

Life with diabetes and digital health: *about connections, data and control*

Claus F. Nielsen





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Life with diabetes and digital health: *about connections, data and control*

Claus F. Nielsen

Co-founder, Public affairs
Data for Good Foundation



PPCN (Thailand) Company Limited



DATA for GOOD
FOUNDATION

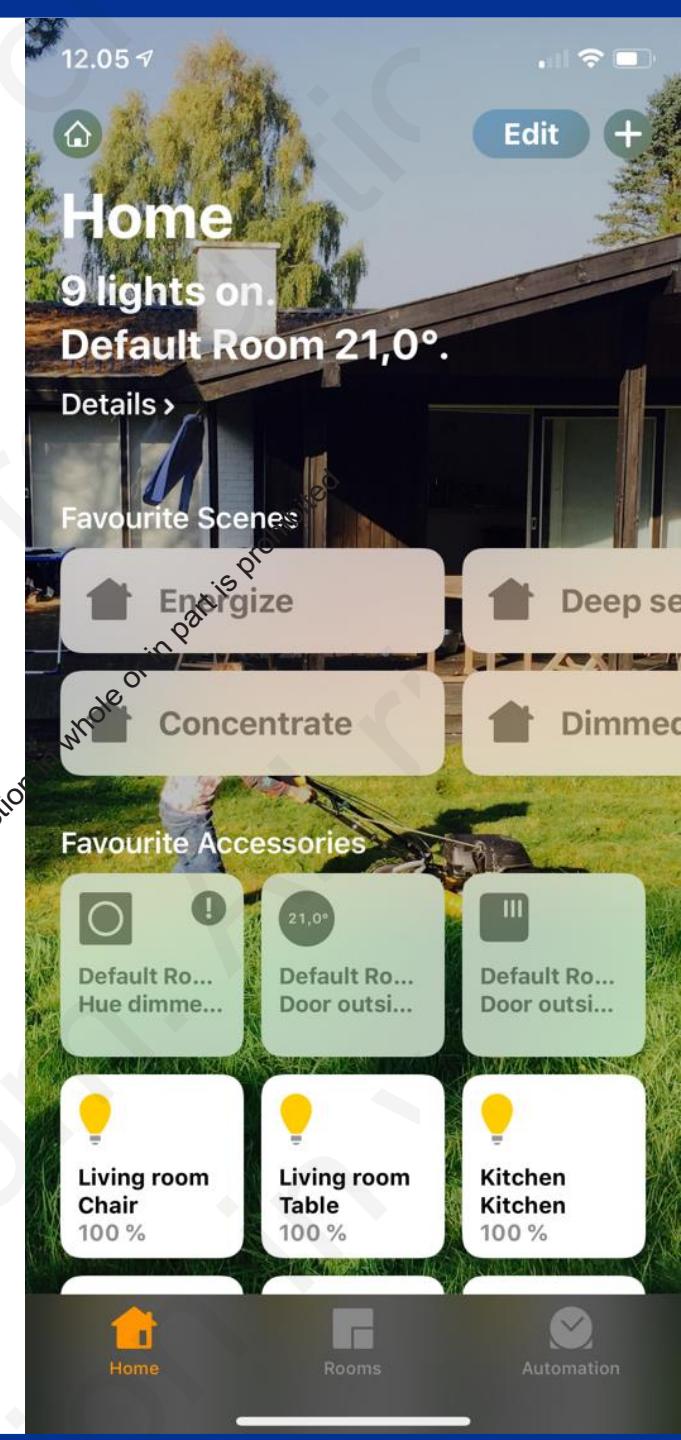
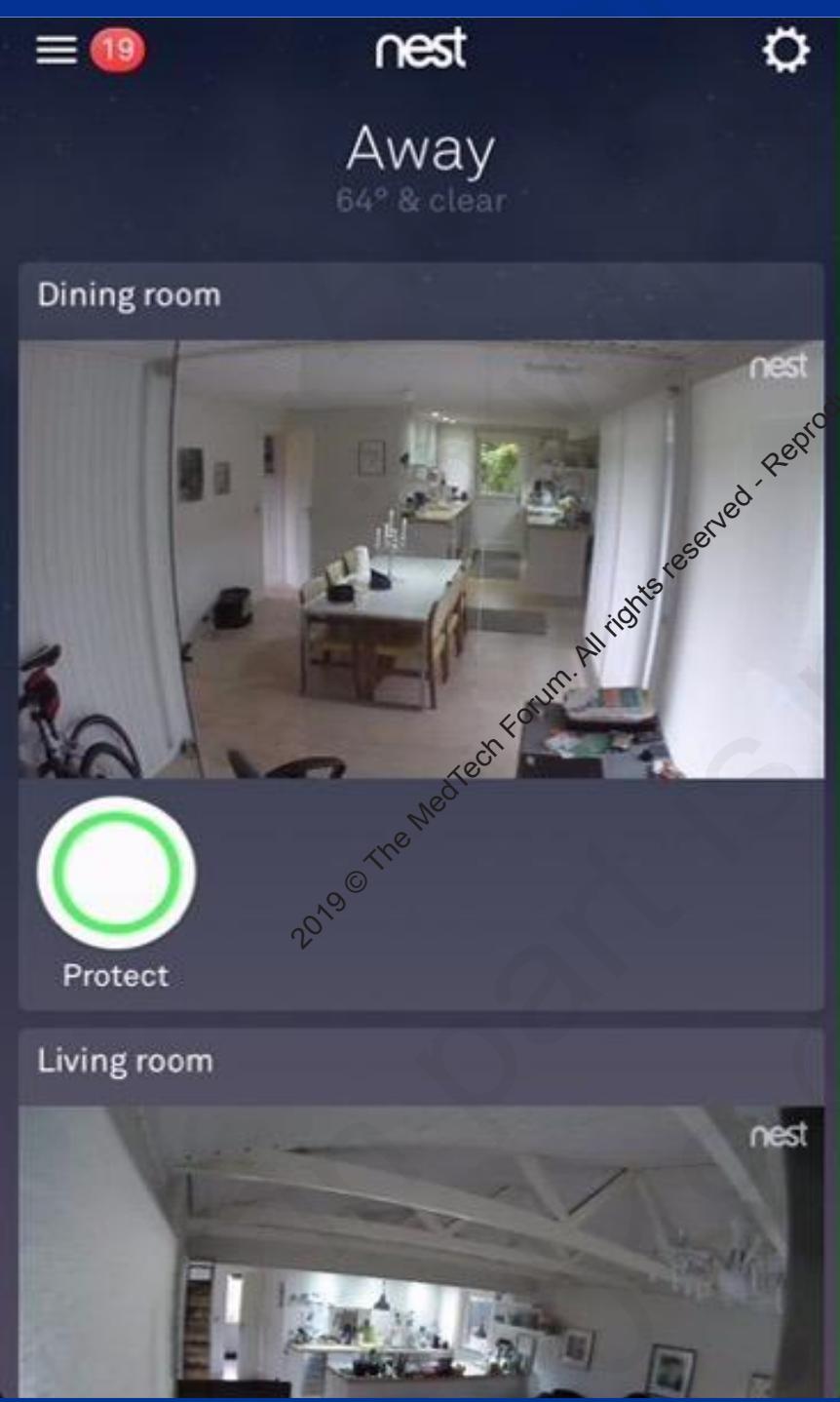


A close-up, high-angle shot of the upper body of the Deadpool character from the movie. He is wearing his signature red and black suit with a textured pattern. His mask is black with white eye holes. He is holding two black, curved blades, likely shuriken, in his gloved hands. The background is plain white.

@DeadpoolNet
@datafgood
#MTF19

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Three Months of Insulin Injections



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**”...only 6% of people with diabetes
are actually in good control; that's the
real battle we have to fight”**

*Camilla Sylvest, Executive vice president, Commercial Strategy & Corporate Affairs, Novo Nordisk
diatribe Foundation's third annual gathering during ADA 2018*

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DREAM) LINE

BOEING



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[Messages \(26\)](#) Anton [Details](#)

6,9 mmol/L 10 mar. 2015
09:59

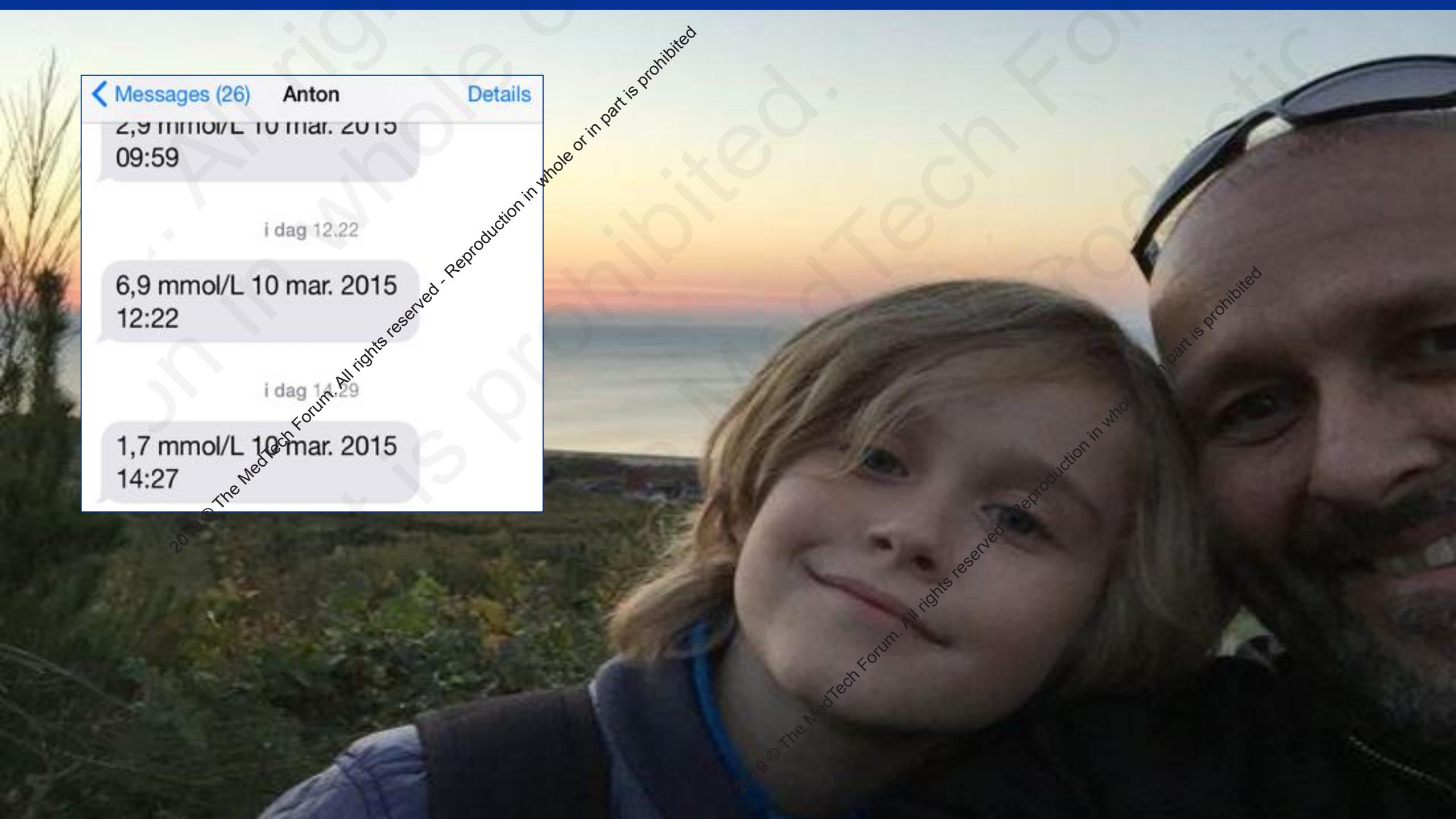
i dag 12:22

6,9 mmol/L 10 mar. 2015
12:22

i dag 14:29

1,7 mmol/L 10 mar. 2015
14:27

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Skema for penbehandling

ID
Navn
Cpr

290405-6181
Nielsen, Anton

HIBA HIB



Mail
Telefon
Doktordato

413

201415430/61160974

Ambulantskema Børneafdelingen Hillerød

Type
Disp
Autoanti

Type 1

| Sign | Morgen | | Middag | | Efter-middag | | After- | | Senge-tid | Total | HbA1c i % | Højde (cm) | Vægt (kg) | BT i mmHg | SMBG (uge) | Korrekt- tion | Ændrer i behandling | Alv. Hypo | Infiltrater (mave, baller, lår) | TLF opkald | |
|-------|--------|-------|--------|------|--------------|------|--------|------|-----------|-------|--------------|---------------|--------------|--------------|---------------|------------------|------------------------|--------------|---------------------------------------|------------------|------------------------------|
| | Før | Efter | N | type | N | type | N | type | | | | | | | CGMS | MÅL for HbA1c | Indl. Keto | | | | |
| 14-13 | Før | Basal | 4 | I | | | | | | | | | | | | | | | | 1 mælt 95-1 | |
| | Efter | Bolus | 2-3 | R | | | | | | | | | | | | | | | | Stikker bagpå | lactose als på gluten. |
| 15-13 | Før | Basal | 5 | I | | | | | | | | | | | | | | | | 8 mmol/l | |
| | Efter | Bolus | 6-7 | R | | | | | | | | | | | | | | | | 40 g/i | |
| 21-14 | Før | Basal | 5 | I | | | | | | | | | | | | | | | | -/- | 1 |
| | Efter | Bolus | 6-7 | R | | | | | | | | | | | | | | | | | |
| SL. | Før | Basal | | | | | | | | | | | | | | | | | | | |
| | Efter | Bolus | | | | | | | | | | | | | | | | | | | |
| 19-19 | Før | Basal | | | | | | | | | | | | | | | | | | | |
| | Efter | Bolus | | | | | | | | | | | | | | | | | | | |
| 19-19 | Før | Basal | | | | | | | | | | | | | | | | | | | |
| | Efter | Bolus | | | | | | | | | | | | | | | | | | | |
| 19-19 | Før | Basal | | | | | | | | | | | | | | | | | | | |
| | Efter | Bolus | | | | | | | | | | | | | | | | | | | |
| 19-19 | Før | Basal | | | | | | | | | | | | | | | | | | | |
| | Efter | Bolus | | | | | | | | | | | | | | | | | | | |
| 19-19 | Før | Basal | | | | | | | | | | | | | | | | | | | |
| | Efter | Bolus | | | | | | | | | | | | | | | | | | | |
| 19-19 | Før | Basal | | | | | | | | | | | | | | | | | | | |
| | Efter | Bolus | | | | | | | | | | | | | | | | | | | |
| 19-19 | Før | Basal | | | | | | | | | | | | | | | | | | | |
| | Efter | Bolus | | | | | | | | | | | | | | | | | | | |
| 19-19 | Før | Basal | | | | | | | | | | | | | | | | | | | |
| | Efter | Bolus | | | | | | | | | | | | | | | | | | | |

Forkortelser: R=Rapid, I=Insulatard, M=Mixtard, Le=Levemir, La=Lantus, A=Actrapid, NM=Novomix, SMBG=blodsukkermålinger pr. uge
 Alv. Hypo: antal hypoglykæmi tilfælde med bevidstløshed eller kramper - husk at udfylde dato og tidspunkt på bagpå i journalen
 Indl. Keto: Indlæggelse med ketoacidose, hvor pH er < 7,30 eller bicarbonat under 15 - husk at udfylde bagsiden med dato og bicarbonat

Cøliaki:
Myxoedem
Andet

Innovating Health & Care Systems

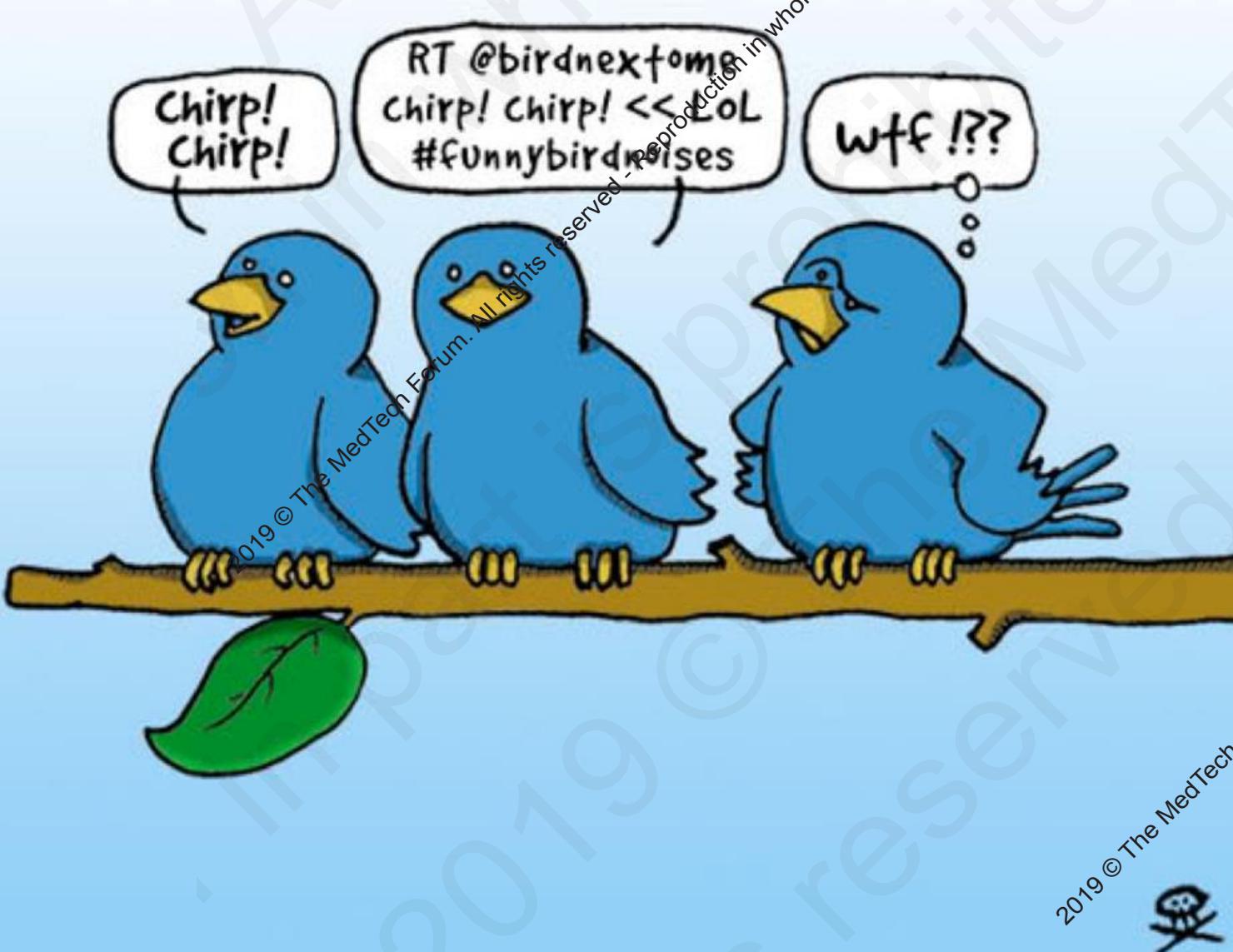




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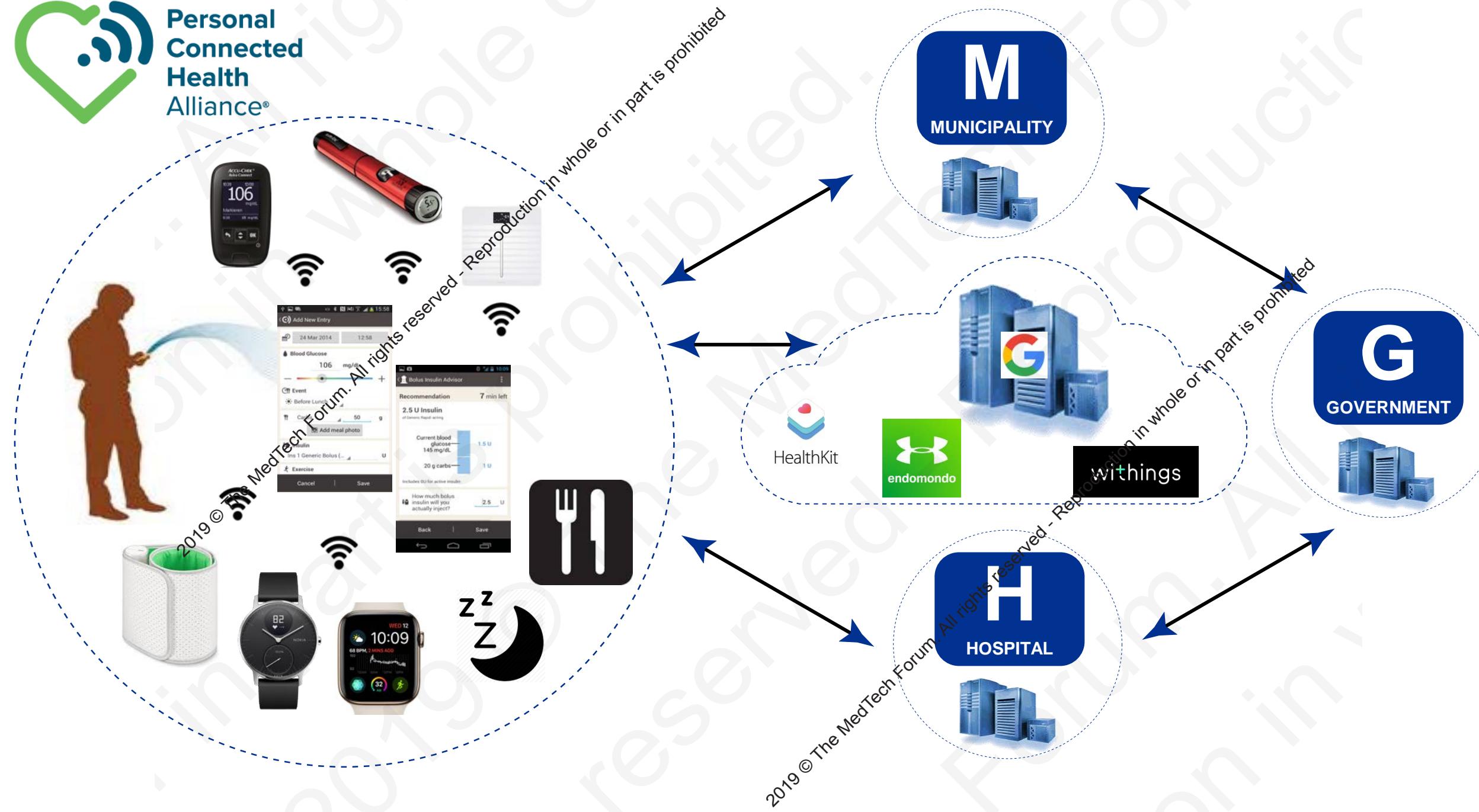
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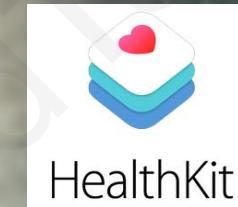
Interoperability – not easy





**Personal
Connected
Health
Alliance®**





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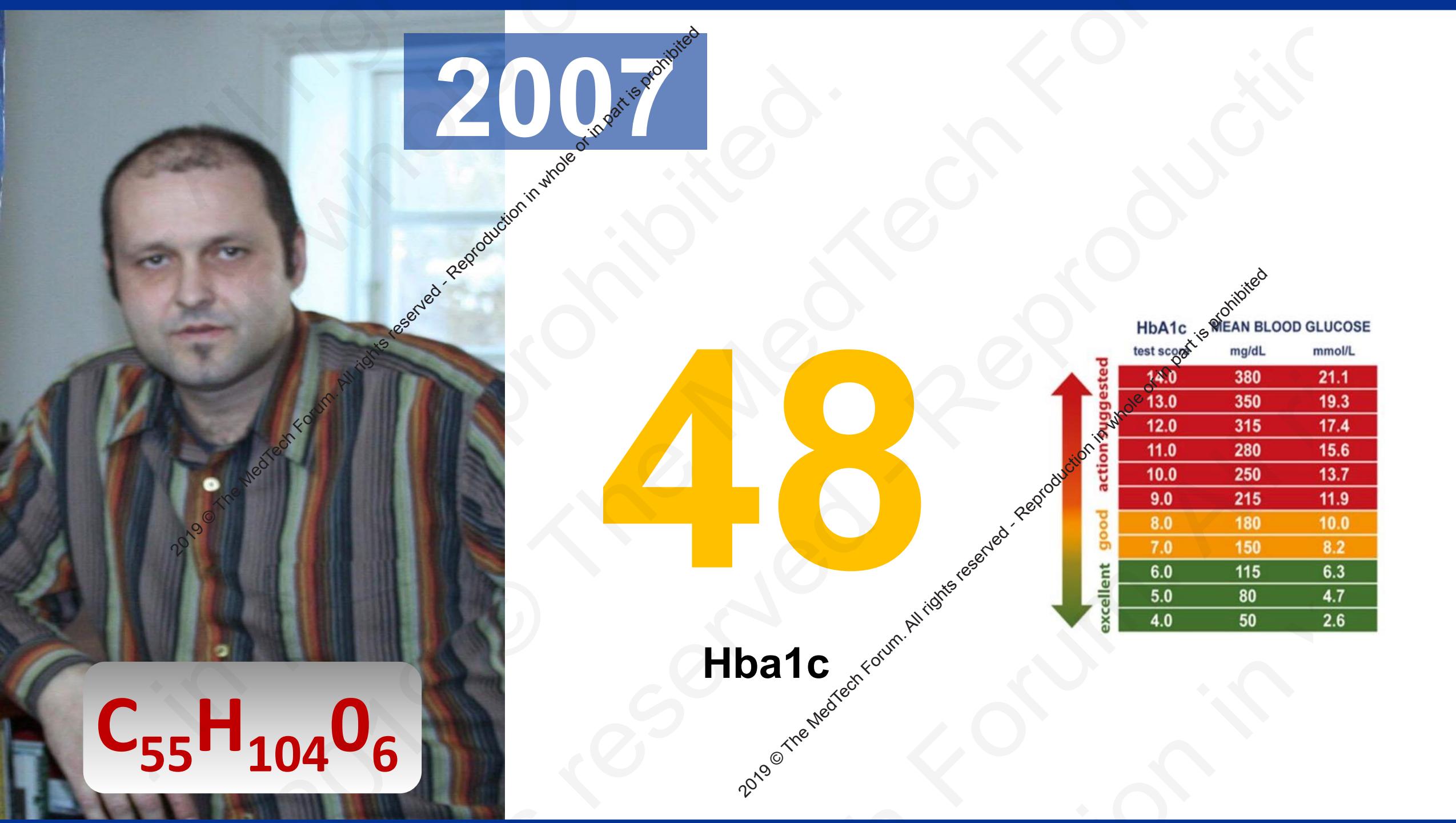
Battleground in Medtech

prohibited



Source: IBM Institute for Business Value.

Figure: Consumer electronics companies and medical device makers have their respective strengths and weaknesses – but who will win?



$C_{55}H_{104}O_6$

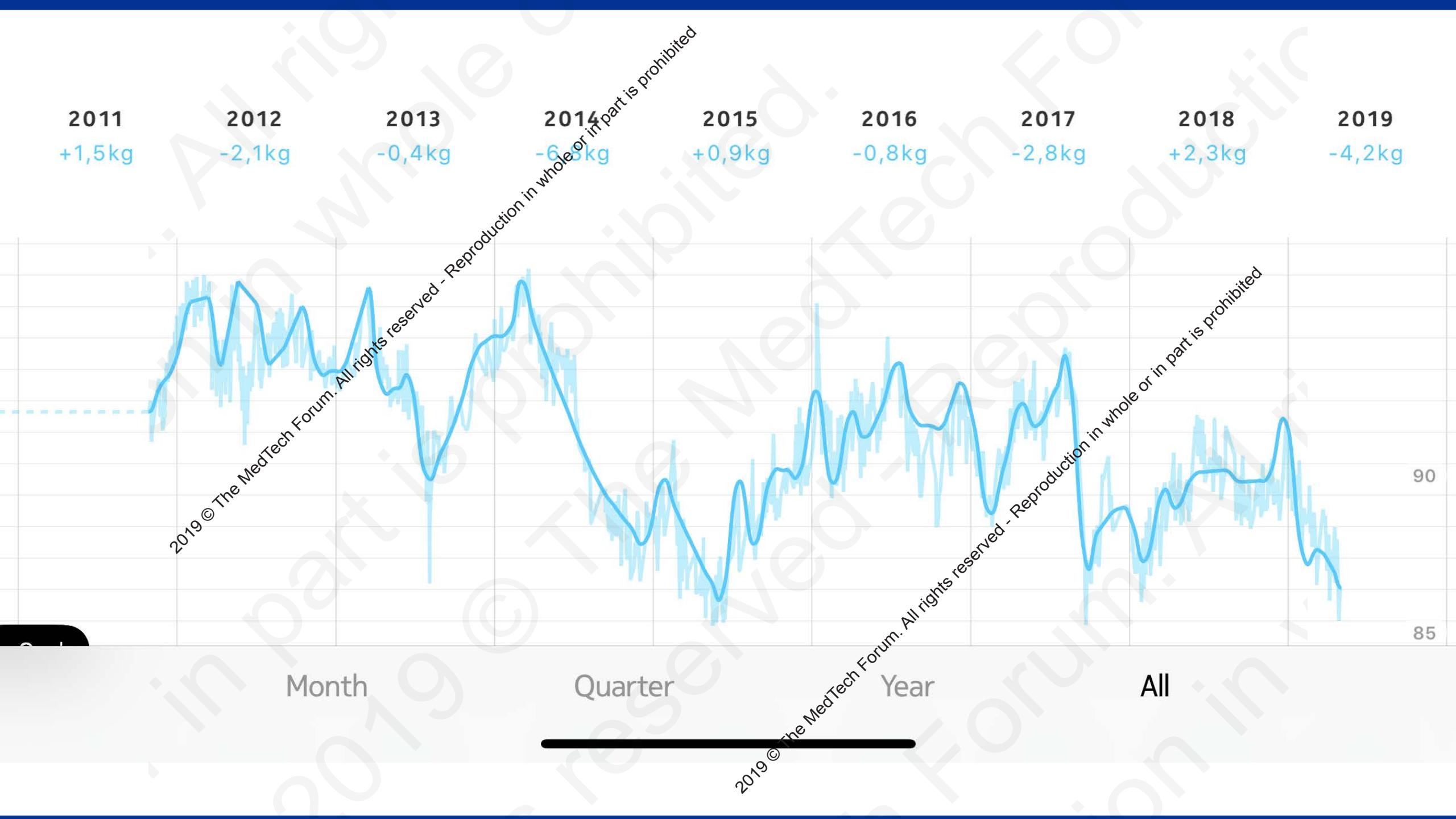
2007

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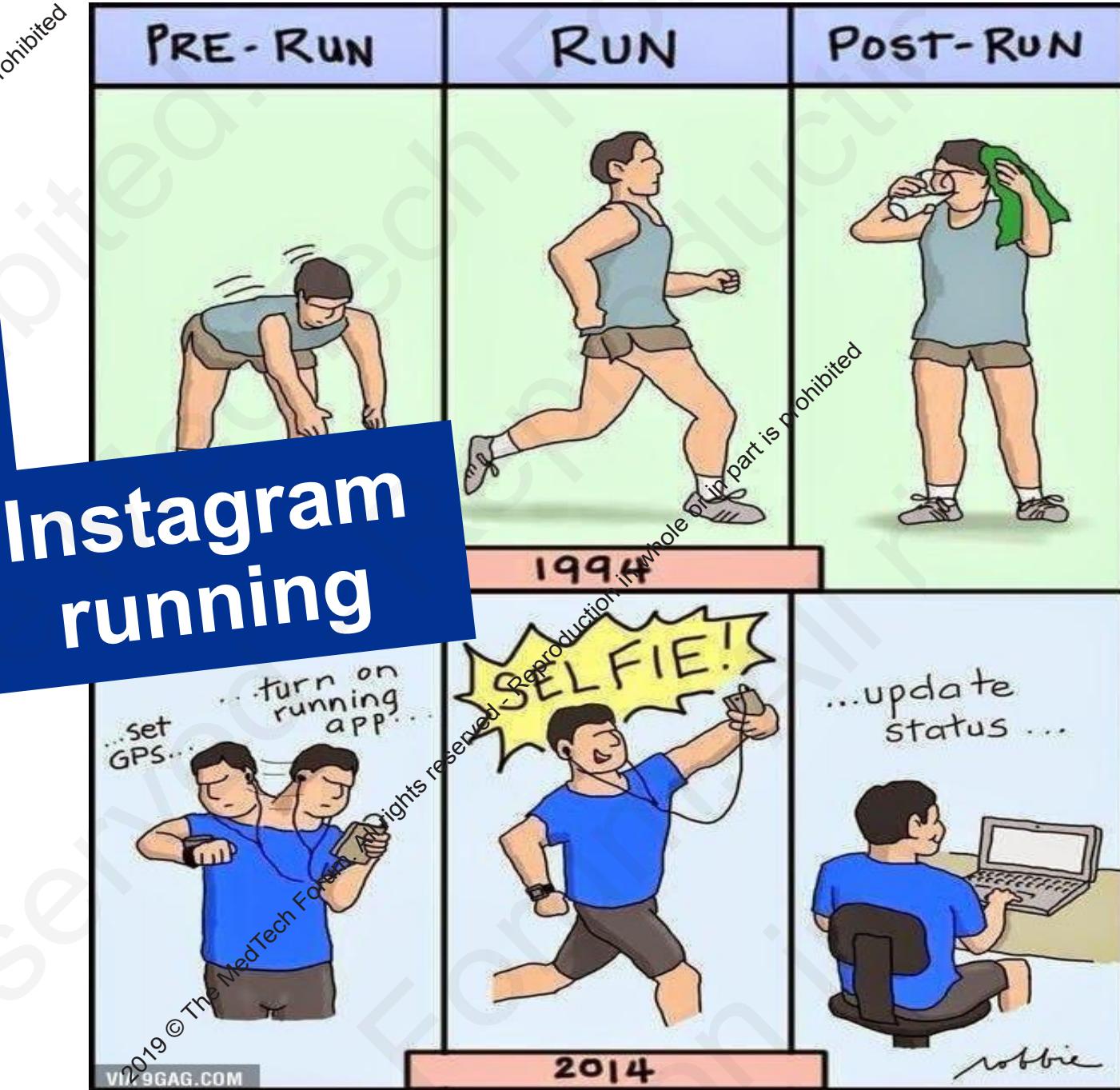
Hba1c

| HbA1c | | |
|------------|-------|--------|
| test score | mg/dL | mmol/L |
| 14.0 | 380 | 21.1 |
| 13.0 | 350 | 19.3 |
| 12.0 | 315 | 17.4 |
| 11.0 | 280 | 15.6 |
| 10.0 | 250 | 13.7 |
| 9.0 | 215 | 11.9 |
| 8.0 | 180 | 10.0 |
| 7.0 | 150 | 8.2 |
| 6.0 | 115 | 6.3 |
| 5.0 | 80 | 4.7 |
| 4.0 | 50 | 2.6 |





MAMIL Phase



54

Hba1c

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DR ANDRE TIER

DET MED AVISEN - 40 SIDER FODBOLD

Fredag 30. november 2018 | nr. 292 | uge 48 | 175. årg. | ekstrabladet.dk | 25.00 kr.

Ekstra Bladet

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Politiet advaret flere gange

Sådan slap Britta af krogen

Trak ZeNITTEN men FCK lever

BRUUNS FEM TRUMFER

SPAREX KRONJYDRE

FORSKERS RÅD TIL 250.000 RAMTE

DIABETES 2 KAN SPISES

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SANGEREN SØREN HUSS UNDGÅR MEDICIN

JACKPOT

10 millioner i puljen lørdag

LOTTO

veds



Patient engagement/motivation is the key!

(Real men don't use fitness trackers & eat vegetables)



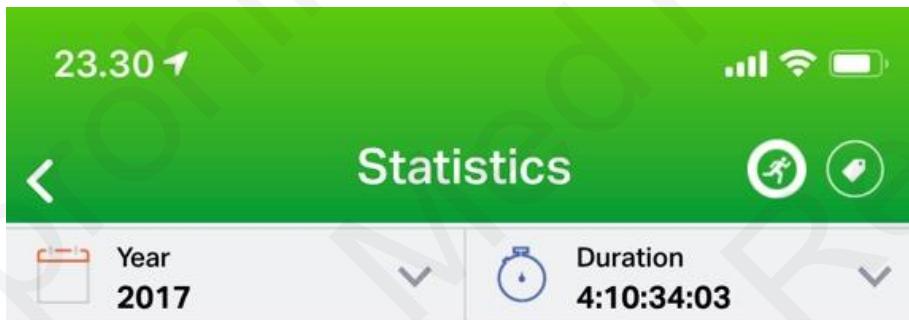


My Magic Pill: Keto diet + exercise!





2017



31

Hba1c

| HbA1c | MEAN BLOOD GLUCOSE | |
|------------|--------------------|--------|
| test score | mg/dL | mmol/L |
| 14.0 | 380 | 21.1 |
| 13.0 | 350 | 19.3 |
| 12.0 | 315 | 17.4 |
| 11.0 | 280 | 15.6 |
| 10.0 | 250 | 13.7 |
| 9.0 | 215 | 11.9 |
| 8.0 | 180 | 10.0 |
| 7.0 | 150 | 8.2 |
| 6.0 | 115 | 6.3 |
| 5.0 | 80 | 4.7 |
| 4.0 | 50 | 2.6 |

Heart attack patient claims Shrewsbury hospital food was 'overcooked' and 'inedible'

A man recovering from a heart attack claims he was served meals he "wouldn't give to a pig" during his stay at the Royal Shrewsbury Hospital – and has taken pictures of the food to prove it.



One meal served during Steve Powell's hospital stay

HOSPITAL FOOD BINGO



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Surgical Pathology Report
Accession number 2017-2-1679

Hospital: SAMITRAJ HOSPITALS
Name: MR. CLAUS FLEMMING NIELSEN
Hospital: PAKPONG WATHANAORAN, DR.
Physician: บริษัท พากพงษ์ จำกัด

Age: 52 Sex: M HN: 11-17-050676
Ward/Clinic: 3521/SC Date Received: 09/SEP/2017
Date Operated: 08/SEP/2017
Date Reported: 14/SEP/2017

Diagnosis:

Small bowel, segmental resection : Malignant small cell neoplasm, morphologic and immunophenotypically consistent with neuroendocrine carcinoma, involving mucosa, muscular layer and serosa (antemesenteric site).
Size 0.9x0.9x0.6 cm.
Lymphatic invasion identified.
Both resected ends are free of the tumor.

Lymph nodes, regional : Mesenteric neuroendocrine carcinoma in 3 out of 13 nodes (3/13).

Gross Description:

The specimen is received in formalin, labeled with patient's name and labeled with an accession number with additional labeled as "small bowel", and consists of a previously opened loop of small bowel, measuring 26.3 cm in length, 2.0 cm. Upon opening reveals a pink white rubbery ulcerated submucosal mass, measuring 0.9x0.9x0.6 cm. The mass is present at the anti-mesenteric side, 10.3 cm from the small resection margin, 12.6 cm from the large resection margin, and 5.5 cm from the mesenteric resection margin. The mass grossly invades into the serosal surface. The remaining mucosa is unremarkable. Lymph nodes, measuring 0.3-1.5 cm in the greatest dimension are identified. The mesentery shows focal hemorrhage. (Fig. 1 and 2)

Representative sections submitted as: A-B: Both enface resection margins, C-D: Perpendicular mesenteric resection margin, E: Shaved mesenteric resection margin, F-H: Mass with serosal surface, I: Small bowel wall with mesenteric tissue, J: Lymph nodes, K: Lymph nodes, L: Hemorrhagic mesentery

Microscopic Description:

The tumor of the small bowel is composed of multiple small and large islands of round cells neoplasia. The tumor is arranged in ribbons and festoons patterns. It is composed of relatively uniform small round cells with oval nuclei and ill-defined cytoplasm. The tumor invades mucosa, muscularis propria and serosa. Lymphatic invasion is noted. Tumor metastasis is seen in 3 out of 13 regional lymph nodes (3/13). Perinodal invasion is observed. The proximal and distal ends are free of the malignancy. However, mesenteric resection margin is not free. (Fig 3 and 4)

IHC study: The tumor cells mark with AE1/AE3 (paramuclear dot), CD57, NSE, synaptophysin and chromogranin. Ki-67 is 2-3% positive. They do not mark with LCA. These results support the diagnosis of well differentiated neuroendocrine carcinoma. (Fig 5)

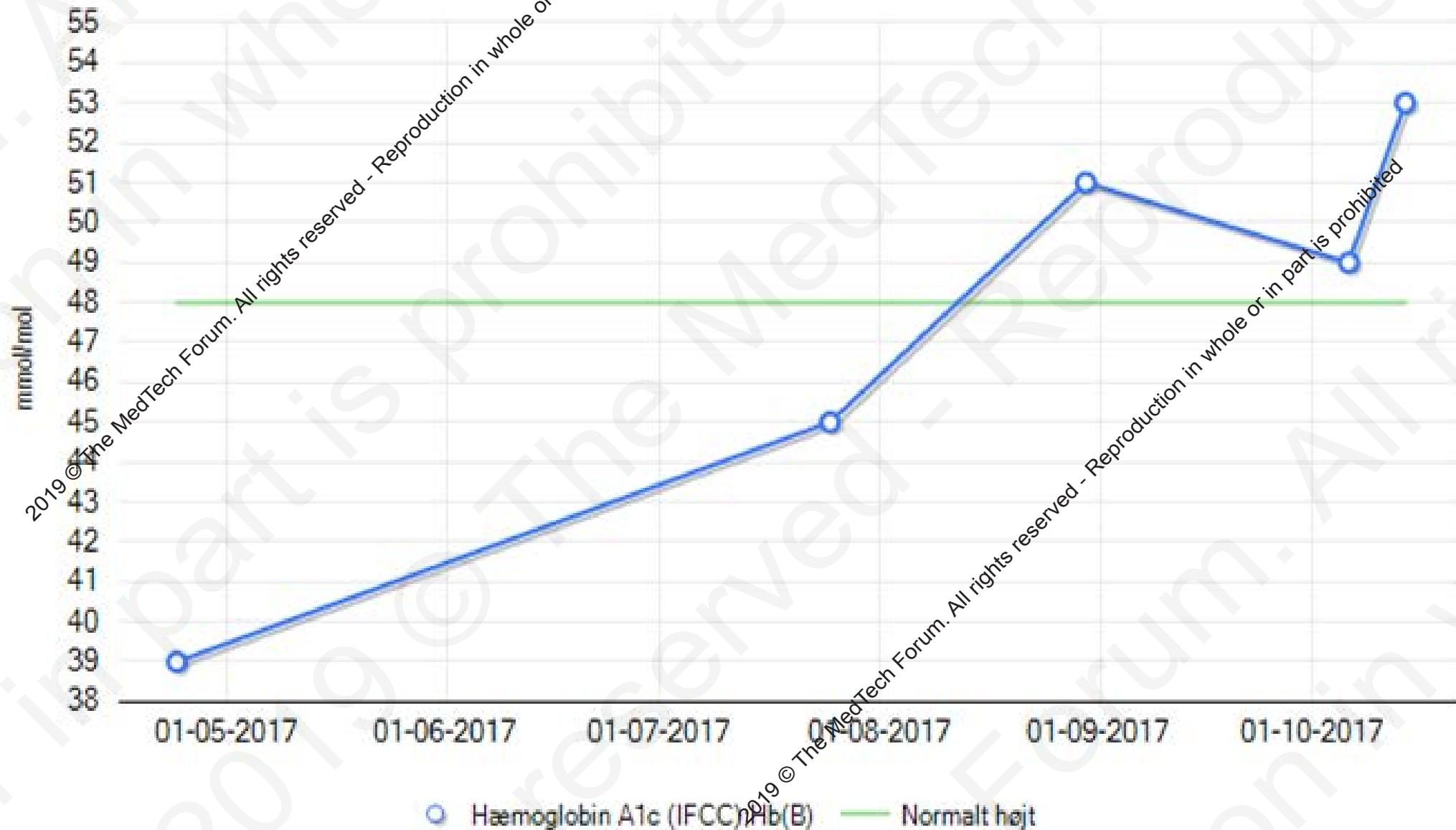
Fig 1: Small bowel and mesentery

Fig 2: Small bowel mucosa

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Long term glucose out of bounce again!





More epic data points!



| Prøvesvar | |
|---------------------------|--------------|
| U. Knigge, Kirurg | 29/11/2018 > |
| Sundhedsfagligt personale | 29/11/2018 > |
| U. Knigge, Kirurg | 14/09/2018 > |
| U. Knigge, Kirurg | 13/09/2018 > |
| MBq Cu-64-Dotataate | 13/09/2018 > |
| U. Knigge, Kirurg | |
| KROMOGRANIN A;P | 12/09/2018 > |
| U. Knigge, Kirurg | |
| VITAMIN B12;P | 12/09/2018 > |
| U. Knigge, Kirurg | |
| KREATININ;P | 12/09/2018 > |
| Sundhedsfagligt personale | |
| HÆMOGLOBIN A1... | 12/09/2018 > |
| Sundhedsfagligt personale | |
| GLUKOSE, MIDDEL... | 12/09/2018 > |
| Sundhedsfagligt personale | |
| EGFR/1.7SM (CKD-...) | 12/09/2018 > |

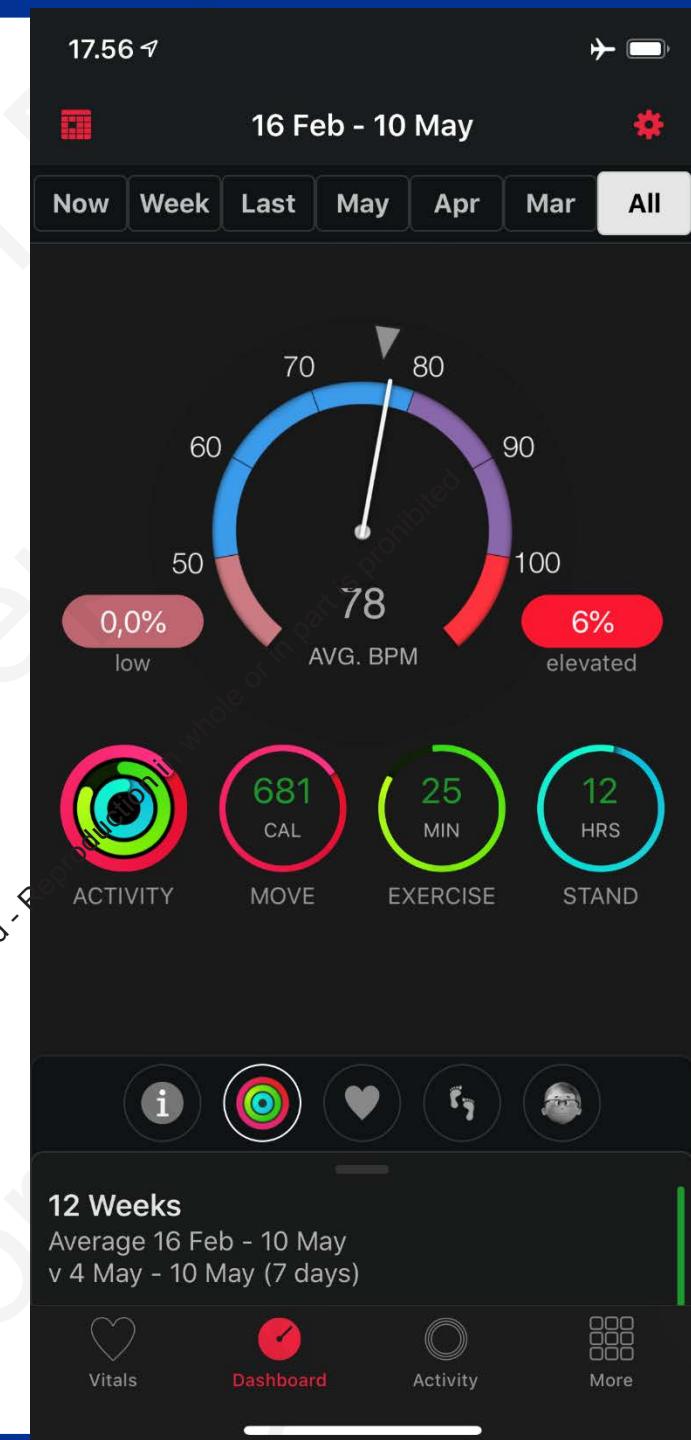
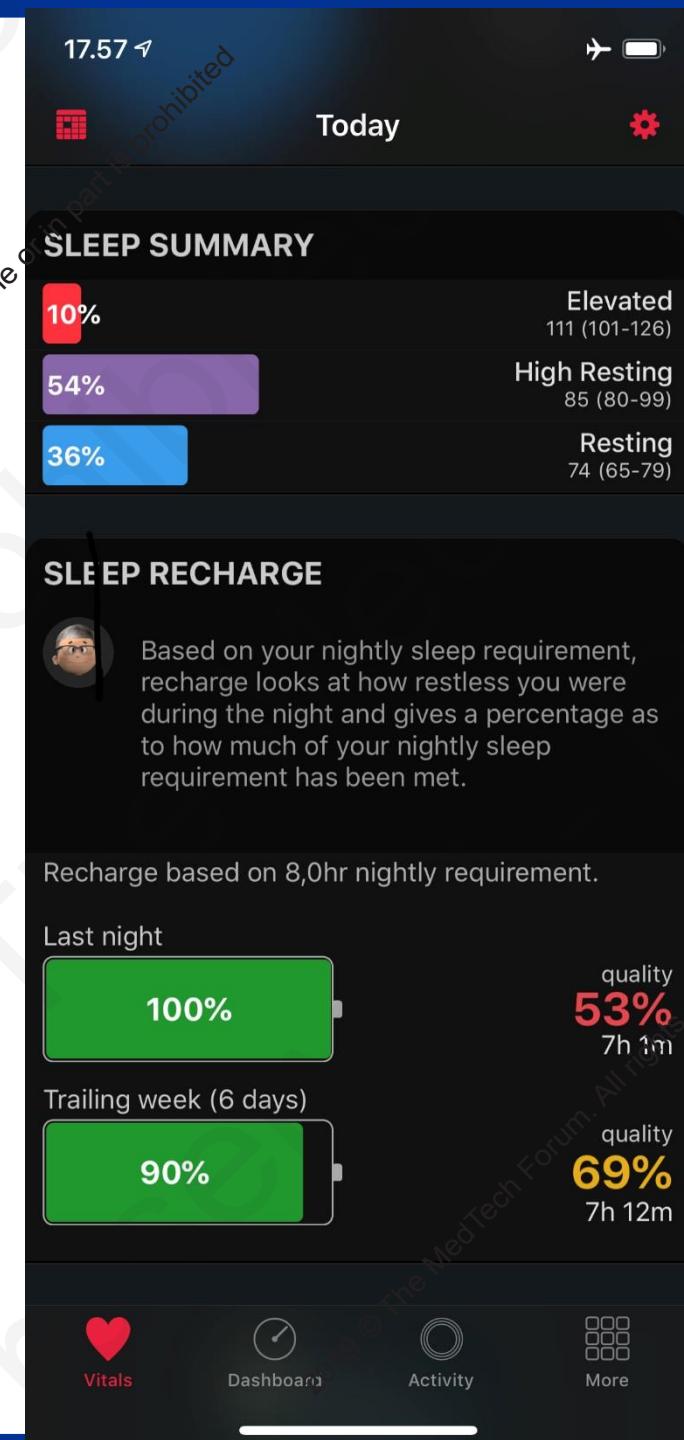
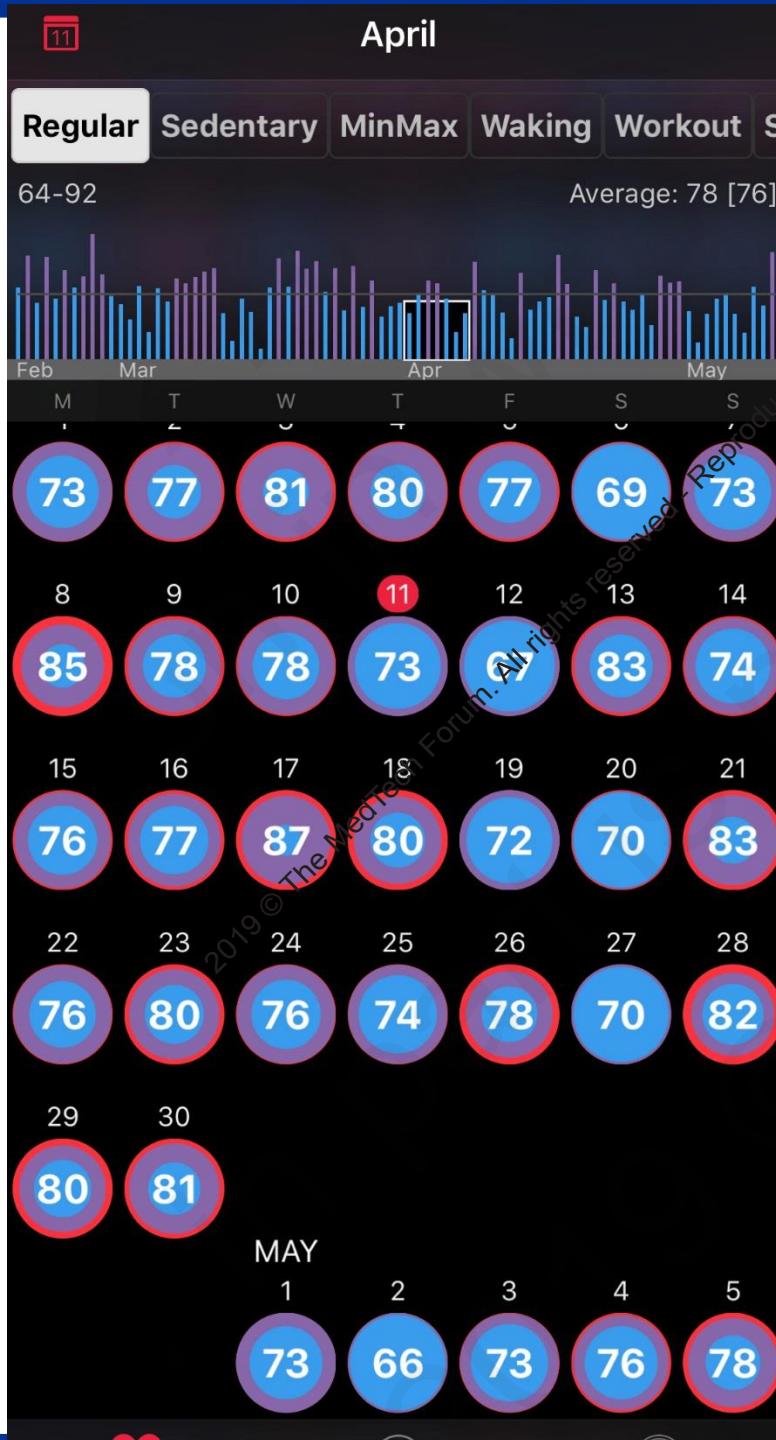
| Prøvesvar | |
|----------------------------------|--------------|
| VOLUMEN;PT(U) | 26/05/2018 > |
| Sundhedsfagligt personale | |
| URINOPSAMLING... | 26/05/2018 > |
| Sundhedsfagligt personale | |
| 5-HYDROXYINDOL... | 25/05/2018 > |
| Sundhedsfagligt personale | |
| 5-HYDROXYINDOL... | 25/05/2018 > |
| Sundhedsfagligt personale | |
| VOLUMEN;PT(U) | 25/05/2018 > |
| Sundhedsfagligt personale | |
| URINOPSAMLING... | 25/05/2018 > |
| Sundhedsfagligt personale | |
| KROMOGRANIN A;P | 23/05/2018 > |
| U. Knigge, Kirurg | |
| CD/DVD-brænding... | 14/05/2018 > |
| U. Knigge, Kirurg | |
| PET-CT Ga-68-DO... | 28/03/2018 > |
| Billeddiagnostisk afdeling, Læge | |
| CT Helkrop (PET-C... | 28/03/2018 > |
| Billeddiagnostisk afdeling, Læge | |
| Ga-68-Dotatoc in... | 28/03/2018 > |

54

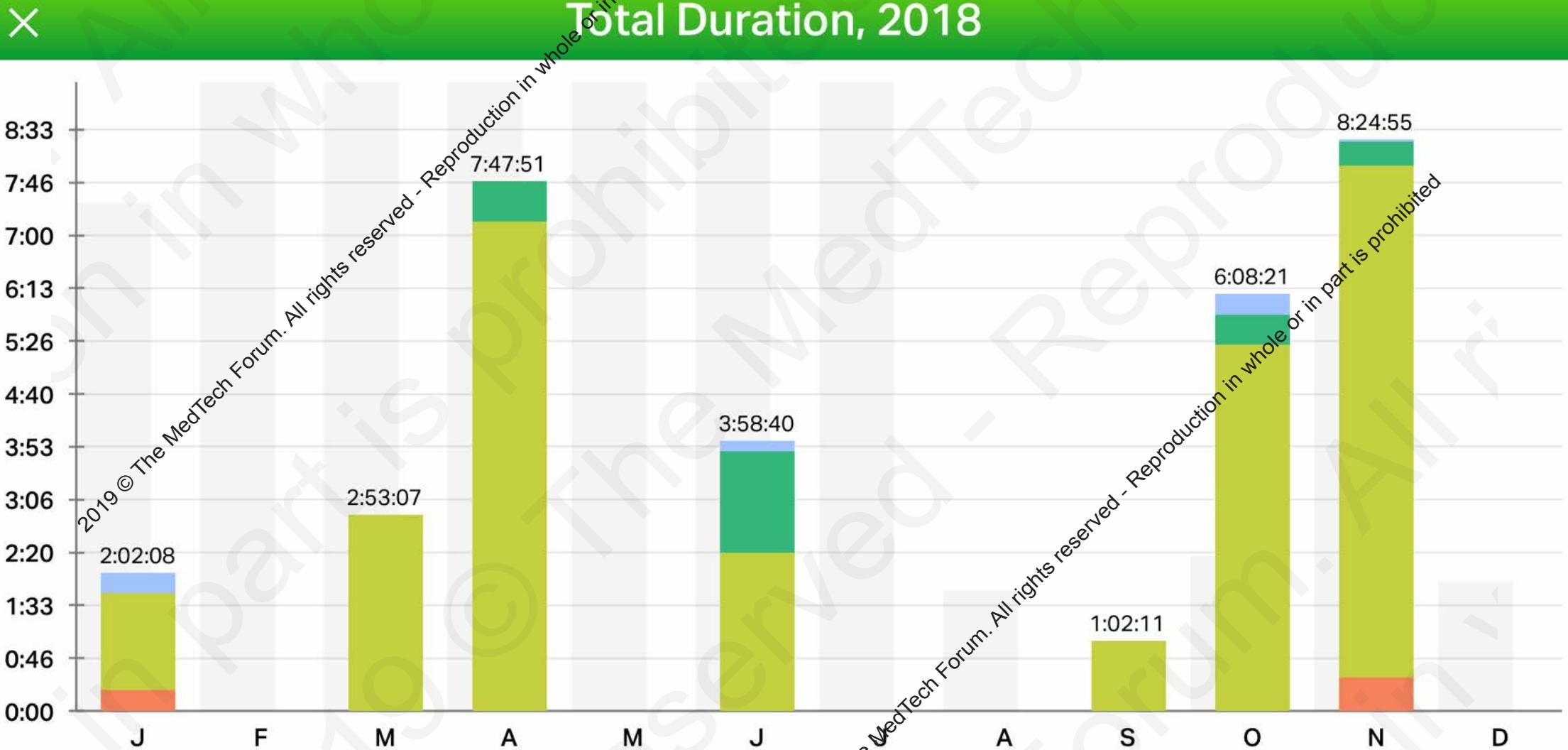
Hba1c

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Exercise in Hours



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Trend

Time Range

12 Weeks ▾

06-09-2019 - 28

8-11-201

Blood Glucose

30 Nov

000

Juc

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十

d Entry

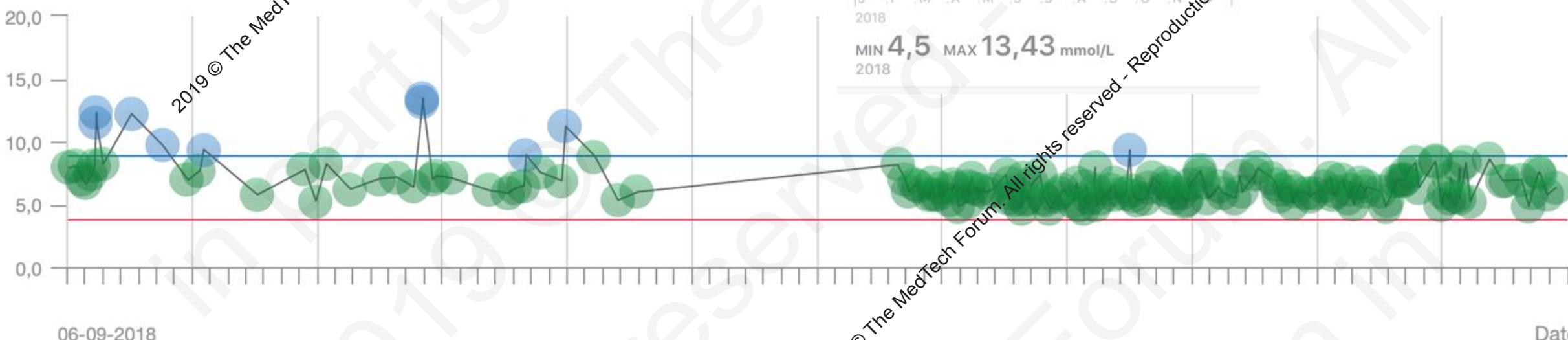
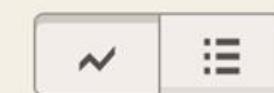
Display Options

JUNE 2018

111

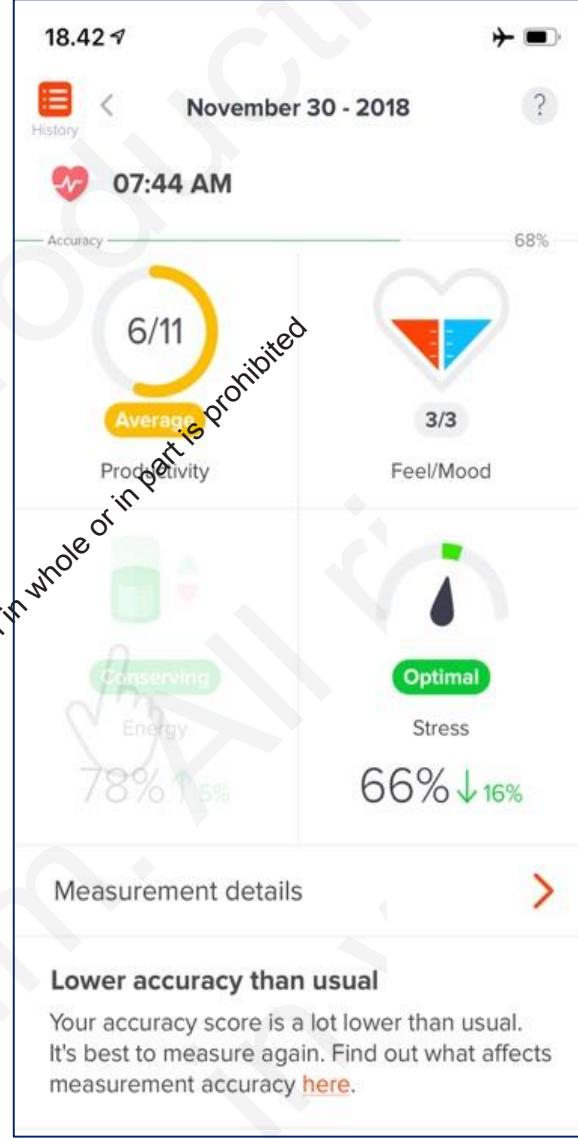
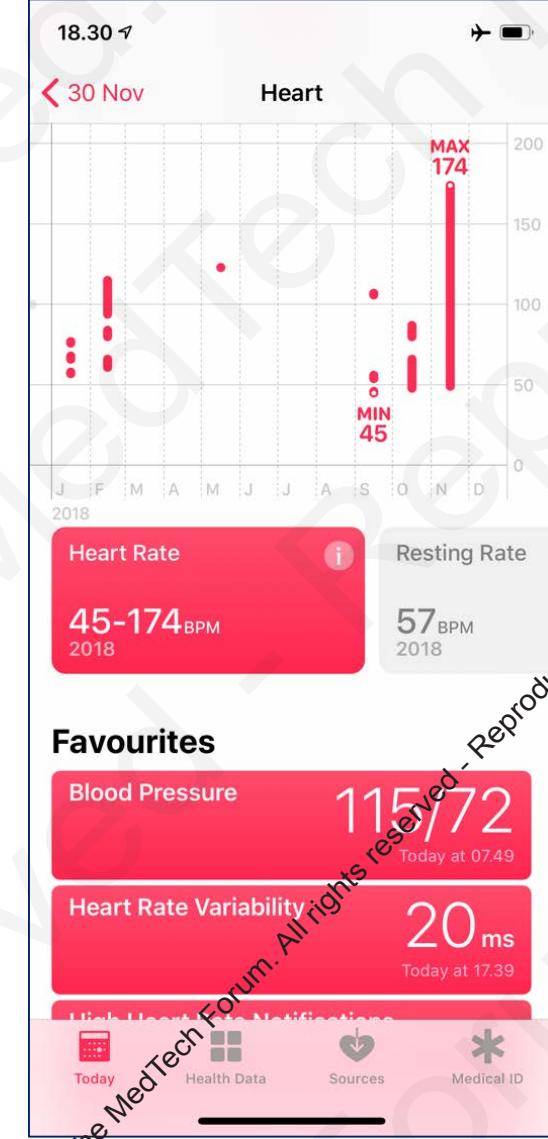
AUGUST

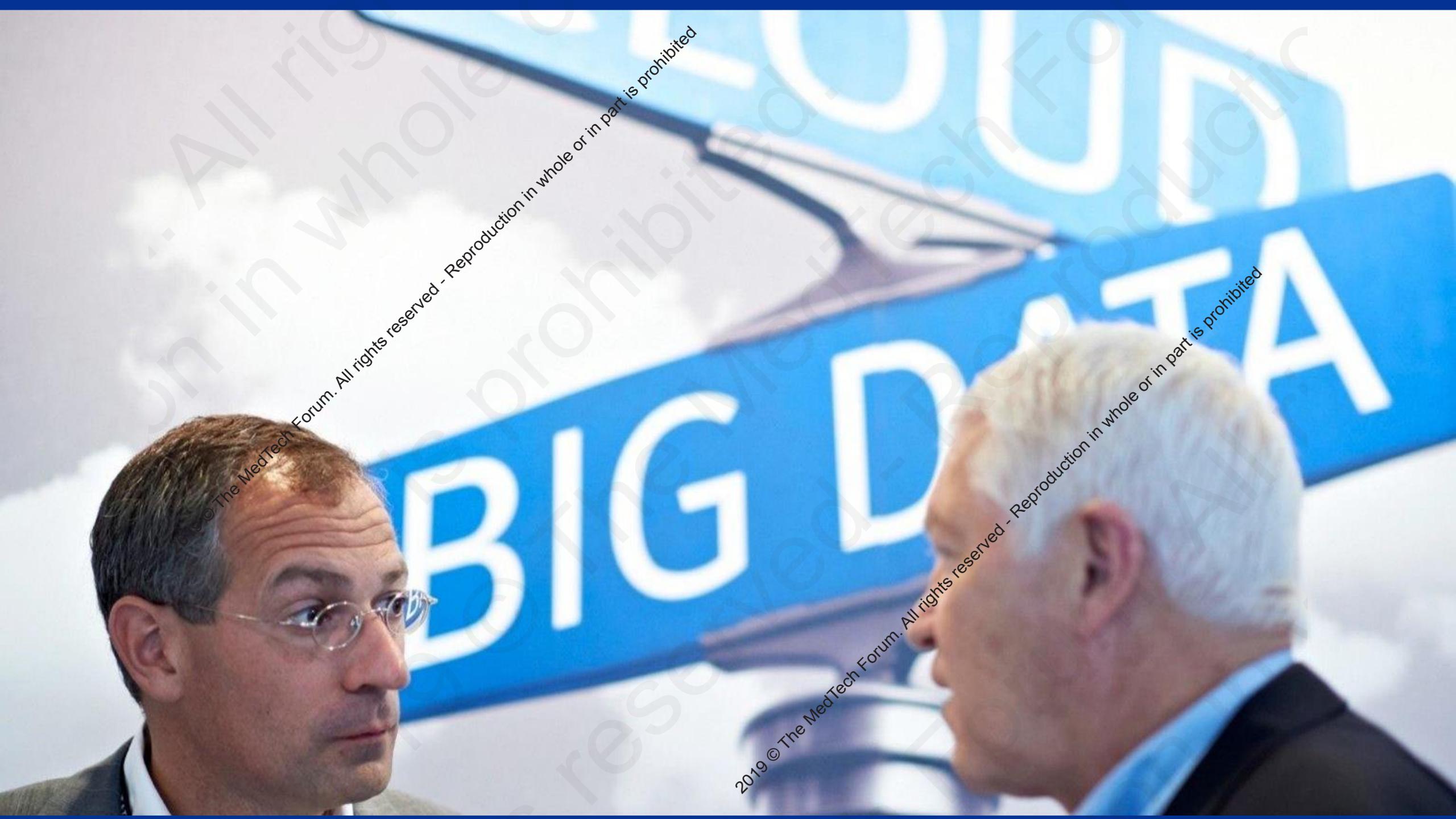
Distribution



Average BG (mmol/L)

6,7 ± 1,5





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Homero Rivas @mHealthSurgeon 5h

@clausfn Excellent lecture at #DHL2015 Your son and family must be very proud of you!!! @Nuviuun

2 3



Enayati عنایتی @EnayatiHomecare 6h

"Give the user full control of their health data" says @clausfn #DHL2015

1 2



Enayati عنایتی @EnayatiHomecare 6h

#DHL2015 @clausfn parents able to see diabetic children's blood sugars on their mobile devices instantly

1 1



Evangelia Balanou @dhGelly 7h

@clausfn on stage at #dhl2015 #interoperability #digitalhealth #interop @Continua #qs



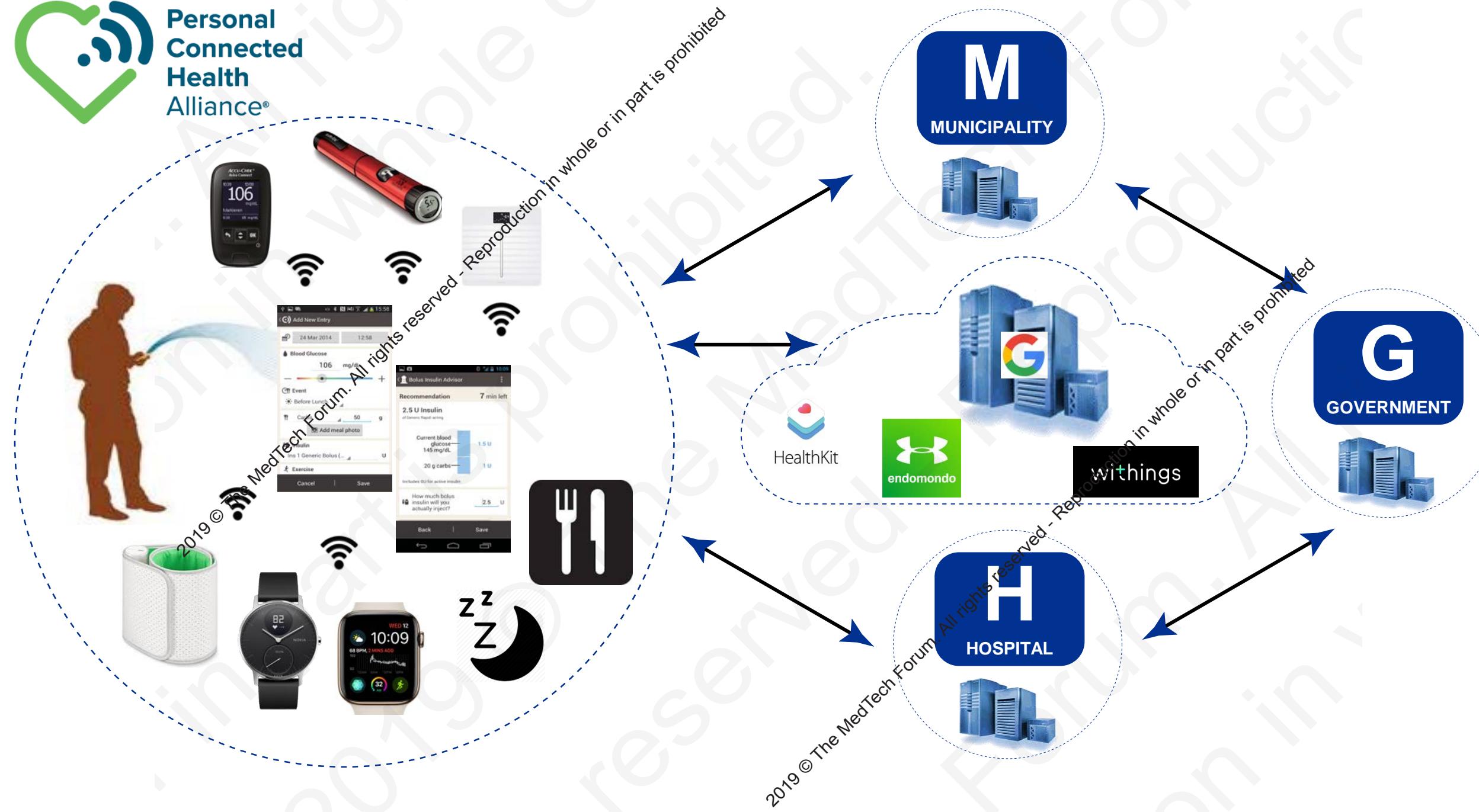
Dubai Digital Health Live 2015



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Health
Alliance®**





David Parkins

Europe

Apple's Tim Cook blasts Silicon Valley over privacy issues



Apple chief executive Tim Cook addressed privacy and artificial intelligence at a European Union conference at the E.U. Parliament in Brussels Oct. 24. (AP)

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Screenshot

**“the business of
selling ads against
personal data has
become a “data
industrial complex”**

**“Personal data
collection is being
‘weaponized against us
with military efficiency’”**

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SAY GDPR



ONE MORE TIME!!!

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“The future is still so much bigger
than the past”

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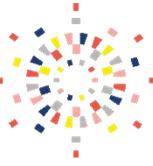
***It's time to reset the balance
of power on the web and
reignite its true potential.***

***Sir Tim Berners-Lee
Inventer of the internet***

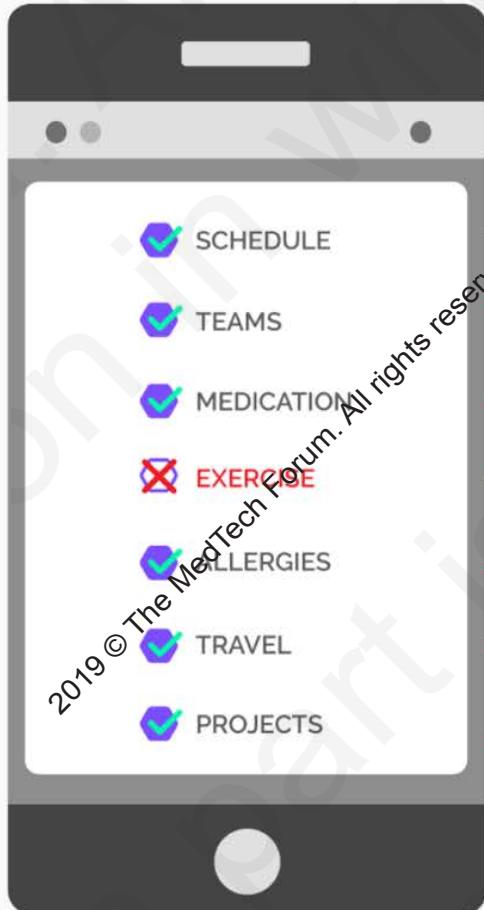
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Decentralized Web 3.0



TRUSTED SOLID APP

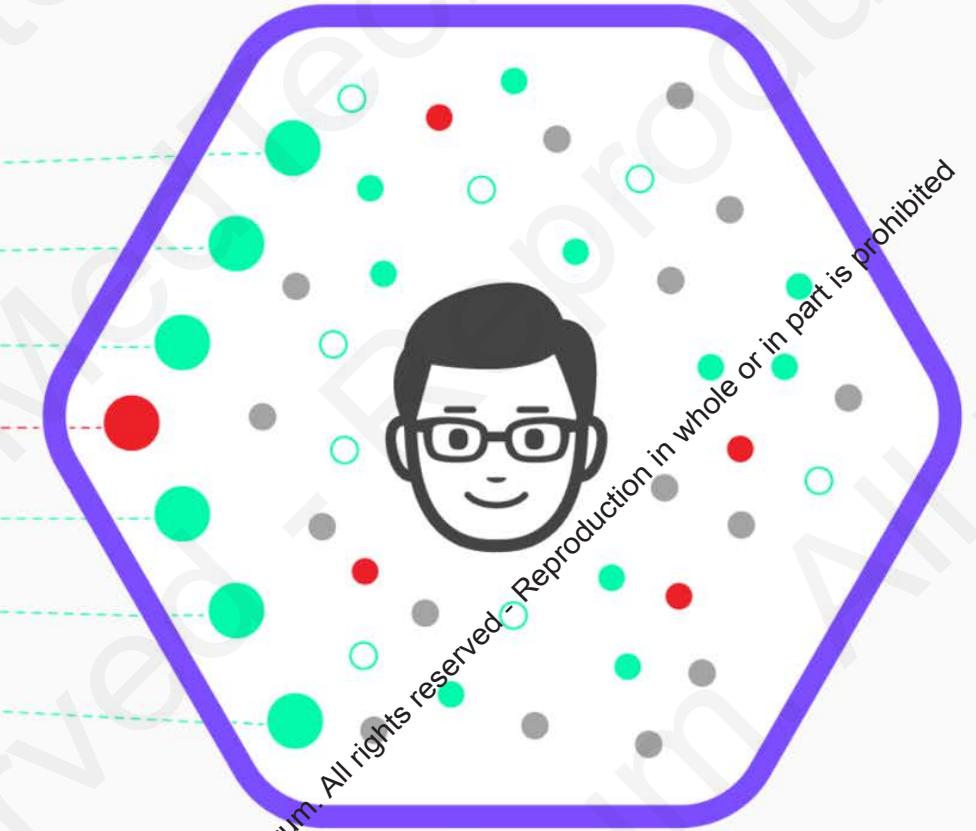


*Confirmation of user's granted permission



*Allocated data given by user can be accessed only by selected app/user

SECURE USER POD



*Indicates requested data



*User's uploaded data



*Denied requested data

Do YOU have a POD on Solid ?

Claus F. Nielsen – Solid Home

This is a public homepage

Data

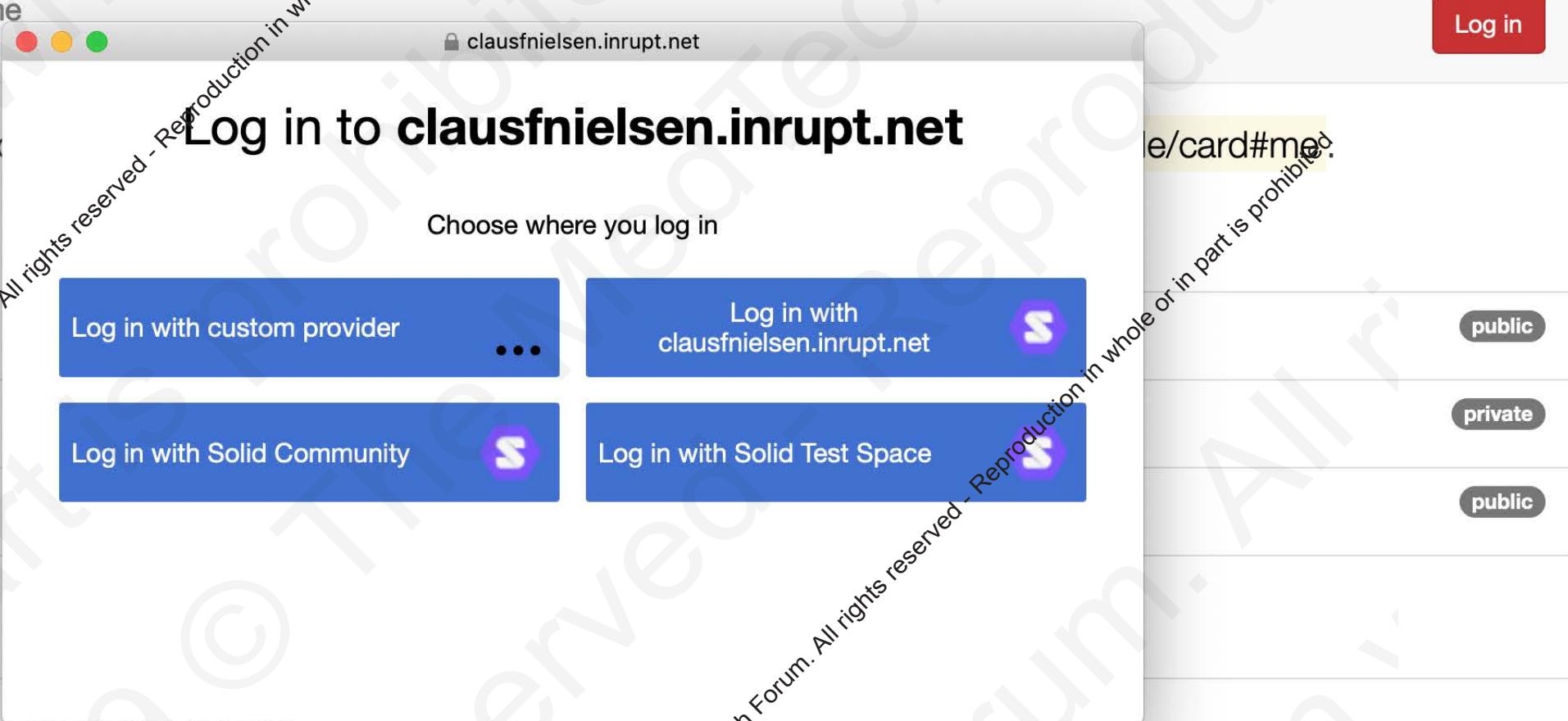
Profile

Inbox

Public Folders

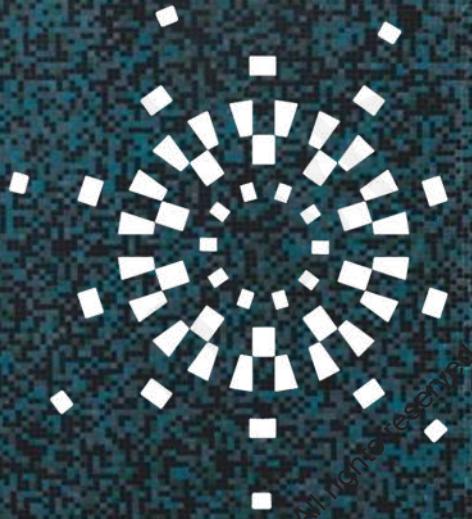
Apps

Getting started with Solid and Data Browser



**“All truth passes through three stages.
First, it is ridiculed.
Second, it is violently opposed.
Third, it is accepted as being self-evident”**

- Arthur Schopenhauer

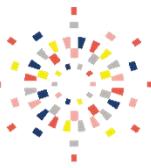


DATA for GOOD FOUNDATION

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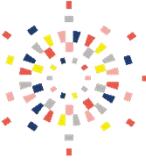
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Creating trust ?

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Dictionary

trust

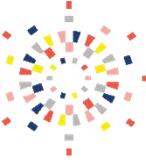
trust
/trʌst/ *[audio icon]*

verb

- LAW**
an arrangement whereby a person (a trustee) holds property as its nominal owner for the good of one or more beneficiaries.
"a trust was set up"
synonyms: safe keeping, [keeping](#), [protection](#), [charge](#), [care](#), [custody](#); [More](#)
- archaic**
allow credit to (a customer).
"all persons are forbid to trust my wife, Sarah"

Translations, word origin, and more definitions

Why D-BOKS?



Civil society:

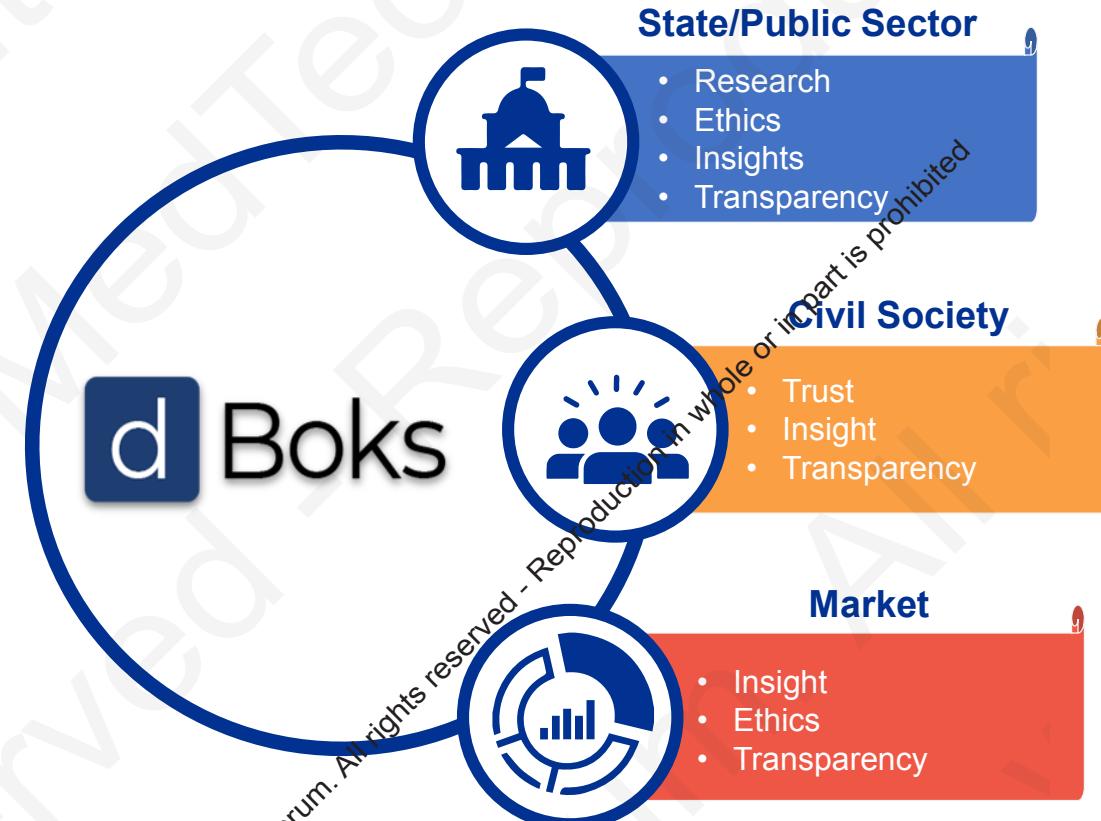
Lack of Trust! - transparency and overview

State / Public sector

Lack of data access and insights (research and development)

Market / Private sector

Lack of data access and insights (business development)





Title...

Data for Good Foundation
is a commercial
foundation in Denmark
with a not for profit
purpose



DATA OVERVIEW Full Transparency on Your Terms and Conditions

borger.dk sundhed.dk



BENEFITS FOR YOU

GET NEW INSIGHT WITH YOUR DATA

- Digital footprints
- Consumption
- Health
- Resources
- Networks & Relationships



DONATE YOUR DATA FOR RESEARCH

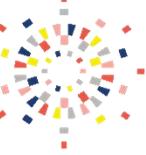
- Heart Association
- Cancer Society
- Universities



MAKE MONEY ON YOUR DATA

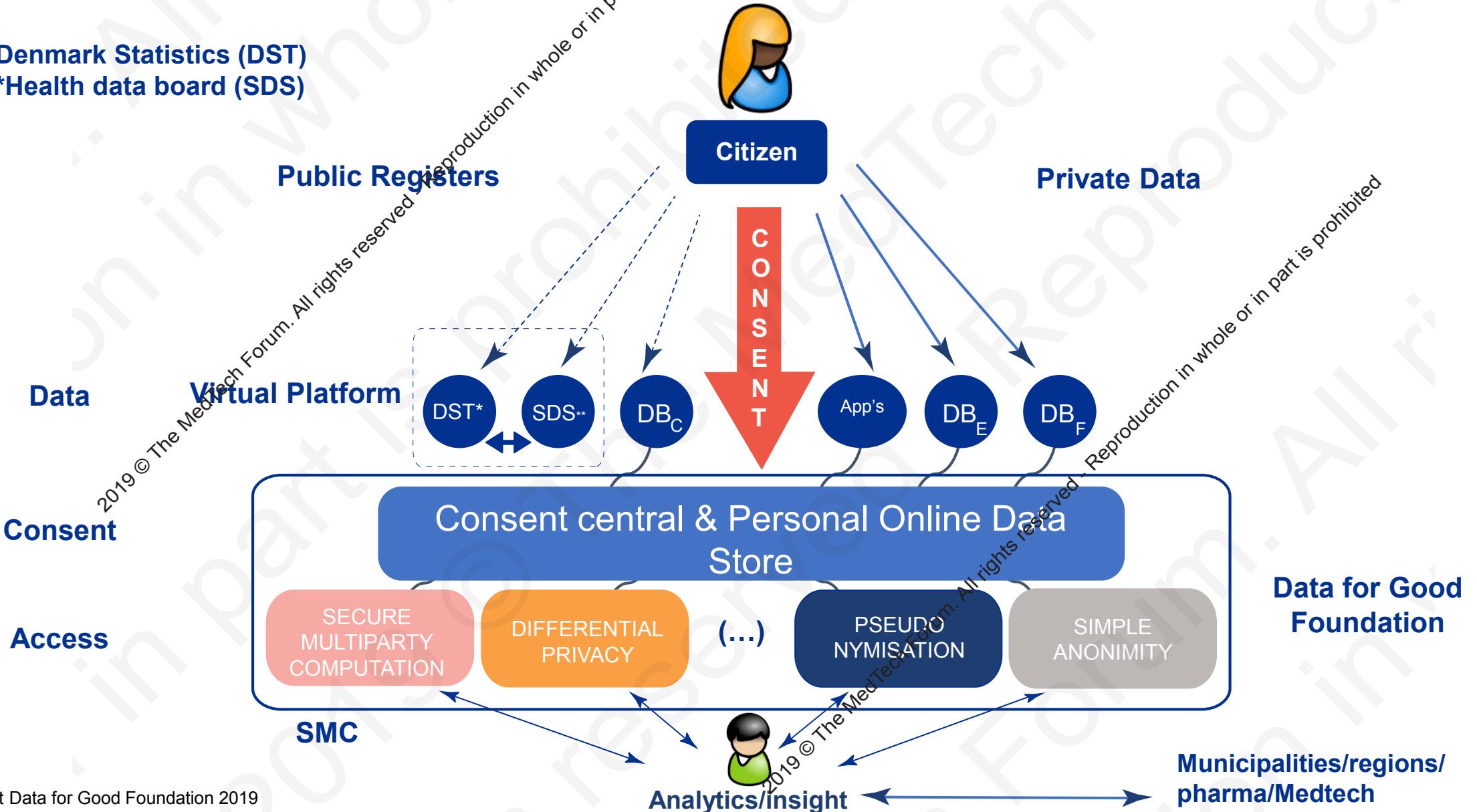
- Get Paid for Your data!





Use cases: cancer, diabetes & mental health

***Denmark Statistics (DST)
Health data board (SDS)



← → C https://dboks.secata.com/my

Apps PPCN Mail OTH gmail DFGF Mail Team Drives Hubspot Timely Trello Peak FC OTH Demo OTH General free ...

Jens Jensen

d Boks

Mine data

Access Requests 1

consents 1

Health

Master data

Height 169 cm

Weight 78 Kg

Doctor Niels Jensen

Medicine Anti-astma inhalator
Painkiller

Treatment Asthma progressed
Physiotherapy course, Center for Sports Injuries

Economy

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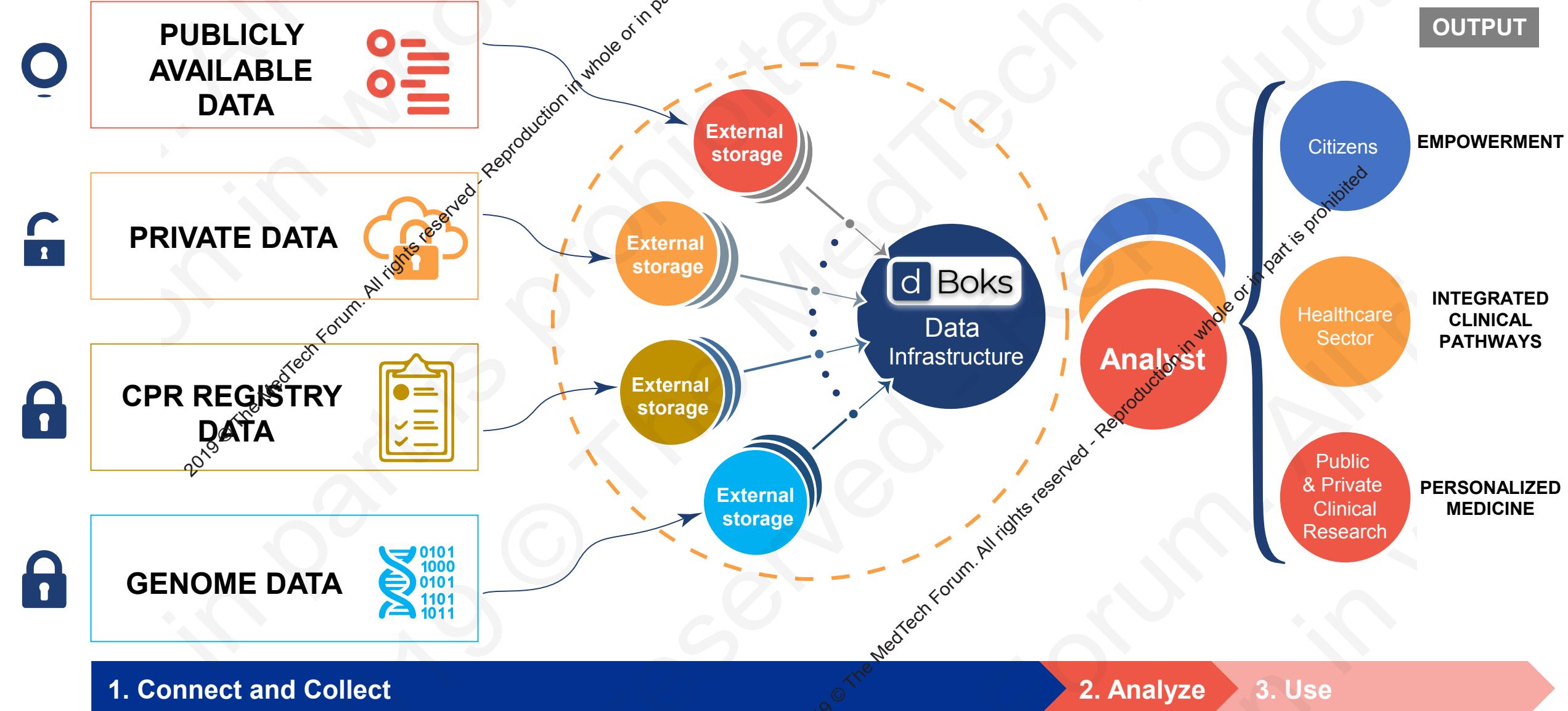
My public health data registry

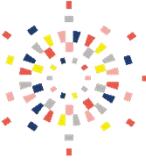
The screenshots demonstrate a mobile application for managing health data, likely a patient portal or a public health registry. The interface is primarily red and white.

- Screenshot 1:** Home screen showing a timeline of entries. The top entry is from 19.15, dated 26. MAJ 2017, titled "Journal(Diabetes UNS med a... NOH, HOSPITALERNE I NORDSJ...)".
- Screenshot 2:** Detail screen for a laboratory test on 19.15. It shows results for "Urin opnødes" (5-Hydroxyindolylacetat;... 32 µmol/d) and "5-Hydroxyindolylaceta... 21,5 µmol/L".
- Screenshot 3:** Detail screen for a medical note on 19.17, titled "Lægens notat EPIKRISE (EPIKRISE)". It contains a detailed description of symptoms and treatment.
- Screenshot 4:** Detail screen for a journal entry on 19.22, dated 21. Marts 2012. It includes sections for "FORLØB" (Diagnose: Akutte mavesmerter, Sted: HOSPITALERNE I NORDSJÆLLAND), "Startdato" (20. marts 2012), and "Slutdato" (22. marts 2012).
- Screenshot 5:** Home screen showing a timeline of entries. The top entry is from 19.14, dated 19. APRIL 2019, titled "Prøvesvar Biokemi (blod, urin m.v.)".

Each screen includes a header with the date, signal strength, and battery level. Navigation icons for "Hjem", "Tidslinje", and "Profil" are at the bottom of each screen.

Health Data Exchange – HedaX project



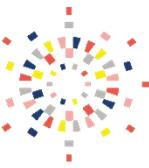


Are Your organisation /Company ready for a data ethical business model?

If Yes, Please Join Us

(If no,it's ok, we can wait)





The
Economist

FEBRUARY 24TH-31ST 2012

Economist.com

Immigration: Obama gets it right
The rift between China and North Korea
Can Egypt's revolution be rescued?
How to reform America's lawyers
The mystery of the Bermuda Triangle

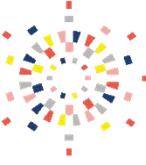
The next supermodel



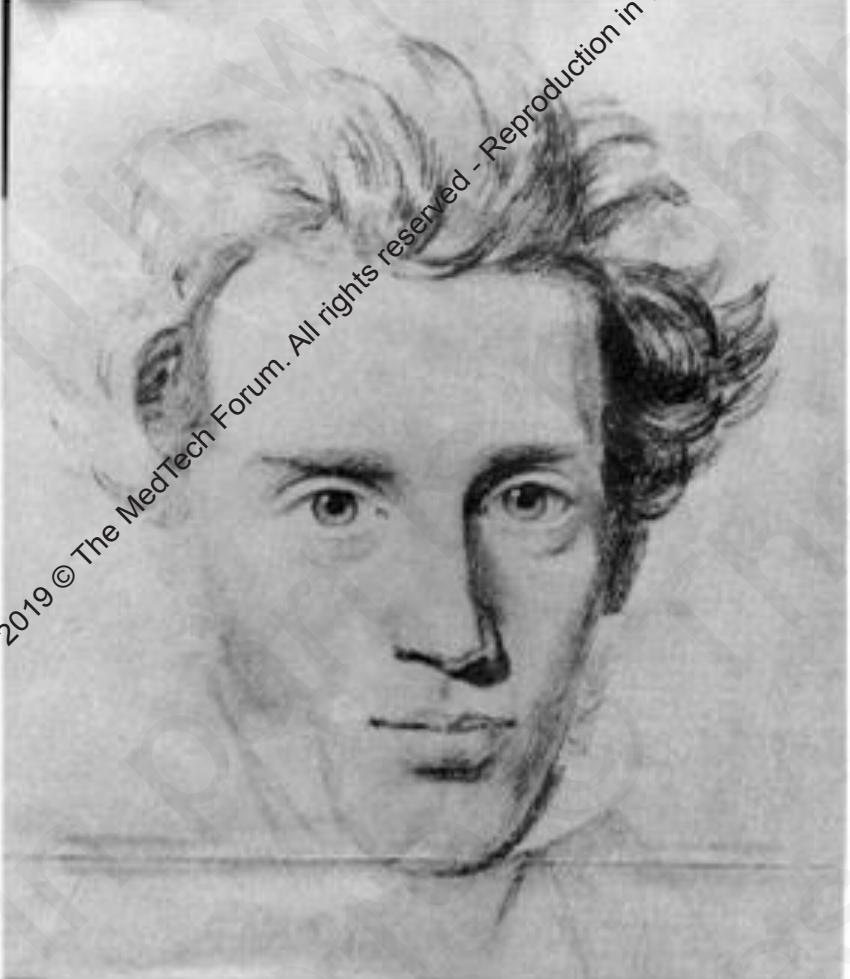
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Can a Danish model gain adoption globally?

Yes, it can!



Finding them where they are



"If one is truly to succeed in leading a person to a specific place, one must first and foremost take care to find him where he is and begin there. This is the secret in the true art of helping"

Soren Kierkegaard
(1863)

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