Open Notes in Sweden

Past, Present, Future

UPPSALA UNIVERSITET

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OpenNotes®

The Swedish Context

- Independent regions responsible for healthcare
  - Private care providers – tax funded
- Electronic Health Records used throughout healthcare
  - both primary care and hospitals
  - Different EHR systems used
- High Internet access and usage (almost 100%) among the population
  - 56% of people over 76 year use Internet
  - eID used for most communication with government organisations (e.g. tax returns, parental leave)
  - National patient portal (1177.se)

Population: 10 million
290 municipalities
20 regions

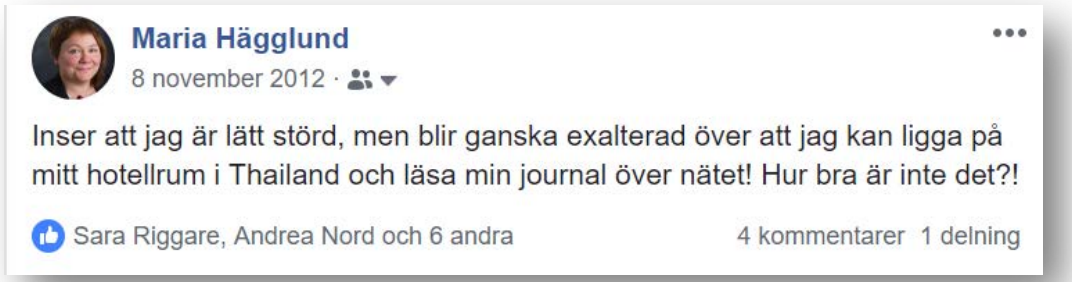
How did note sharing develop in Sweden?

1997 - pilot in Uppsala, GP + 500 patients

2002 - Data Inspection Board shuts down broader implementation

2008 - New Patient Data Act!

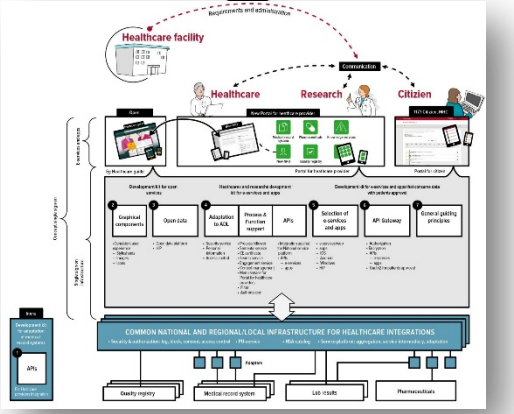
2012 - All patients in Uppsala Region get access!


Maria Hägglund
8 november 2012 ·
Inser att jag är lätt störd, men blir ganska exalterad över att jag kan ligga på mitt hotellrum i Thailand och läsa min journal över nätet! Hur bra är inte det?!
Sara Riggare, Andrea Nord och 6 andra
4 kommentarer 1 delning

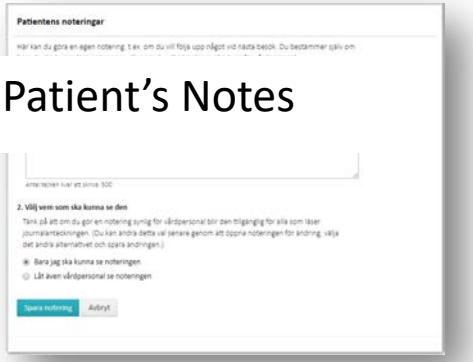
How did note sharing develop in Sweden?

2014 - the local Uppsala solution is moved to a National Health Information Exchange platform.

V.1 of the National Regulatory Framework (plenty of room for healthcare providers to choose what to share and when)



2015 - 6 more regions connect and start sharing notes

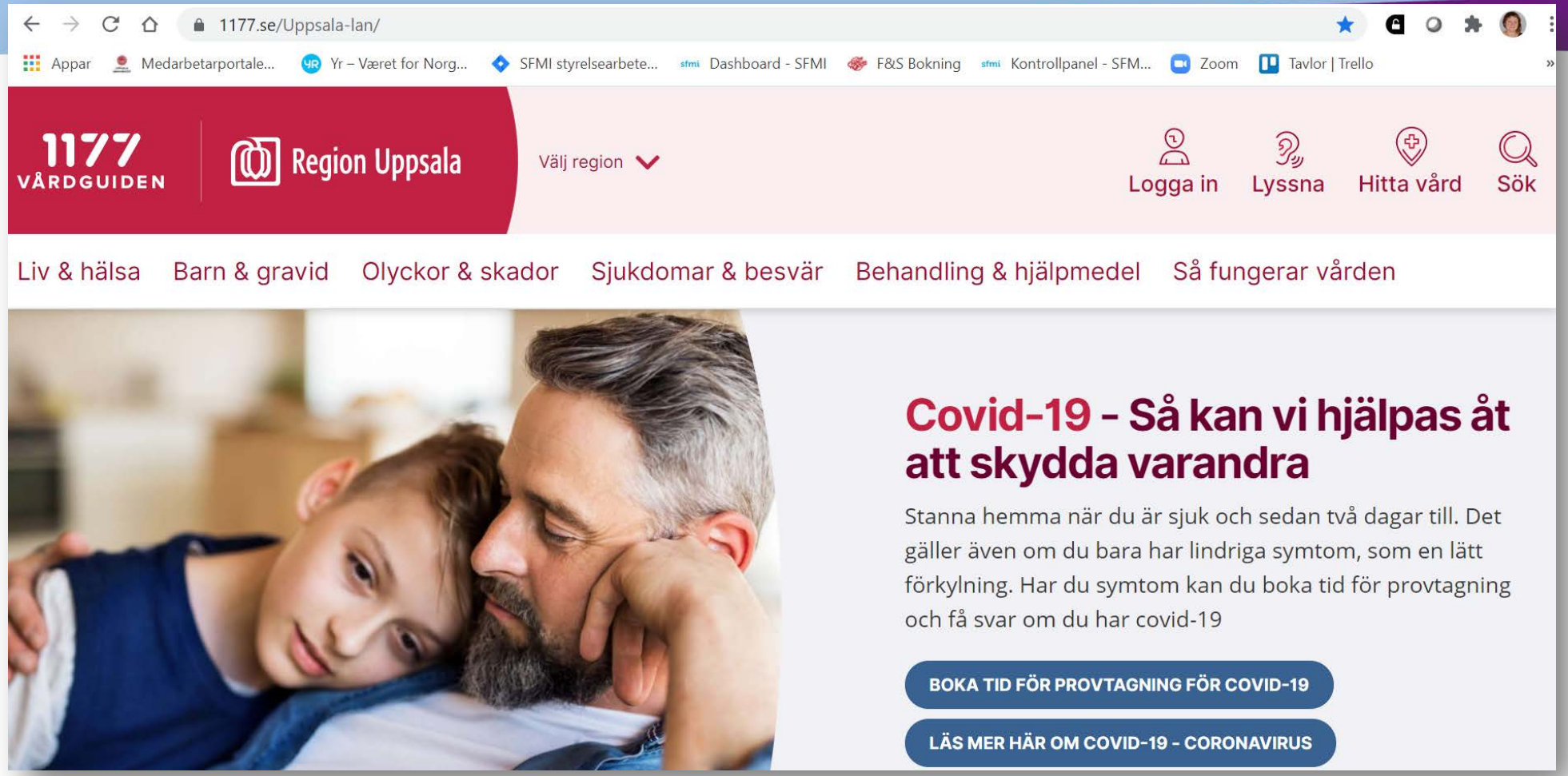


2016 - v.2 of National Regulatory Framework

All patients should have immediate online access to all documentation in tax-funded healthcare (including dental care). Few exceptions.

2018 - last of Sweden's 21 regions start sharing notes.

Current status of note sharing in Sweden

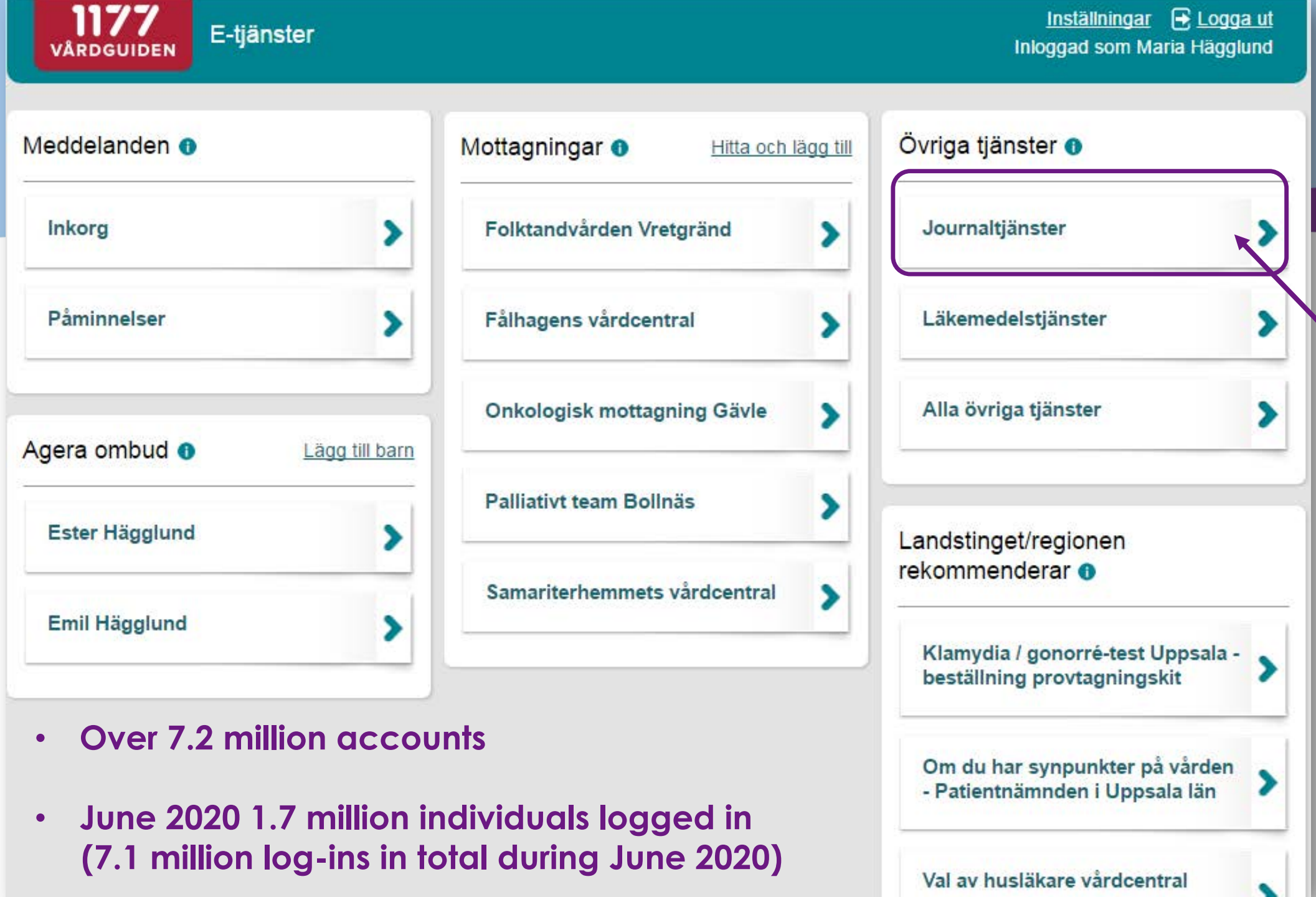


Current status of note sharing in Sweden

1177 – the National Patient Portal

In June 2020 the site had over **14 million visits**

@mariahagglund



- Over 7.2 million accounts
- June 2020 1.7 million individuals logged in (7.1 million log-ins in total during June 2020)

Journalen

Du är inloggad som: **Maria Hägglund** | 0

Sök

Start | Journal | Patient | Ombud & loggar | Frågeformulär | Om Journalen | Alternativ

Välkommen till Journalen

Här kan du läsa dina och dina barns journaluppgifter från vården, samt dela med dig av valda delar ur din journal till andra personer.

Visa min journal

- Anteckningar »
- Diagnoser »
- Läkemedel »
- Mödravård »
- Provsvar »
- Remisser »
- Uppmärksamhetssignaler »
- Vaccinationer »

Vad kan du se i Journalen?

Vad som visas och inte visas i Journalen beror på var vården har ägt rum.

Läs mer om vad som visas från olika delar av Sverige

Karta från SCB

Växla journal

Du har tillgång till följande personers journal.

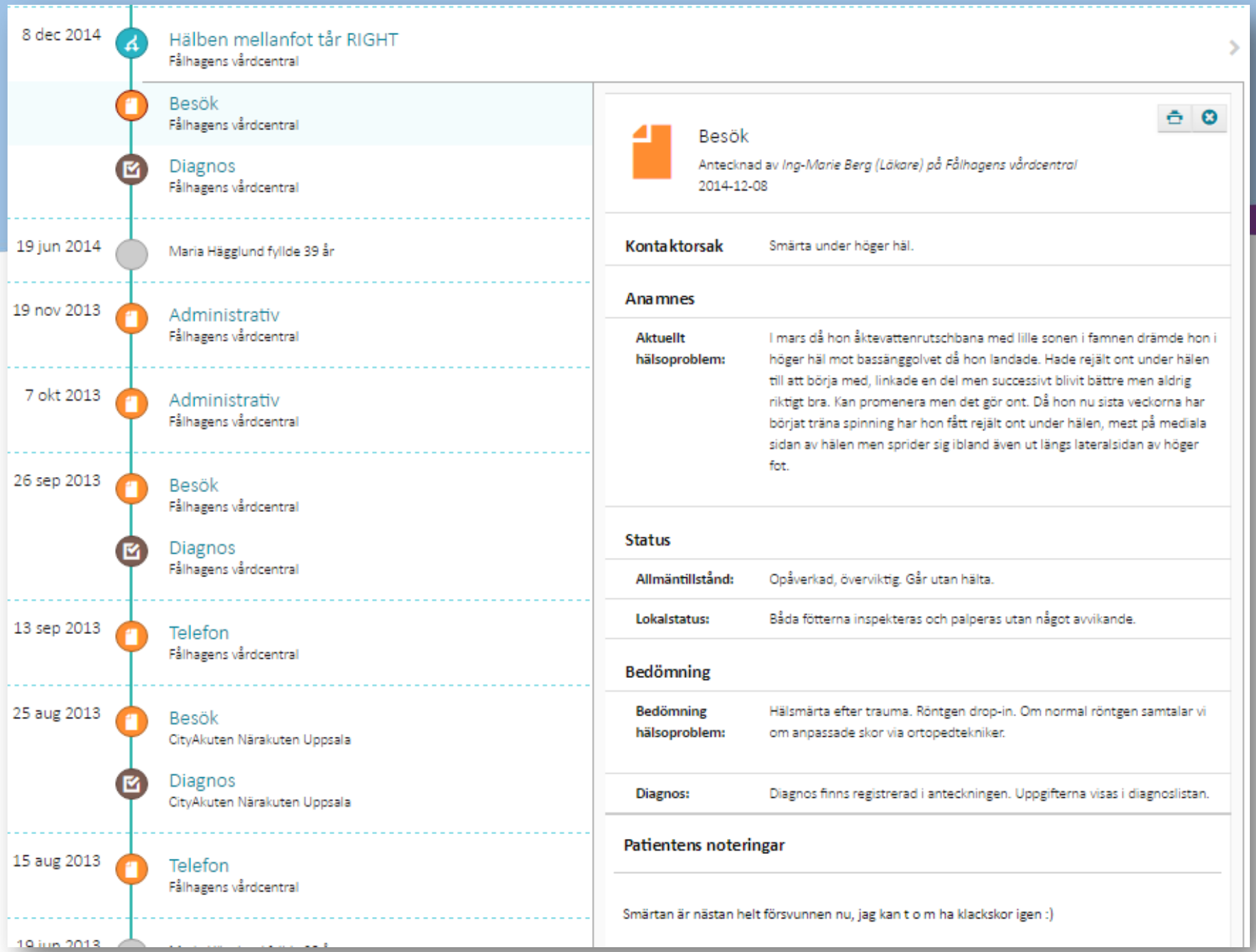
Emil Hägglund — Visa

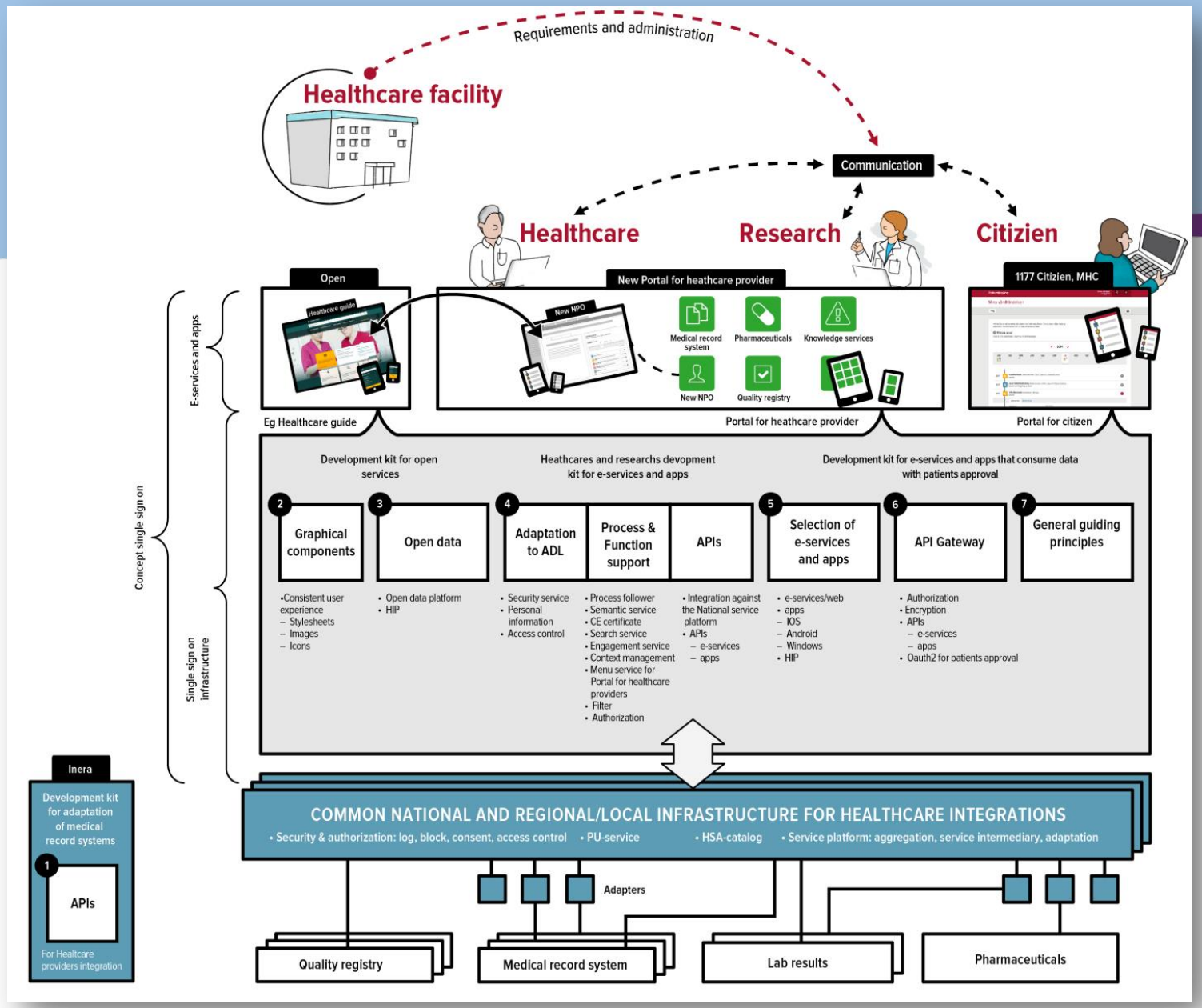
Ester Hägglund — Visa

Dela min journal

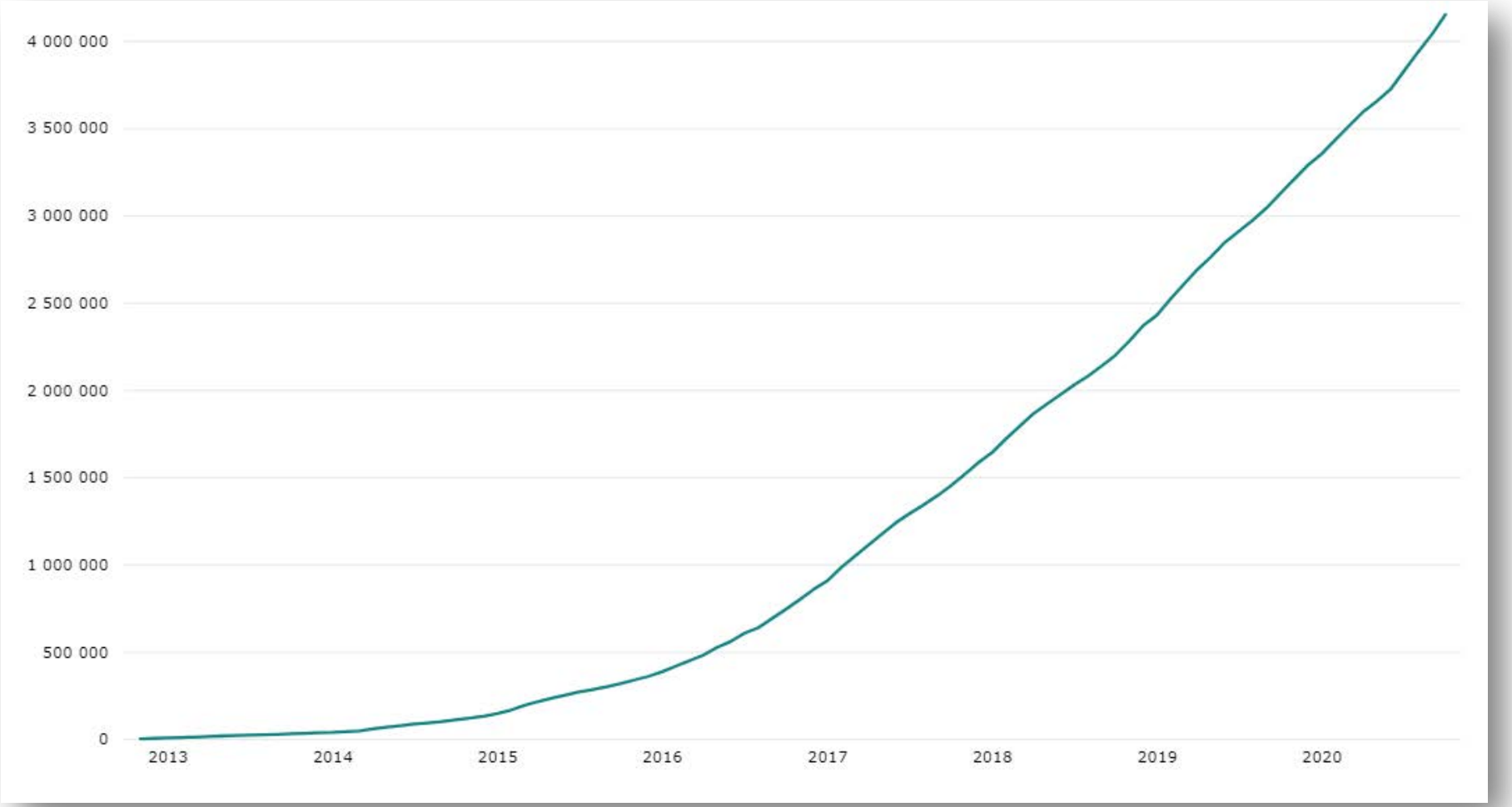
Har du frågor? ›

Vad tycker du? ›

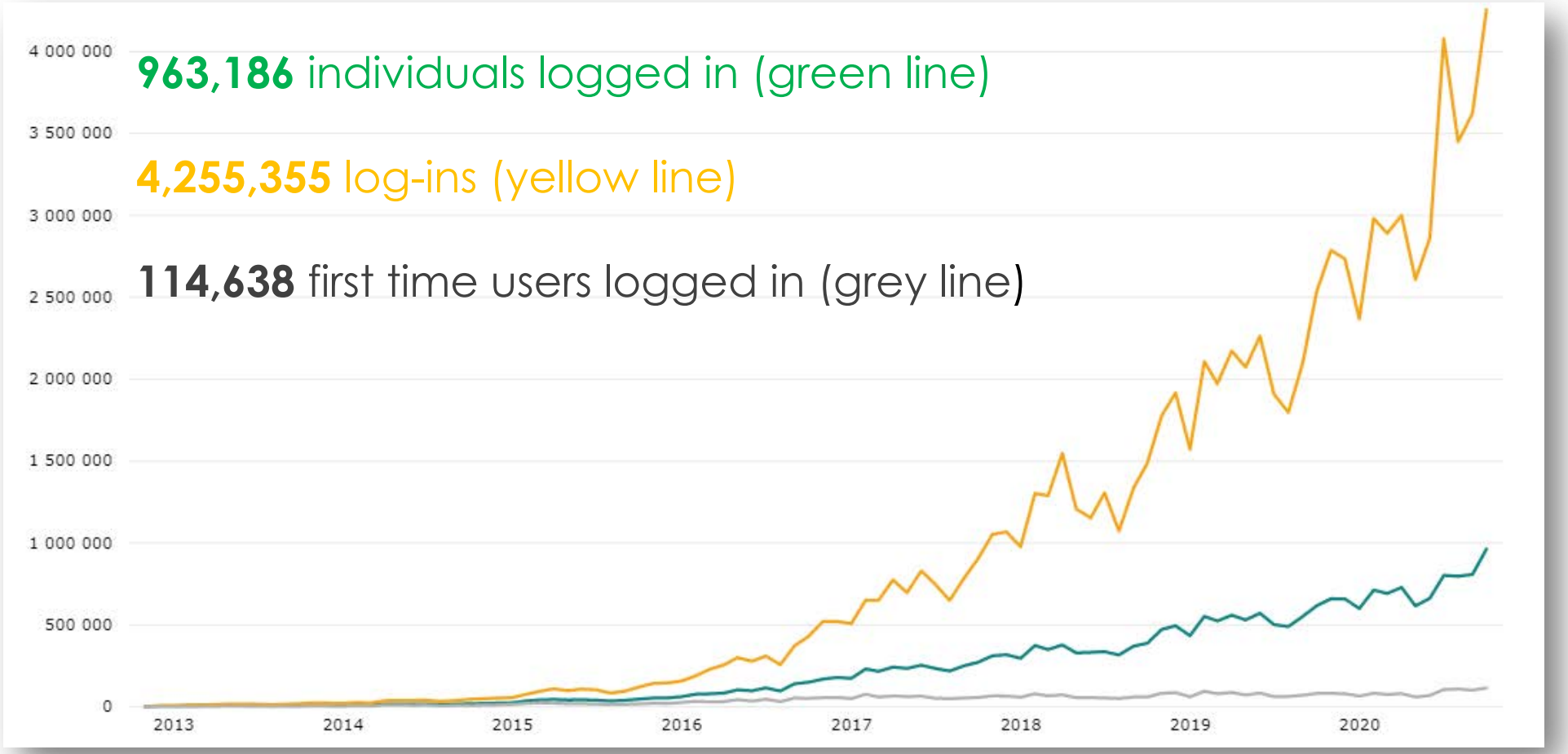

8 dec 2014
Hälben mellanfot tår RIGHT
Fålhagens vårdcentral
Besök
Fålhagens vårdcentral
Diagnos
Fålhagens vårdcentral
19 jun 2014
Maria Hägglund fyllde 39 år
19 nov 2013
Administrativ
Fålhagens vårdcentral
7 okt 2013
Administrativ
Fålhagens vårdcentral
26 sep 2013
Besök
Fålhagens vårdcentral
Diagnos
Fålhagens vårdcentral
13 sep 2013
Telefon
Fålhagens vårdcentral
25 aug 2013
Besök
CityAkuten Närakuten Uppsala
Diagnos
CityAkuten Närakuten Uppsala
15 aug 2013
Telefon
Fålhagens vårdcentral
Besök
Antecknad av Ing-Marie Berg (Läkare) på Fålhagens vårdcentral
2014-12-08
Kontaktorsak
Smärta under höger häl.
Anamnes
Aktuellt hälsoproblem:
I mars då hon åktevattenrutschbana med lille sonen i famnen drämde hon i höger häl mot bassänggolvet då hon landade. Hade rejält ont under hälen till att börja med, linkade en del men successivt blivit bättre men aldrig riktigt bra. Kan promenera men det gör ont. Då hon nu sista veckorna har börjat träna spinning har hon fått rejält ont under hälen, mest på mediala sidan av hälen men sprider sig ibland även ut längs lateralsidan av höger fot.
Status
Allmäntillstånd:
Opåverkad, överviktig. Går utan hälta.
Lokalstatus:
Båda fötterna inspekteras och palperas utan något avvikande.
Bedömning
Bedömning hälsoproblem:
Hälsmärta efter trauma. Röntgen drop-in. Om normal röntgen samtalar vi om anpassade skor via ortopedtekniker.
Diagnos:
Diagnos finns registrerad i anteckningen. Uppgifterna visas i diagnoslistan.
Patientens noteringar
Smärtan är nästan helt försvunnen nu, jag kan t o m ha klackskor igen :)


Requirements and administration
Healthcare facility
Communication
Healthcare
Research
Citizien
Open
New Portal for heathcare provider
1177 Citizien, MHC
Healthcare guide
New NPO
Medical record system
Pharmaceuticals
Knowledge services
New NPO
Quality registry
E-services and apps
Concept single sign on
Single sign on infrastructure
Eg Healthcare guide
Portal for heathcare provider
Portal for citizen
Development kit for open services
Heathcares and researchs devopment kit for e-services and apps
Development kit for e-services and apps that consume data with patients approval
2 Graphical components
•Consistent user experience
– Stylesheets
– Images
– Icons
3 Open data
• Open data platform
• HIP
4 Adaptation to ADL
• Security service
• Personal information
• Access control
Process & Function support
• Process follower
• Semantic service
• CE certificate
• Search service
• Engagement service
• Context management
• Menu service for Portal for healthcare providers
• Filter
• Authorization
APIs
• Integration against the National service platform
• APIs
– e-services
– apps
5 Selection of e-services and apps
• e-services/web
• apps
– IOS
– Android
– Windows
• HIP
6 API Gateway
• Authorization
• Encryption
• APIs
– e-services
– apps
• Oauth2 for patients approval
7 General guiding principles
Inera
Development kit for adaptation of medical record systems
1 APIs
For Healtcare providers integration
COMMON NATIONAL AND REGIONAL/LOCAL INFRASTRUCTURE FOR HEALTHCARE INTEGRATIONS
• Security & authorization: log, block, consent, access control • PU-service • HSA-catalog • Service platform: aggregation, service intermediary, adaptation
Adapters
Quality registry
Medical record system
Lab results
Pharmaceuticals

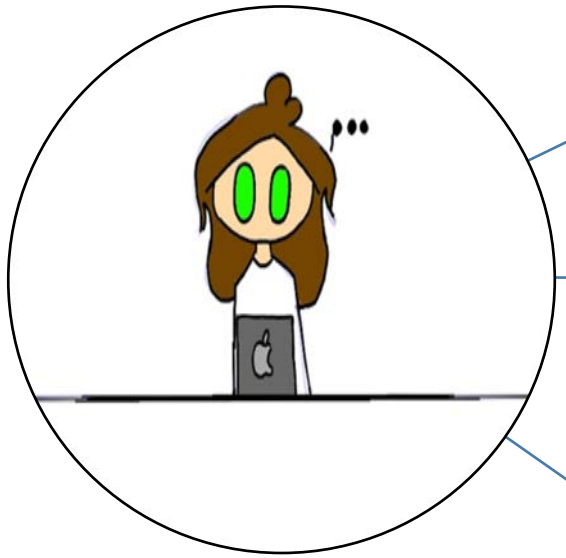
In total 4,154,417 unique users (until Sep 2020)



September 2020



What's next for note sharing in Sweden?



Patient generated data

- Patients notes
- Self-tracking and monitoring

Remaining challenges

- Mental health
- Proxy access
- Adolescent access
- Vulnerable populations

National platform

- Infrastructure update
- New digital services (telemedicine, triage)

OpenNotes Lessons From Canada

Selina Brudnicki, MBA, PMP
Program Lead of Digital Patient Experience,
University Health Network, Toronto

Health Care in Canada

- Publicly funded -- universal coverage for medically necessary health care services provided on the basis of need, rather than the ability to pay.[1]
  - Provincial/territorial governments have most of the responsibility for delivery of health and social services.
  - Federal government responsible for some delivery of services for certain groups of people.

- 85% of family practice physicians, and 79% of specialist physicians report using an electronic medical record.[2]
  - 22% of Canadians can access portions of their medical records electronically.[3]

Population: 37,971,020
13 provinces and territories

94% of Canadians have home Internet access [4]
71% of seniors report Internet use

[1] Government of Canada, 2020
[2] Leaver, C. Use of electronic medical records among Canadian physicians, 2017
[3] Canada Health Infoway. Connecting patients for better health, 2018
[4] Statistics Canada. Canadian Internet Use Survey, 2019

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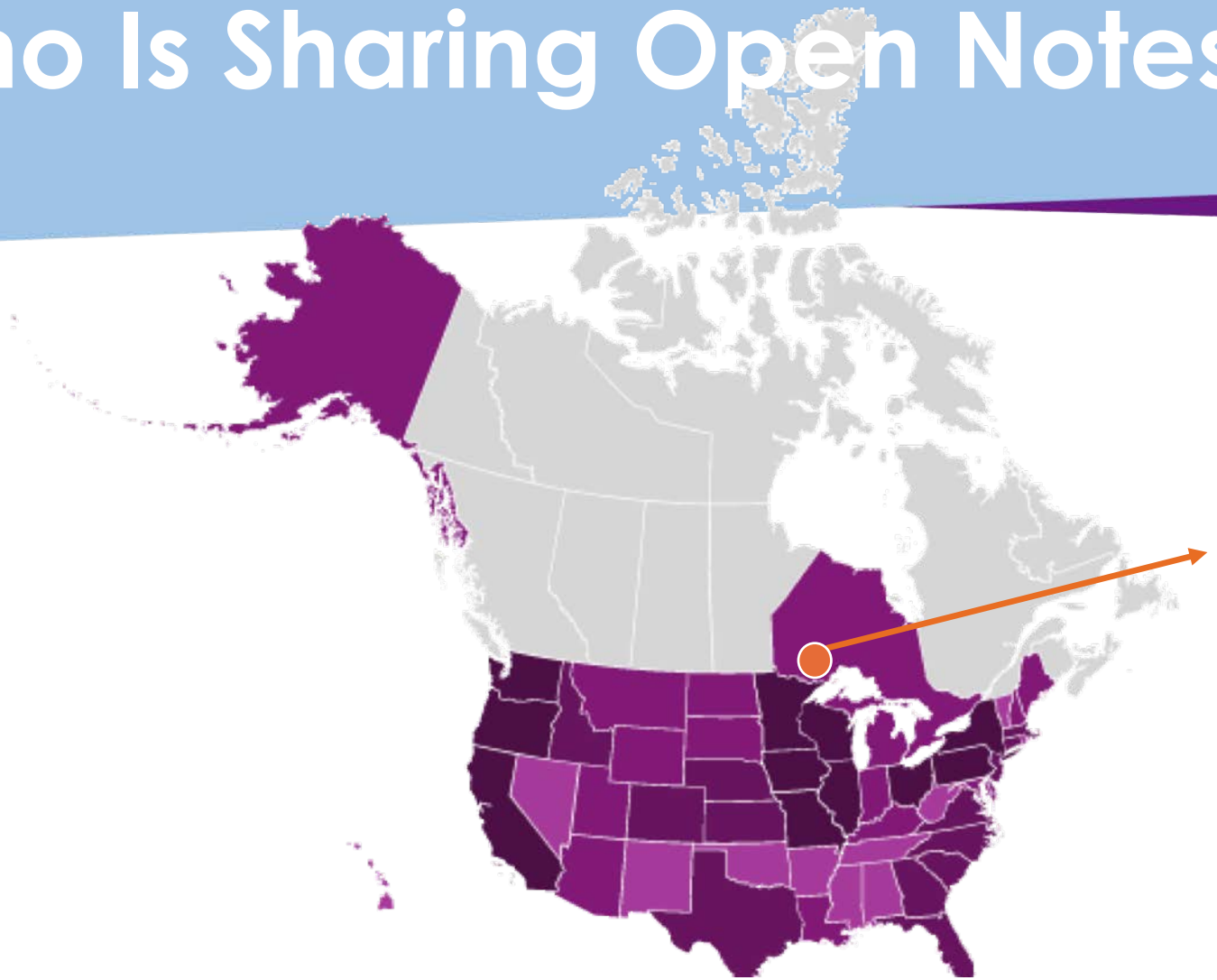
Who Is Sharing Open Notes In Canada?



Map Key:
= 0 institutions | = 1-5 institutions | = 6-10 institutions | = 11-15 institutions | = 15-20 institutions | = over 20 institutions

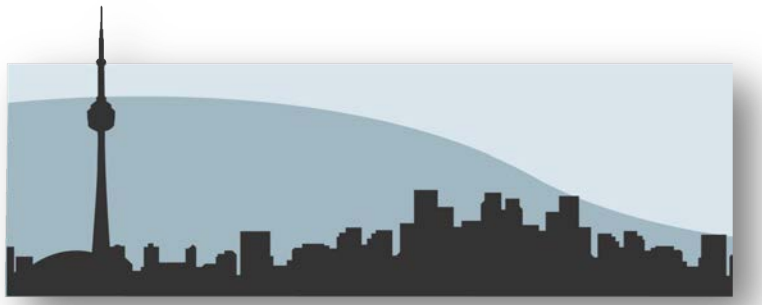
- Centre for Addiction and Mental Health
- Holland Bloorview Kids Rehabilitation Hospital
- Ontario Shores Centre for Mental Health Sciences
- University Health Network

OpenNotes. The Map, 2020

University Health Network, Toronto

Largest hospital-based research program in Canada:

cardiology, transplantation, neurosciences, oncology, surgical innovation, infectious diseases, genomic medicine and rehabilitation medicine



1,258 Inpatient beds
1,183,968 Ambulatory visits
125,886 Emergency visits

16,671 Employees
1,103 Full time staff physicians
1,068 Researchers

UHN
Toronto General
Toronto Western
Princess Margaret
Toronto Rehab
Michener Institute

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Journey: Real-Time Patient Access and Open Notes

Hematology
Leukemia, Lymphoma
UHN lab results (bloodwork)
(n=30)

2004

2006 / 2008

InfoWell
Breast Cancer Survivors &
Chronic Kidney Disease
UHN lab results (+pathology), reports
(n=900)

myUHN

Early Adopters & Enterprise
UHN lab results, reports, notes
(n=3100 → enterprise rollout)

2015 / 2017

*Years represent launch dates

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Initial Concerns

What clinicians think

- It would be difficult for the patient to receive news about their results online without proper support. Release of sensitive results and reports should be delayed.
- Notes from clinicians may not be appropriate for patients to view since they are used as a communication tool between clinicians.
- The relationship between the patient and healthcare provider will change. There will be an increase of calls by the patients to their healthcare providers.

What patients think

- Having information contributes to being informed, and decreases the anxiety and mental stress of waiting. This allows us to be better prepared for appointments and focus on other topics related to care rather than results.
- Having access to clinic notes is useful. It is an opportunity to clarify and confirm the patient's understanding and interpretation of the visit, to get information corrected, or to act as an information safety net.
- Access will help improve communication. Patients will be informed about their health and will take more responsibility to share more context regarding their health.

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"The patient is entitled, upon request, to inspect and copy all information in the patient's medical file which the physician considered in administering advice or treatment."

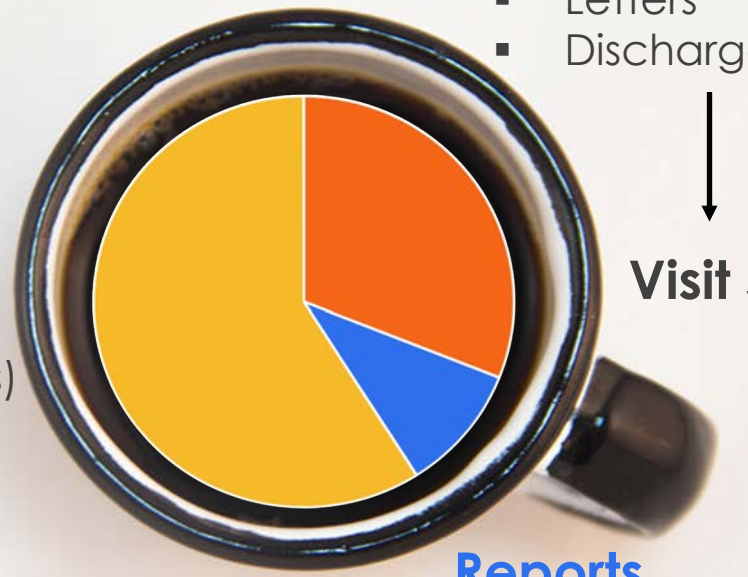
McInerney vs MacDonald
Canadian Supreme Court Ruling (1992)

Your Medical Record

Notes
- Doctor/clinic notes
- Letters
- Discharge summaries

Visit Summaries

Results
- Hematology (e.g. bloodwork)
- Pathology (e.g. tissues)
- Chemistry (e.g. bodily fluids)
- Microbiology (e.g. organisms)



Reports
- Diagnostic Imaging textual reports (e.g. CT, MRI, X-ray)

Diagnostic Images

The Needs of Patients Come First

- UHN appointment schedules and reminders
- Real-time access to UHN medical record (lab results, reports, notes)
- Links to patient education resources
- Share health record with others
- Access to Ontario Lab results (including COVID-19 results) from >150 healthcare organizations, community and public health labs (August 2020)

January 2017

myUHN One-Year Evaluation Results

10% of patients found out-of-date or incorrect information

No significant impact on Princess Margaret Cancer Centre triage call volumes for majority of sites

Anecdotal feedback that calls about results to physicians and their offices increased (data not available)

University Health Network
Patient Post-Survey: n=9827, Sep 2017
Staff Post- Survey: n=783, Feb 2018

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94% of Patients Prefer Real-Time Access

"I prefer to have my results right away even if they may be worrisome because I have a right to the information. I find it more worrisome to not have the information. And when I do feel worried about my ability to interpret the results or when I don't want to know until I consult my health care team, I simply don't look."

UHN
Toronto General
Toronto Western
Princess Margaret
Toronto Rehab
Michener Institute

University Health Network, 2019 (n=18,578)

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myUHN Activities and Adoption Dashboard

Go to Daily Stats Report

Month End Report

Month End Summary Stats for Aug 2020

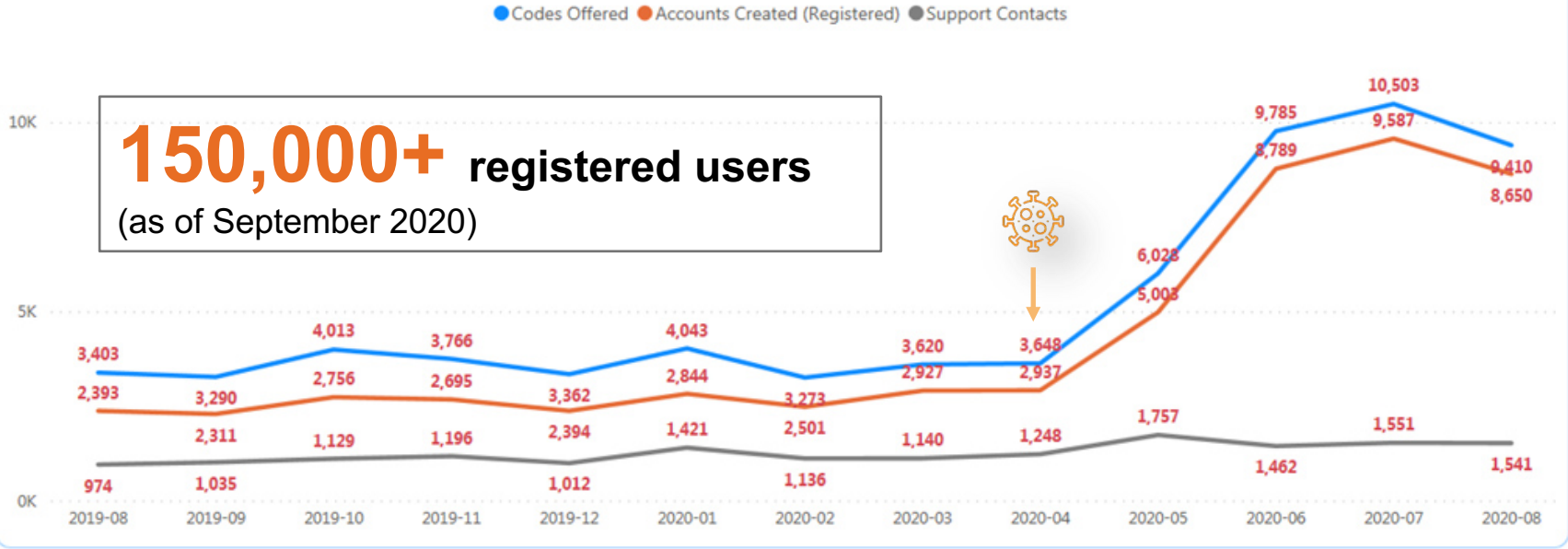
Total # of Registered Users
141,879

Total # of Codes Offered
214,188

Total Accounts by Sites
- **48,235 (35%)** PM
- **37,857 (27%)** TG
- **2,489 (2%)** TR
- **42,961 (31%)** TW
- **7,235 (5%)** Admitting and Info Desk

90-Day Adoption Rate
91%

Monthly Trend | Accounts Created (Registered) by Sites

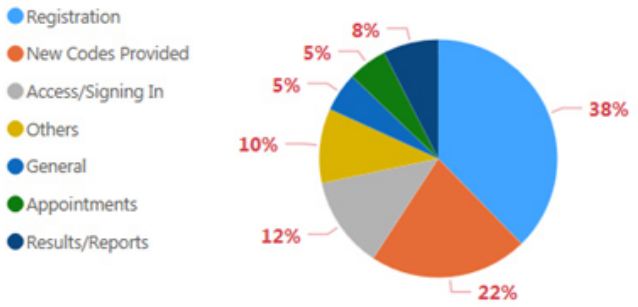


Total Support Contacts

1,541

840 Calls	**689** Emails
0 In-person	**6** Feedback form
5 Social Media	**1** Service Now

Reasons for Contacting



Quality & Safety

- **54** Duplicate MRNs reported and merged
- **89** Demographic changes and record changes facilitated
- **2** Privacy incident reported through use of myUHN

Real-Time Release

- Patients access their information as it becomes "final" and available in the hospital's electronic record, at the same time it becomes available to the patient's care team.

- Blocking patient access to their data is by exception only, based on legal and/or bioethical reasons (e.g. risk of serious harm to treatment or recovery of patient, risk of serious bodily harm to another person, etc.). Reason must be documented in the Health Information System and is audited on a monthly basis.

Advice From Colleagues

1. Explain to the patient what and why specific tests are being ordered, and prepare the patient for possible test outcomes. Provide information about what to expect next.
2. Accuracy of documentation is key. Double-check accuracy of residents, fellows or medical students who dictate on the physician's behalf to reduce need to correct notes due to inaccuracy in dictation.
3. Be sensitive to the patient, but do not omit or avoid important information that is relevant to their care.

Use factual, objective and descriptive statements.
Don't include bias, blame, value judgments and discriminatory comments.

If you think a patient may become anxious, advise them to look at their results during or after their visit to review results together, or to remember what was said at the appointment.

Building a new paradigm of trust through patient immediate access to all of their medical records will empower patients like never before and improve the patient-provider relationship.

There is no going back.