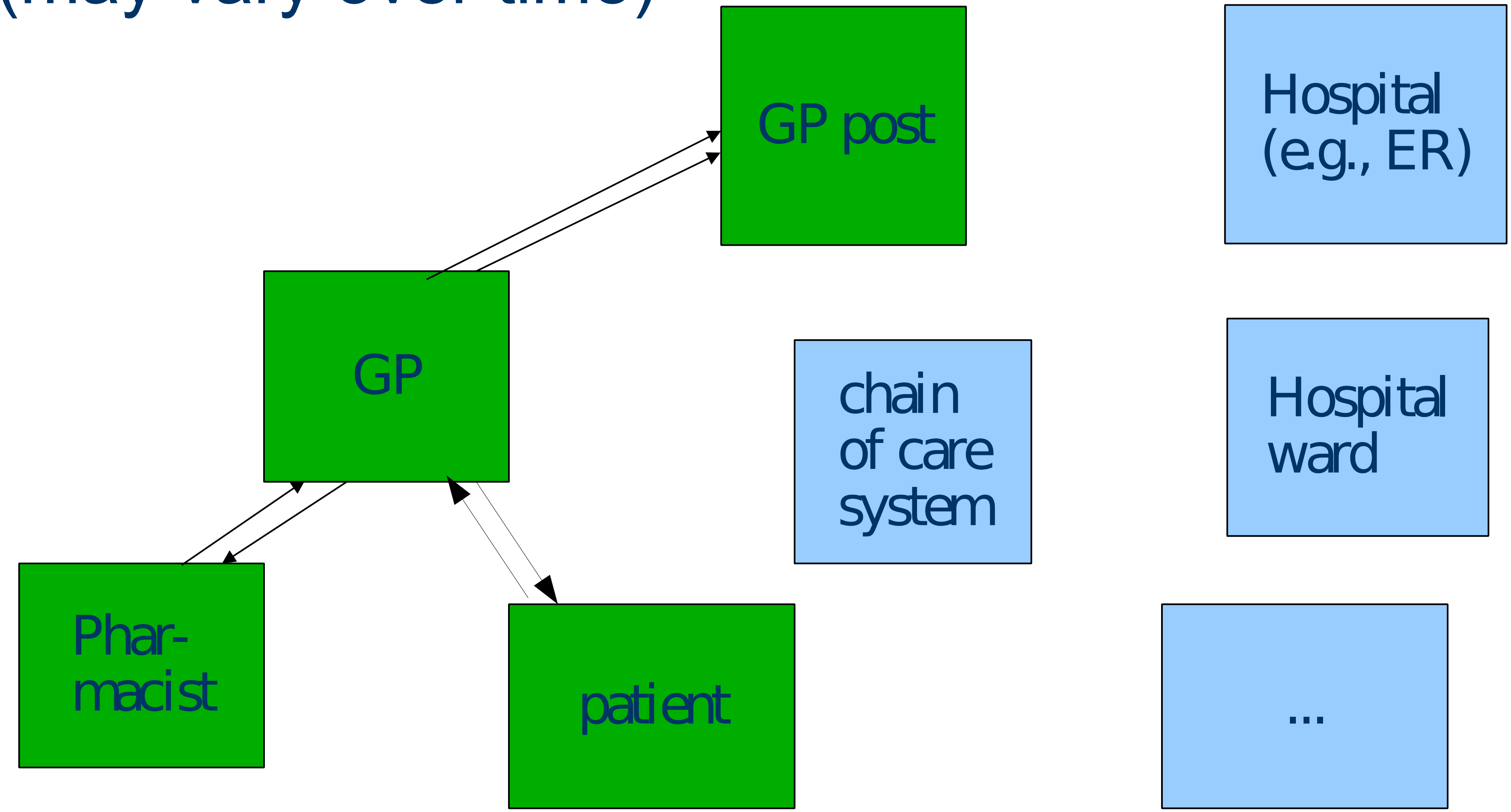
(may vary over time)



Network of access ..

… around the patient

(may vary over time)



Advantages

Scales around the patient: not tied to region or country

Access (and access related risk) does not scale “with the system's scale”

Embeds **humans as responsible actors:** active decisions to *push* authorization

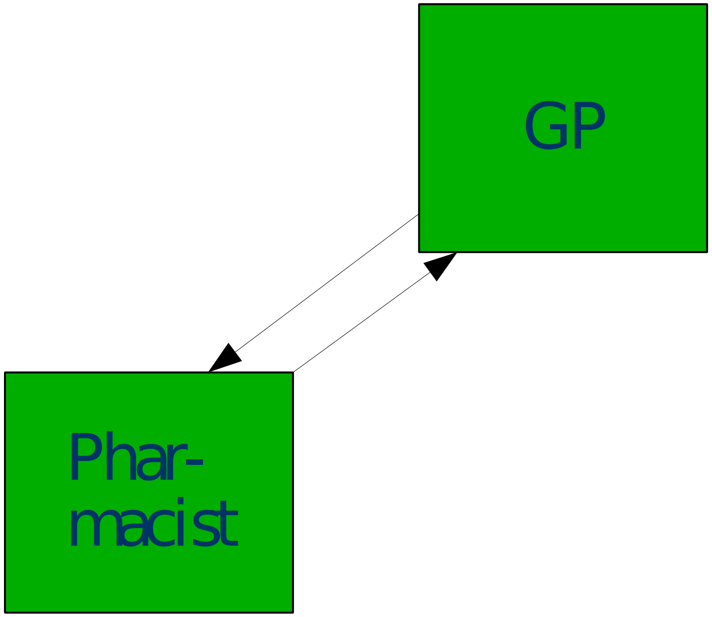
GP / health professional at the center

Follows healthcare workflow by default

Pull access, but controllable like push, and without disadvantages of centralization

Extra scenario (pull motivation)

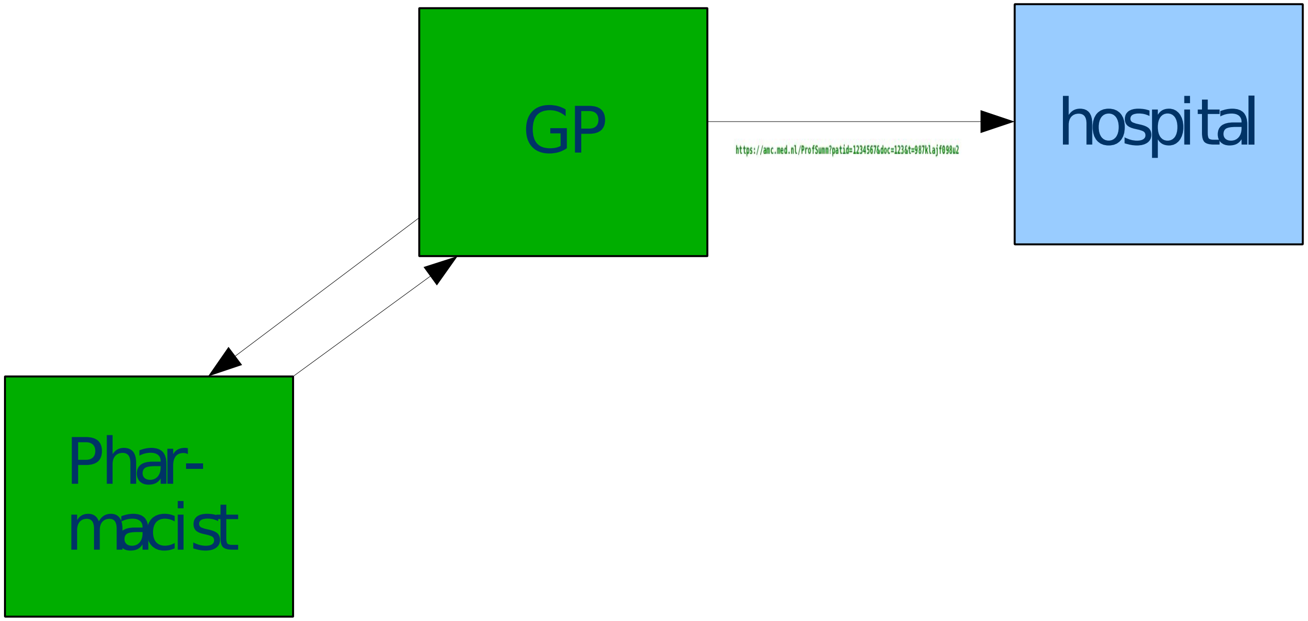
Medication reconcilliation (note difference with push)



Starting point: GP and pharmacist know patient's med.record;

Extra scenario (pull motivation)

Medication reconcilliation (note difference with push)


GP
hospital
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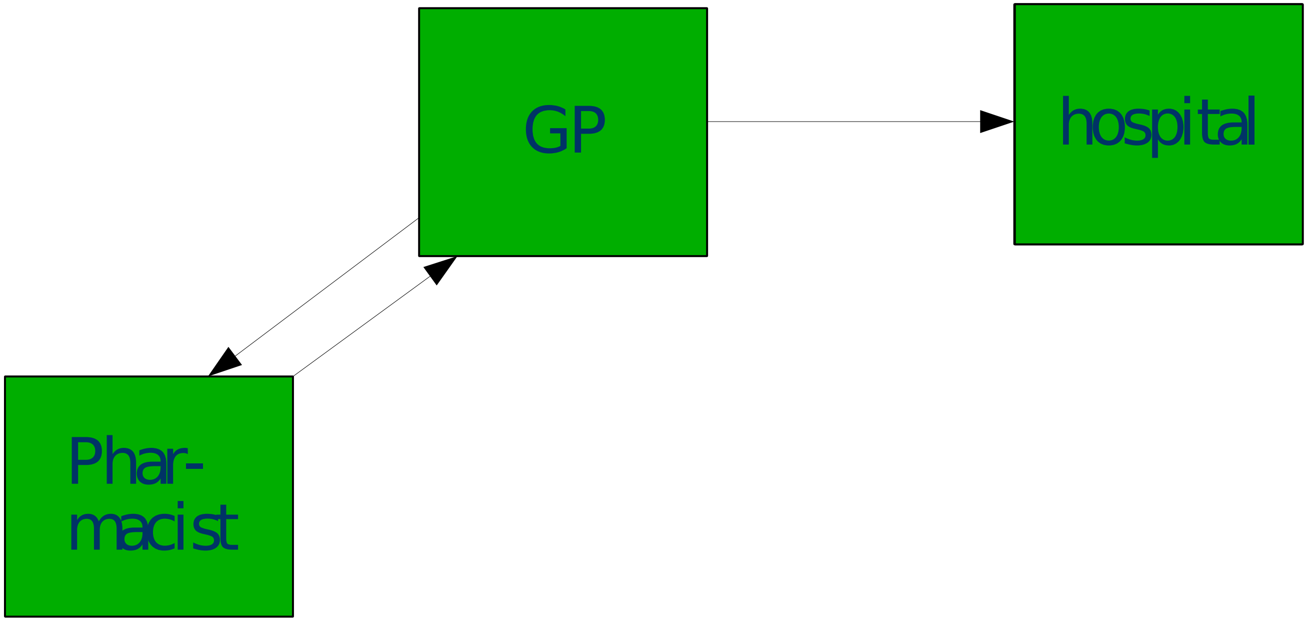
macist

Patient referred to hospital; time=0. Referral letter sent

Extra scenario (pull motivation)

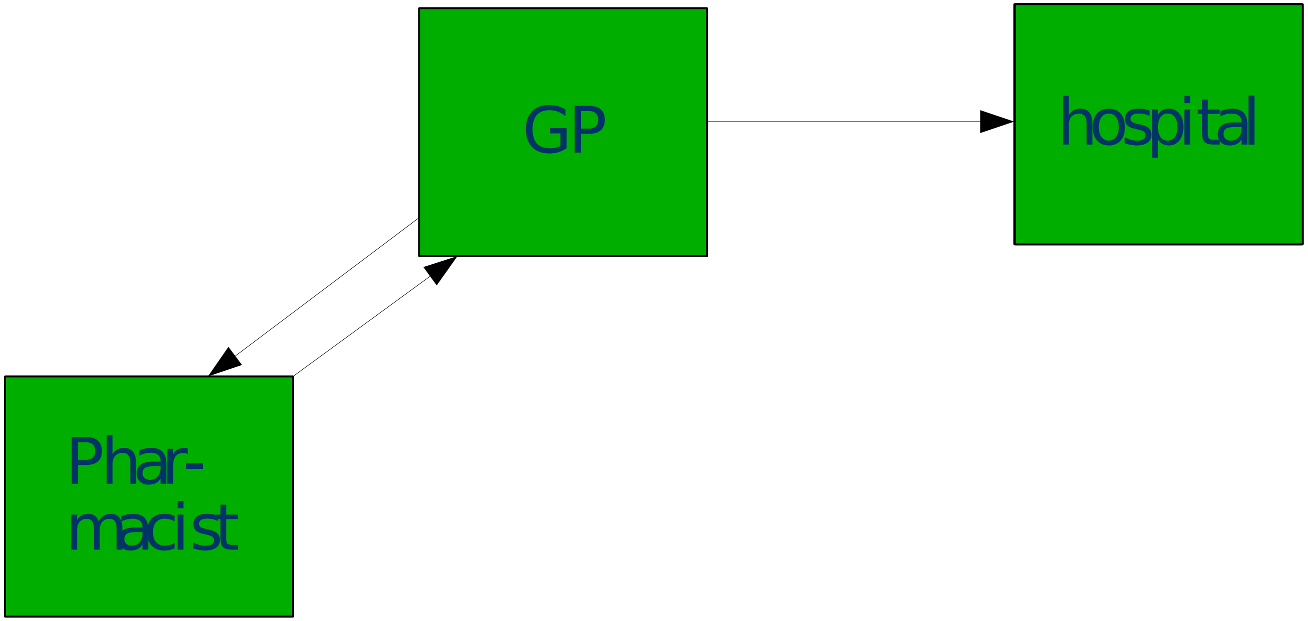
Medication reconcilliation (note difference with push)



Hospital admission: +6 weeks.

Extra scenario (pull motivation)

Medication reconcilliation (note difference with push)



GP

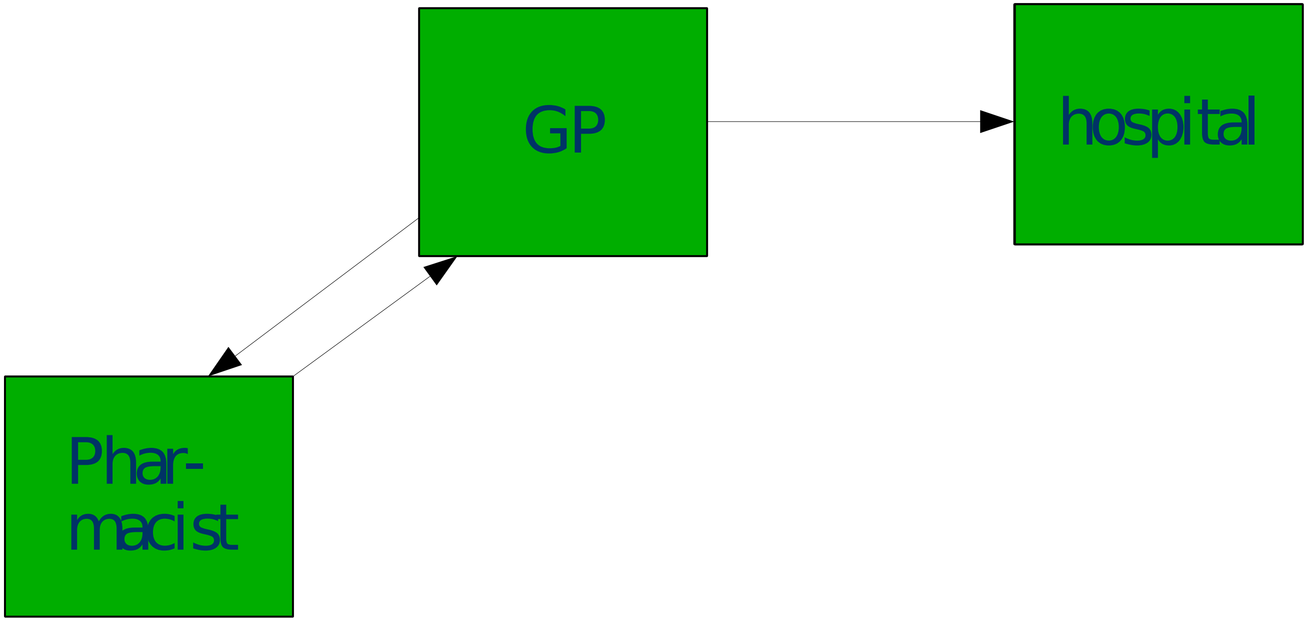
hospital

Phar-
macist

Hospital admission -2 weeks pre-surgery screening at hospital;
Hospital admission -3 weeks: request medication overview patient

Extra scenario (pull motivation)

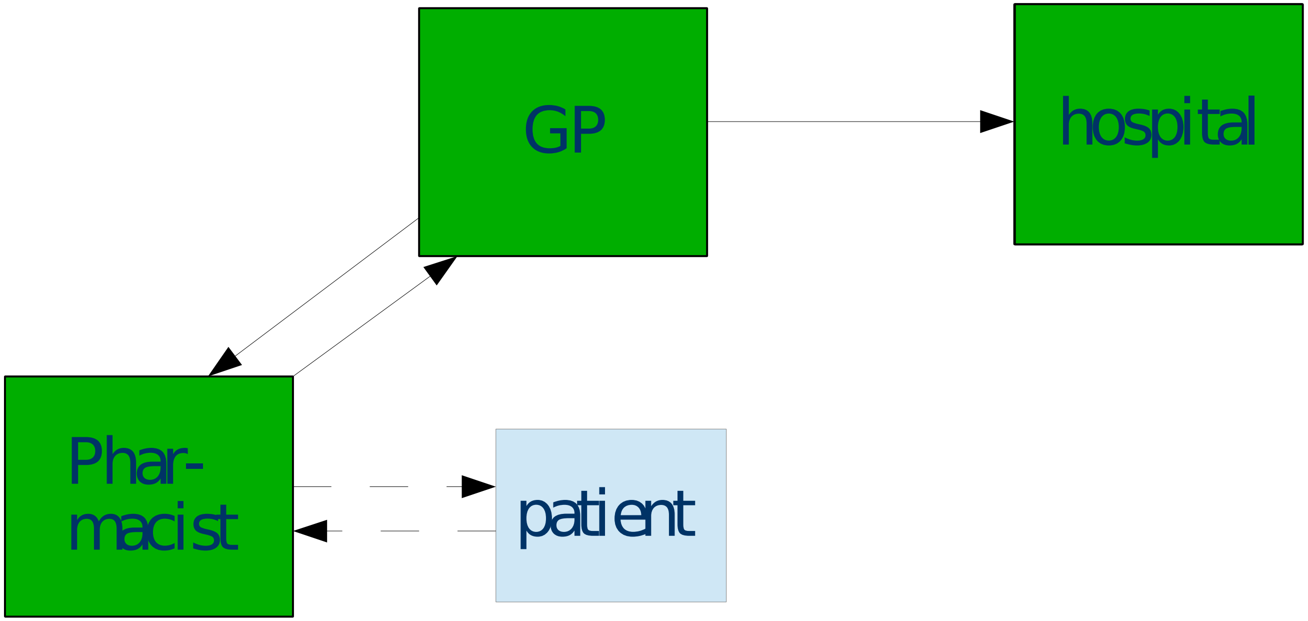
Medication reconcilliation (note difference with push)



Patient at pharmacist or GP: checkup + medication review

Extra scenario (pull motivation)

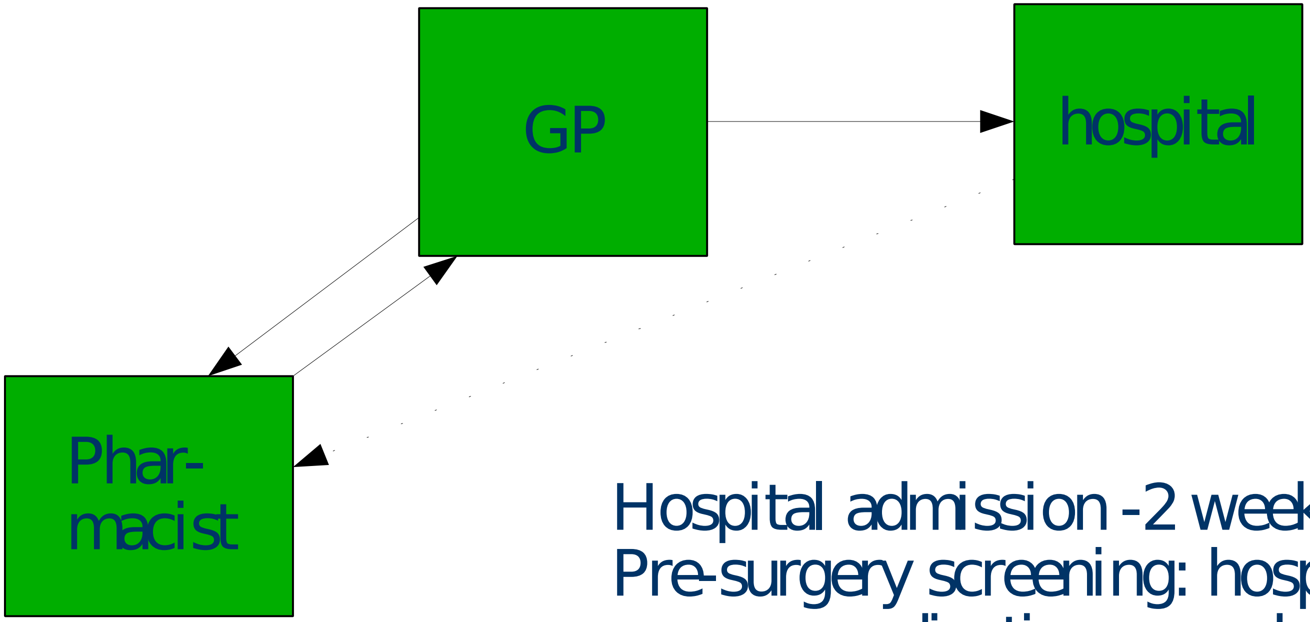
Medication reconcilliation (note difference with push)



(Patient checkup + medication review *could* be online)

Extra scenario (pull motivation)

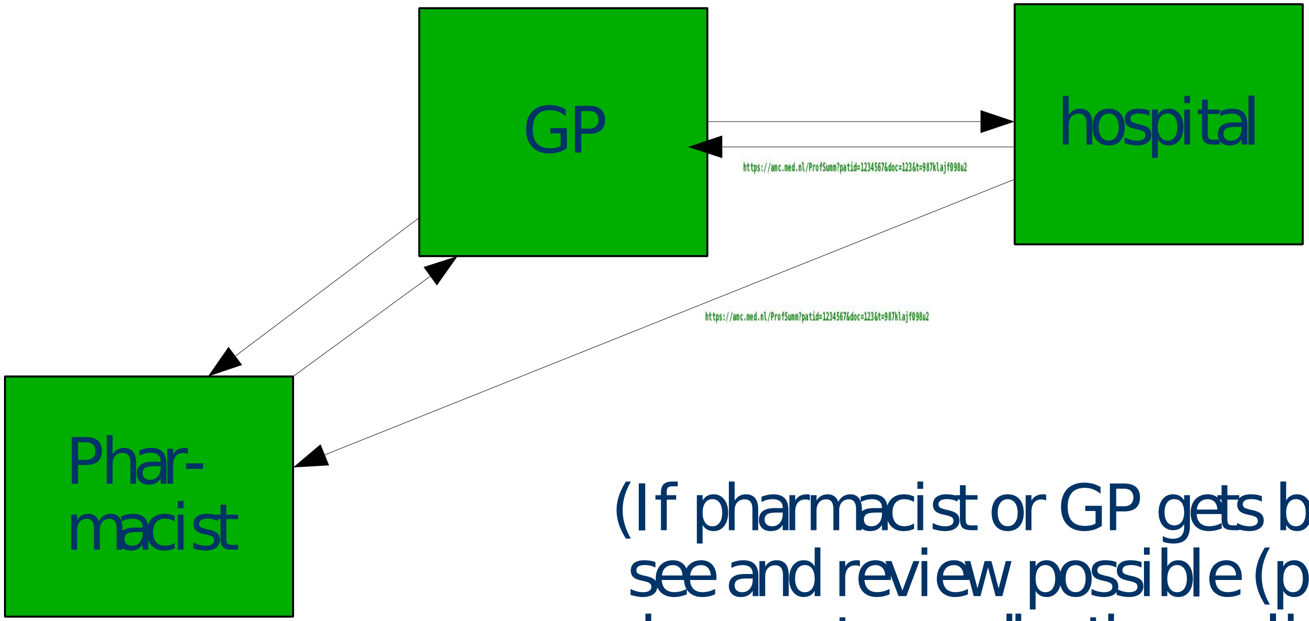
Medication reconcilliation (note difference with push)



Hospital admission -2 weeks:
Pre-surgery screening: hospital retrieves *current* medication record

Extra scenario (pull motivation)

Medication reconcilliation (note difference with push)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Phar-
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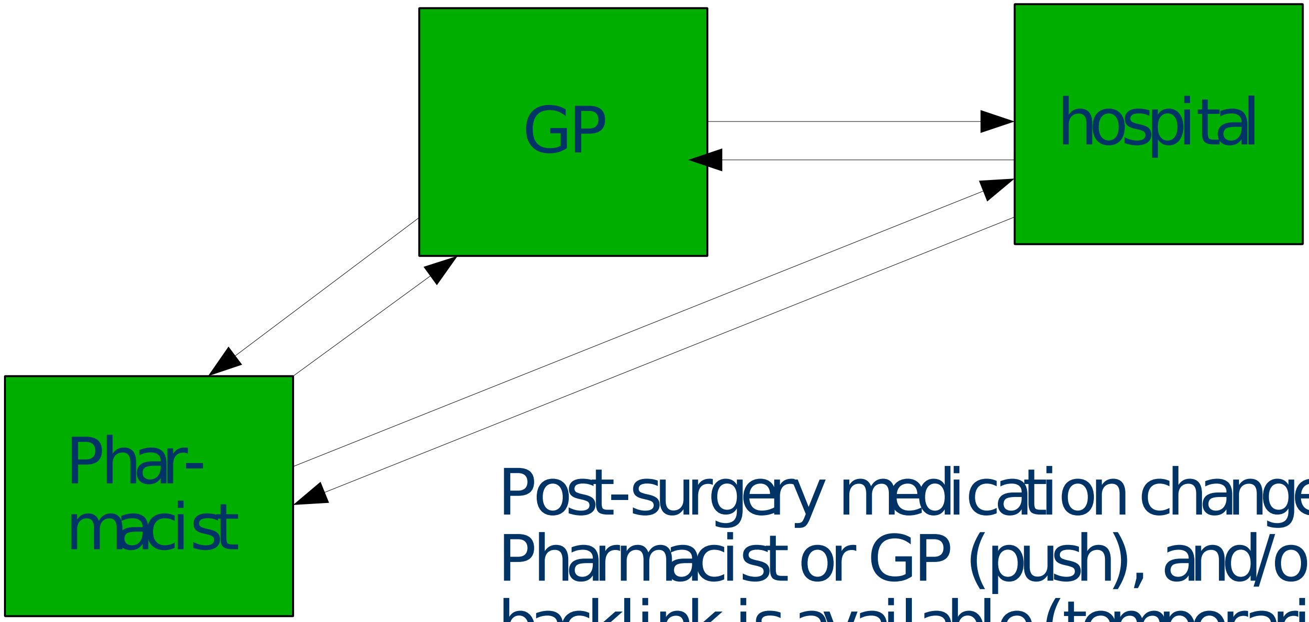
(If pharmacist or GP gets backlink, can see and review possible (pre)surgery changes to medication policy
2 weeks time to Interact with hospital)

Extra scenario (pull motivation)

Medication reconcilliation (note difference with push)

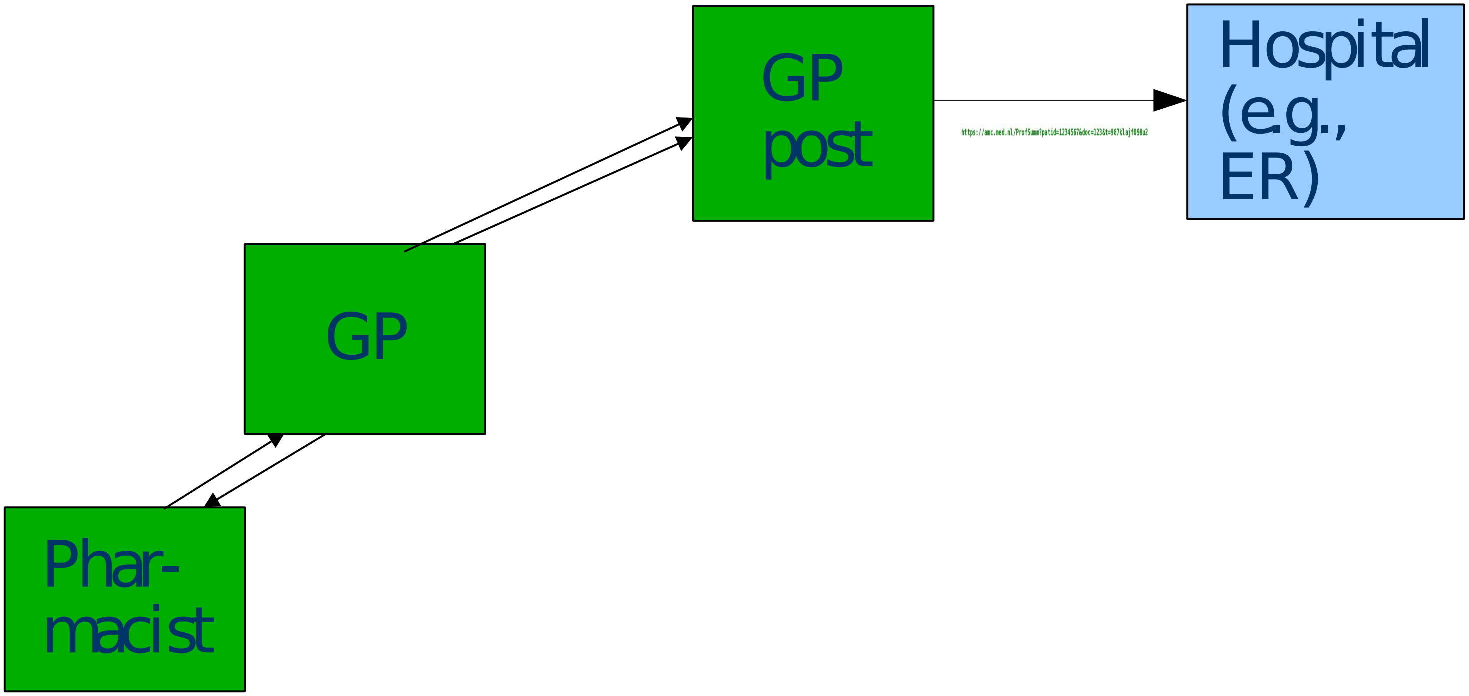


Post-surgery medication changes: send to Pharmacist or GP (push), and/or ensure backlink is available (temporarily)

Extra scenario: emergencies

Patient/GP worried about missing information in emergency?

1) GP-post route


GP post
Hospital (e.g., ER)
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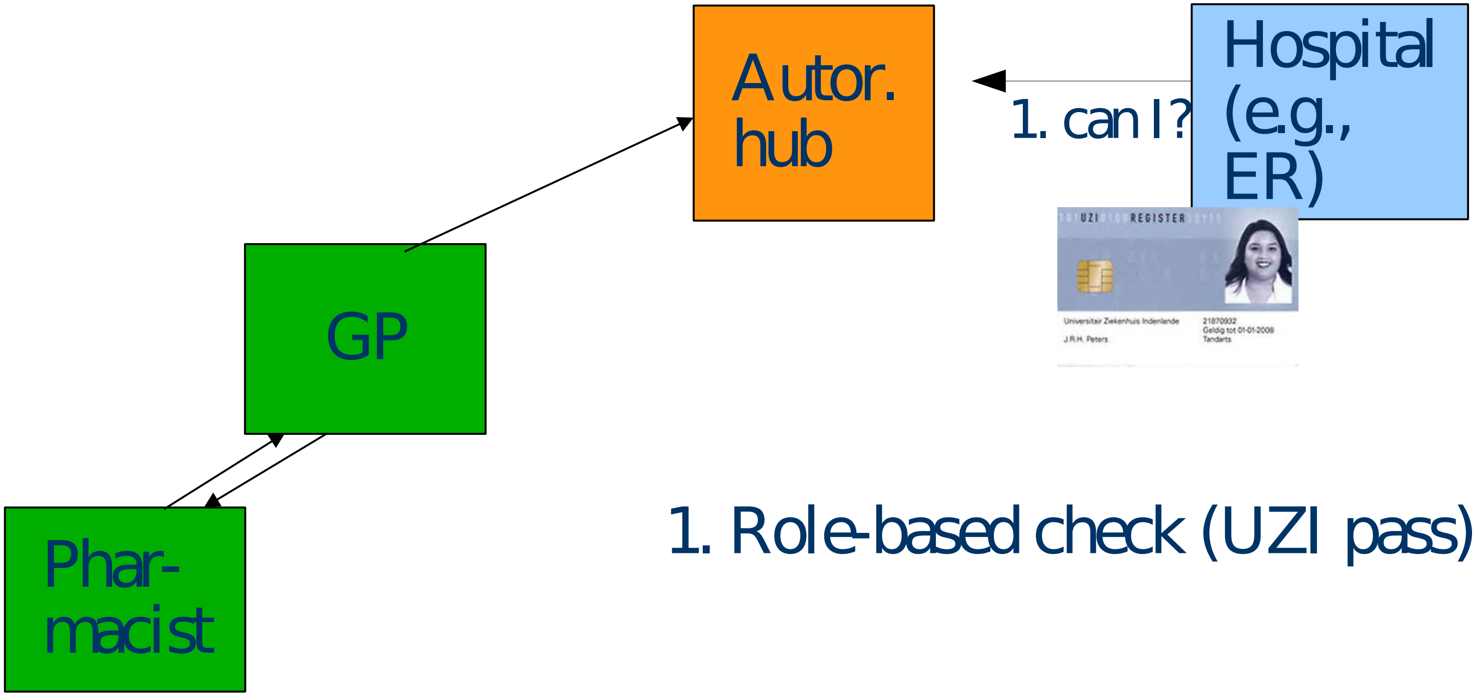
GP
Phar-macist

Extra scenario: emergencies

Patient/GP worried about missing information in emergency?

2) External service = real “pull”

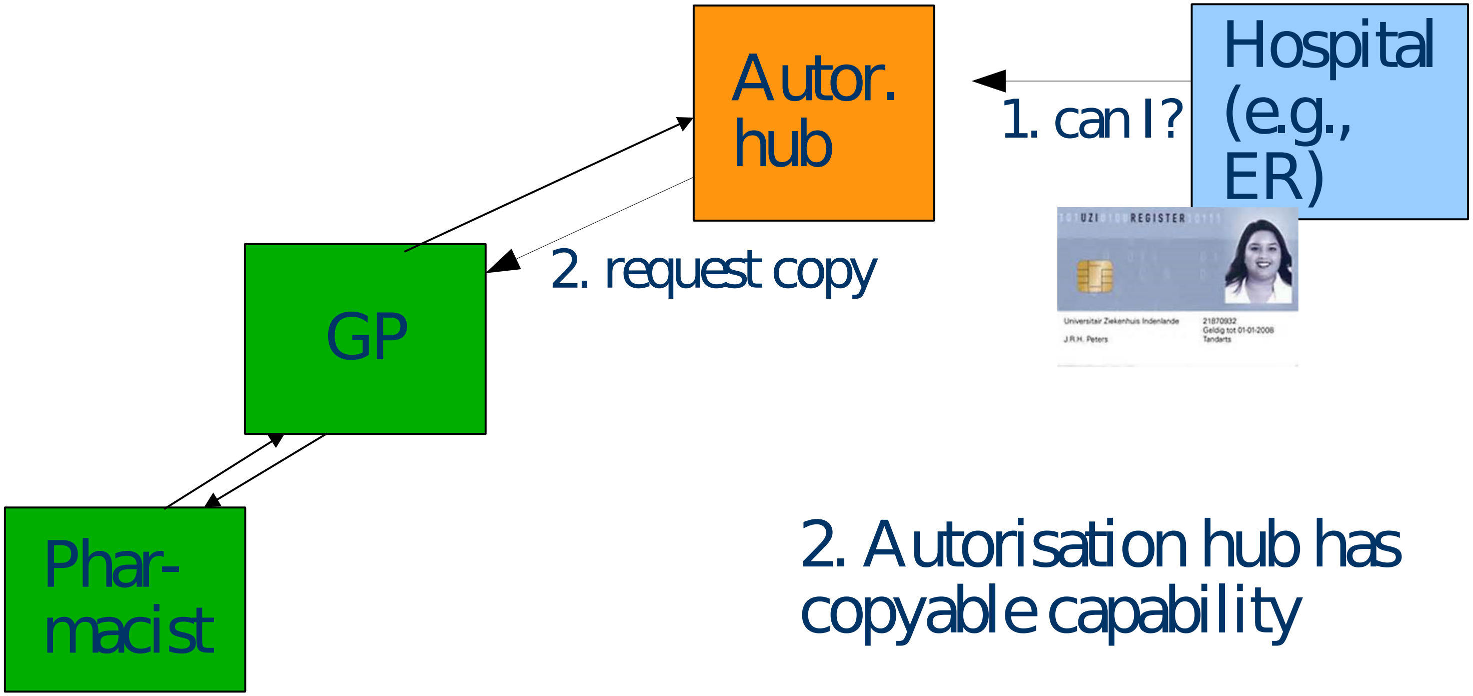


1. Role-based check (UZI pass)

Extra scenario: emergencies

Patient/GP worried about missing information in emergency?

2) External service

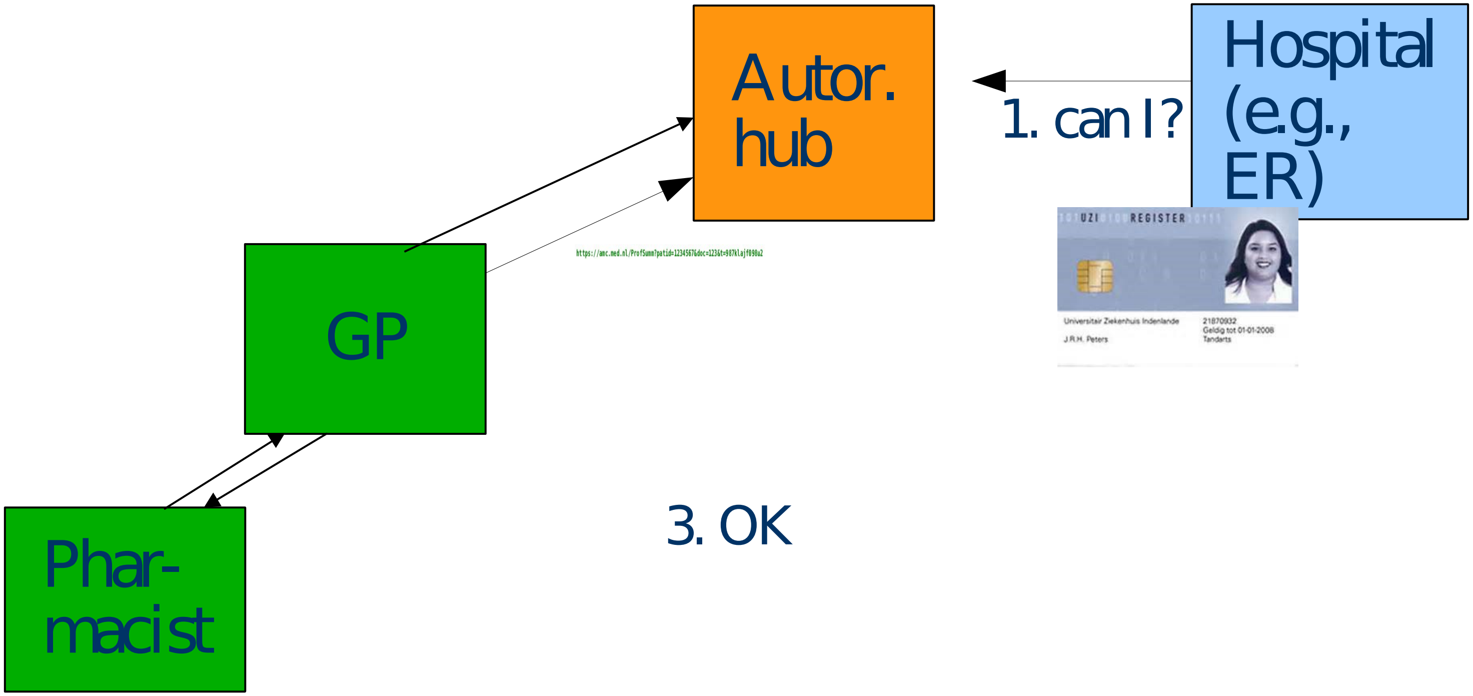


2. Autorisation hub has copyable capability

Extra scenario: emergencies

Patient/GP worried about missing information in emergency?

2) External service



Autor. hub

Hospital (e.g., ER)

1. can I?

https://amc.med.nl/ProfSumm?patid=1234567&doc=123&t=987klajf098u2

GP

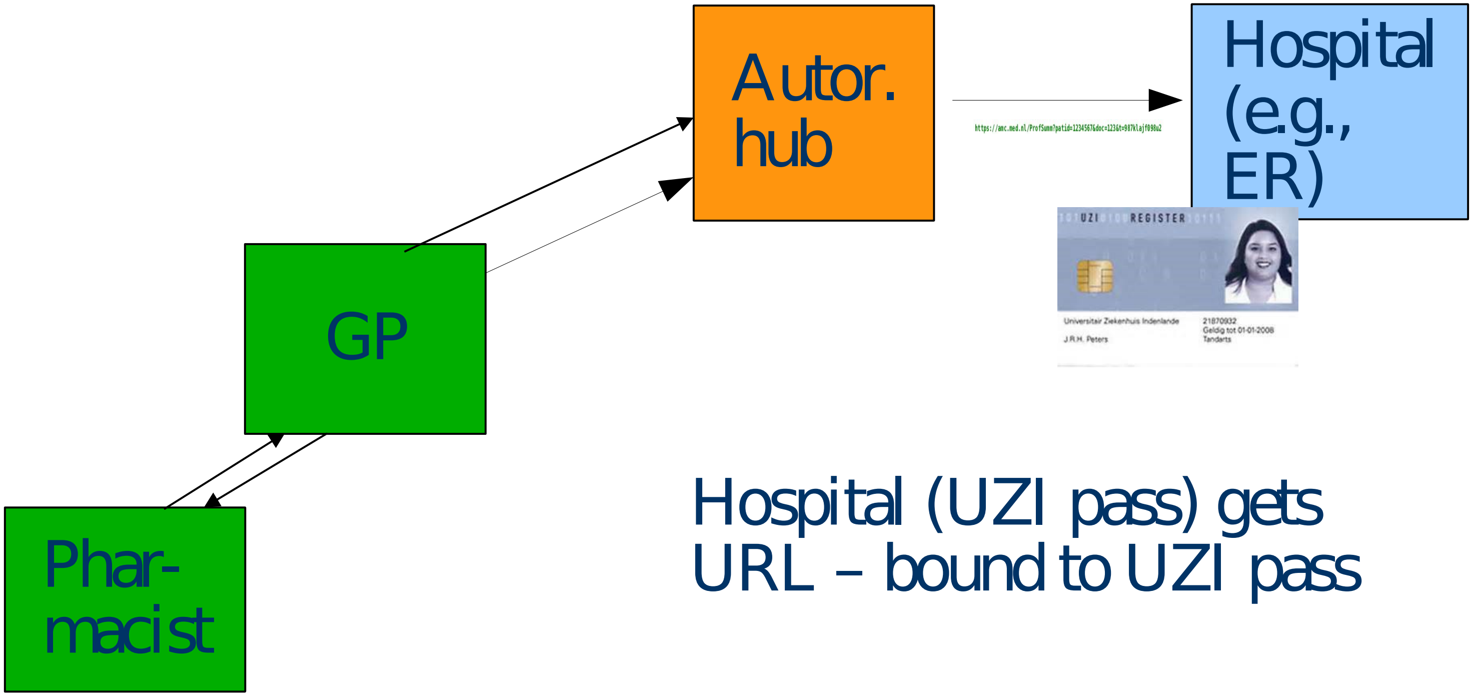
Phar-macist

3. OK

Extra scenario: emergencies

Patient/GP worried about missing information in emergency?

2) External service

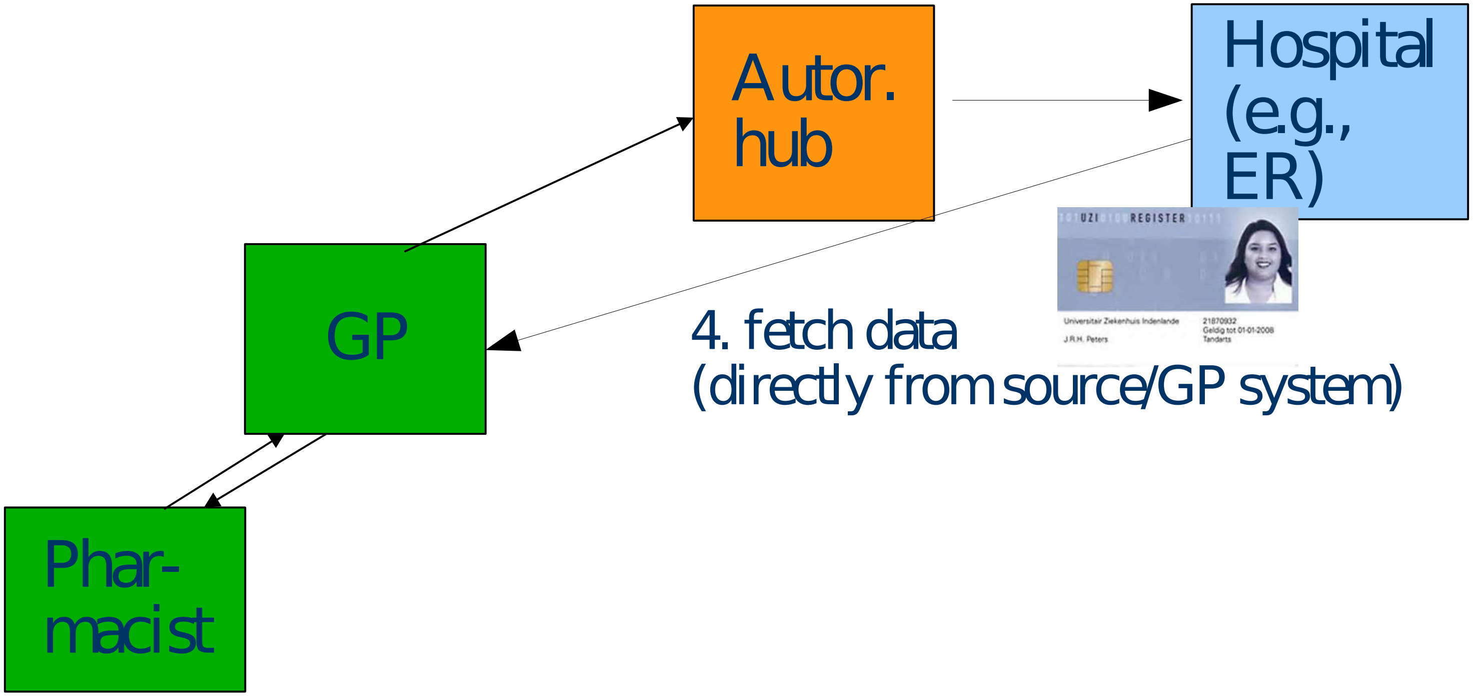


Hospital (UZI pass) gets URL – bound to UZI pass

Extra scenario: emergencies

Patient/GP worried about missing information in emergency?

2) External service



Autor. hub

Hospital (e.g., ER)

GP

Phar-macist

4. fetch data
(directly from source/GP system)

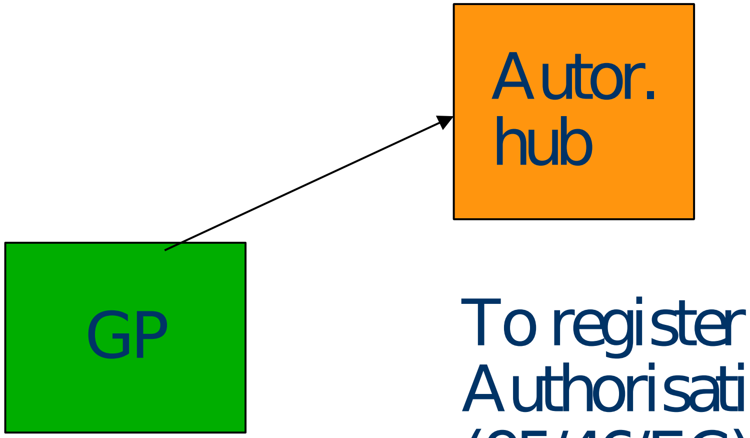
Extra scenario: emergencies

Why acceptable?

1) there may actually be real use cases

2) proportional: *only if needed, w/consent*

3) *specific* consent



To register info in emergency
Authorisation hub: consent needed
(95/46/EC)

Summary

Default cases: active“push authorization”, one-to-one, URLs bound to UZI cards

Capability model: can allow chain authorization, assuming policy permits

Use cases for pull access covered

Proportional: only scale out when needed

Access organized around patient

Always consent if more than 1 person not directly related to care authorized

Questions, remarks

Soon: https://hka-pilot.nl/