Udfordringer og læring fra danske FHIR-profileringer af PRO og hjemmemonitorering


NYHAVN

FHIR

De lette valg

- STU3 vs R4 vs R5
  - … eller hvad?

Det (første) tunge slæb (borgerorienteret)

- Potentielt konfliktende profileringer/definitioner
  - Patient vs. Person
  - Projektets opfattelse af udfordring og model
- Pårørende
- (Gængse) udfaldsrum?
  - Hvad med rigsfællesskabet?
- Terminology og nomenklatur

Det (kommende, tunge) slæb

- Input tilbage til HL7 DK FHIR SIG
  - Enighed?
  - Interesser?
- Input fra det fjerne udland i form ændringer til standarden
  - Hvad hvis (subtile) elementer ændrer sig?
- Input fra det nære udland
  - Det nordiske fællesskab (Sverige, Norge, Finland, Island, Færøerne)

Modenhed

HL7 has five descriptive terms that describe the level of stability and implementation readiness associated with different aspects of the specification. They are as follows:

Standard Level	Description
Normative	This content been approved by the ANSI standards process. It has been subject to review and production implementation in a wide variety of environments. The content is considered to be stable and has been 'locked', subjecting it to FHIR Inter-version Compatibility Rules. While changes are possible, they are expected to be infrequent and are tightly constrained.

For all content marked with one of the following indicators - i.e. not 'Normative', the following statement applies:

> The information contained in this (portion of a document) is not part of this American National Standard (ANS) and has not been processed in accordance with ANSI's requirements for an ANSI Standard. As such, this (portion of a document) may contain material that has not been subjected to public review or a consensus process. In addition, it does not contain requirements necessary for formal conformance to the standard.

Trial Use	This content has been well reviewed and is considered by the authors to be ready for use in production systems. It has been subjected to ballot and approved as an official standard. However, it has not yet seen widespread use in production across the full spectrum of environments it is intended to be used in. In some cases, there may be documented known issues that require implementation experience to determine appropriate resolutions for. **Future versions of FHIR may make significant changes to *Trial Use* content that are not compatible with previously published content.**
Draft	This portion of the specification is not considered to be complete enough or sufficiently reviewed to be safe for implementation. It may have known issues or still be in the "in development" stage. It is included in the publication as a place-holder, to solicit feedback from the implementation community and/or to give implementers some insight as to functionality likely to be included in future versions of the specification. Content at this level should only be implemented by the brave or desperate and is very much "use at your own risk". The content that is *Draft* that will usually be elevated to *Trial Use* once review and correction is complete after it has been subjected to ballot
Informative	This portion of the specification is provided for implementer assistance and does not make rules that implementers are required to follow. Typical examples of this content in the FHIR specification are tables of contents, registries, examples, and implementer advice
Deprecated	This portion of the specification is outdated and may be withdrawn in a future version. Implementers who already support it should continue to do so for backward compatibility. Implementers should avoid adding new uses of this portion of the specification. The specification should include guidance on what implementers should use instead of the deprecated portion

"Men Device ressourcen er jo endnu ikke normativ!"

Paradigmeskifte i forhold til brug af standarder

FHIR ressourcernes modenhed afhænger af at de bliver brugt

Innovative løsninger er lettere at smede mens jernet er varmt
- så længe standarderne ikke er modne kan de lettere påvirkes

Buschauffør vs. bagsædepassager

Mange danske løsninger ...

- er meget innovative i forhold til standarderne på området. For at bevare det innovative indhold må fokus være på at "spænde disse løsninger foran udviklingen af standarderne" og derved **drive udviklingen** fremad i en god retning.

Vælger man i stedet at **vente på standarderne**, kommer man bagud på innovation.

Vælger man at **ignorere standarderne**, vil de udvikle sig langsommere og måske i en helt anden retning, således at ens forretning ender på et sidespor i fremtidens marked.

HL7 DK FHIR SIG

- Skabe overblik over forskellige profileringer
- Etablere/kurere fælles profiler
  - På tværs af domæner
  - På tværs af problemstillinger
- Etablere fælles eller forenelig terminologi
- Etablere best practice i DK
- Etablere nordisk sammenhæng

Gravide med komplikationer (GMK)

Region Midt / Aarhus Universitetshospital afd. Y

FHIR profiler publiceret på 4S's Confluence:
https://issuetracker4s.atlassian.net/wiki/spaces/FDM/overview

(senest publicerede profilering er baseret på STU3, men en opdatering er på vej, baseret på R4).

FUT Fælles (U) Telemedicin

Alle regioner, alle kommuner

FHIR dokumentation findes på
https://docs.ehealth.sundhed.dk/latest/ig/index.html

- Bleeding edge, STU3

Læringer, generelt

HL7, PCHA, IHE. IEEE og lignende standardiseringsfællesskaber og arbejdsgrupper er meget åbne for deltagelse og input fra early adopters - også uden at man nødvendigvis skal være betalende medlem eller committe sig til en masse arbejde.

Læringer, generelt

Flere af de standarder, vi er begyndt at anvende i GMK og FUT er udviklet af grupper bestående næsten udelukkende af teknikere og stort set uden input fra kliniske brugere eller empiri fra konkret anvendelse. Dette har bestemt ikke været ønsket fra standardiseringsorganisationernes side, men brugerne har hverken prioriteret at deltage eller at sende feedback tilbage. Samtidig er der sikkert mange potentielle anvendere af standarderne der forholder sig afventende (efter det gamle paradigme) i forventning om at standarderne modnes. Men hvordan forventer de, at dette kommer til at ske?

Læringer, fra GMK

GMK gør noget, som resten af verden ikke tør (den kliniske praksis i stort set hele verden er, at nogle af de patientgrupper, man i GMK lader gå hjemme, vil skulle indlægges)
- kan nævnes i forbindelse med at vi i DK er på forkant med mange ting, og derfor hverken kan eller bør forvente at standarderne er modne til de ting, vi ønsker at bruge dem til.

> *There are only two hard things in Computer Science: cache invalidation and naming things.*
>
> *-- Phil Karlton*