

MyData-4-Pandemics Running Meeting Minutes

July 2021 to ...

Links

[Google drive for the project](#)

[Website](#)

[Charter - original \(up to June 2020\)](#)

[Charter - renewed \(up to June 2021\)](#)

[Logo](#)

[Archives minutes - June 2020 to October 2020](#)

[Archives minutes - November 2020 to June 2021](#)

[Work plan slides](#) (June 2020)

HOW TO CONTRIBUTE TO THIS DOC:

- To suggest edits, use suggest mode
- To comment or ask a question, use the commenting tool

If in doubt ask help from Slack from the #mydata-4-pandemics channel

ONGOING INFO	3
FUNDING Potential follow-up	3
OPEN actions (as of current date)	3
Wednesday 27th April - 14:00 - 15:00	4
Wednesday 2nd February - 14:00 - 15:00	8
Wednesday 16th February - 14:00 - 15:00	10
Wednesday 3 February 2022 - 14:00 - 15:00	13
Wednesday 19 January 2022 - 14:00 - 15:00	14
Wednesday 14 January 2022 - 11:00 - 12:00 (Isabelle/Jay)	18
Agenda/Objectives	18
Discussion (highlights)	18
Actions	18
Wednesday 5 January 2022 - 14:00 - 15:00	20
Wednesday 8 December 2021 - 14:00 - 15:00	23
Wednesday 24 November 2021 - 14:00 - 15:00	26
Wednesday 10 November 2021 - 14:00 - 15:00	28
Wednesday, 13 October 2021 - 14:00 - 15:00	32
Wednesday, 29 September 2021 - 14:00 - 15:00	33
Wednesday, 15 September 2021 - 14:00 - 15:00	35
Wednesday, 1st September.2021 - 14:30 - 15:00	37
Wednesday, 20 July 2021 - 14:00 - 15:00	38
Wednesday, 7th July 2021 - 14:00 - 15:00	42

ONGOING INFO

FUNDING Potential follow-up

([letter](#) - intro + description of ICAWAS
[draft budget](#) for the 4 phases

Organisation	Amount	Status	Results
CLOSED/ Rejected			
EIT digital	500 K	March 2020	failed: no business case
eSSIF - 1st phase	15 K	May 2020	approved
https://www.lb-foundation.ch/	?	April 2021	failed: out of scope
https://oakfnd.org/	?	April 2021	failed: out of scope
https://haslerstiftung.ch/en/welcome-to-the-hasler-foundation/	?	April 2021	no answer
https://www.edmondderothschildfoundations.org/what-we-do/health/default.aspx	?	April 2021	no answer
https://i4trust-open-call.fundingbox.com/	120K	< 6 Sep 2021, 2 pm CET	not submitted, too complicated
Data Trust Initiative [ref]	150 K	25 Nov	not approved
TO DO			
Horizon Europe	3 MEUR	April 2022	

OPEN actions (as of current date)

WHAT	WHO	DATE IN
Identify Citizens/ HCPs groups from Asia/Africa that could be interested to collaborate on ICAWAS	Jay	14 Jan
Contact organisations in Asia/Africa that could be interested to collaborate (and fund) M4P related initiatives	Jay	14 Jan

Propose some date + objective + agenda for presentation to Fujitsu (early March) proposal slide decks created by MyData side to get approval from Fujitsu. • MyData4Children (Date: Nov 26) • Human Colossus Foundation (Date: Jan 21)	Isabelle	5 Jan
Resubmit White paper for publication	Isabelle	8 Dec
Definition of proper onboarding process to M4P (and to the TG in general)	Fredrik	8 Dec
check connection with people that could help promote M4P (from Deloitte)	Sterling	10 Nov

Wednesday 27th April - 14:00 - 15:00

Present: Jay, Isabelle, Fredrik,

Apologies:

Action Points:

OPEN

- (Dixon). Follow up with Lucy on opportunity to have support from board on M4P
- (Isabelle) Fujitsu presentation - **key messages** (Isabelle to prepare slides afterwards) => DELAYED ?
 - For employees of Fujitsu, in Europe and elsewhere. Several different presentations; AI ethics, AI Governance etc.
- (Frederik) Definition & Onboarding to M4P: updated charter ??, 1h basic welcome and updating

Agenda

- Lessons learned from discussing M4P principles outside of the normal MyData forum
- Data Act - [ref] and more specifically comments related to crises situations (17.1 and 18.5)
- What do we want to do with the M4P TG.
 - Does it make sense to keep it and what for (we know there will be other pandemics)
 - or should we close it as a TG (what can we do more/differently - who is interested) ?

Discussion

1. Horizon Europe ICAWAS proposal: Lessons learned from discussing M4P principles outside of the normal MyData forum
 - Isabelle:
 - lack of understanding/ knowledge outside of MyData of DGA
 - we need more than MyData operators (see 5 pillars of ICAWAS)
 - public authorities: why bother as we can have access to data by other means (see Data Act)

- Fredrik - same feeling that authorities are pushing more data altruism
- 2. Data Act 17.1 and 18.5 do allow authorities to have access to potentially identifiable data in context of emergencies.
 - Jay -
 - authorities need data - as much as possible identifiable to manage data. And there is an issue in the consent related model (with Data intermediaries) that not all the population is involved => dilemma
 - in terms of monetization; there are individuals and organisations (e.g. data intermediaries but not checking on how data are shared , and data processors who are managing their data) => need to navigate across the different models
 - Isabelle: we need to make MyData operators aware that we need more than pure data intermediaries services
 - Fredrik: need to push this during the MyData conference
- 3. What do we want to do with M4P TG
 - Isabelle - close the TG officially - we have a clear concept and we even proposed it as a proposal for a funded project (Horizon Europe).
 - Ian: If the group is to close, i'd still be in favour of doing so with that paper/ post we have long discussed - what went wrong in the pandemic around personal data; and therefore what we should do differently for next time. We need that published somewhere we can all point to on an ongoing basis.
 - Fredrik - right thing to do - have a plan to when and if we want to reactivate it - we need to have enough information to reactive it whenever needed
 - Jay - we should keep track -
 - lessons of the pandemics have not been learned and the pandemic is not gone yet (60 Millions of people in lockdown in China, what about contact tracing, what about information that went to public health authorities, why vaccine hesitancy like in the US one of the most advanced economy in the world)
 - is our work in TG finished as a MyData group

- Data Trusts is a new model for data sharing mediating by the provider - and has the benefit of being routed in a community; offers a model that may work very well
- Isabelle - at this point from a MyData perspective we are probably at the end of what we can do as a TG - but we need to be ready to reactivate... if new elements are popping up

Close but be prepared to reactivate - putting conclusion on a white paper

Wednesday 2nd February - 14:00 - 15:00

Present:, Dixon, Isabelle, Dan, Rupert, Lotta, Lal

Apologies:,

Action Points:

NEW

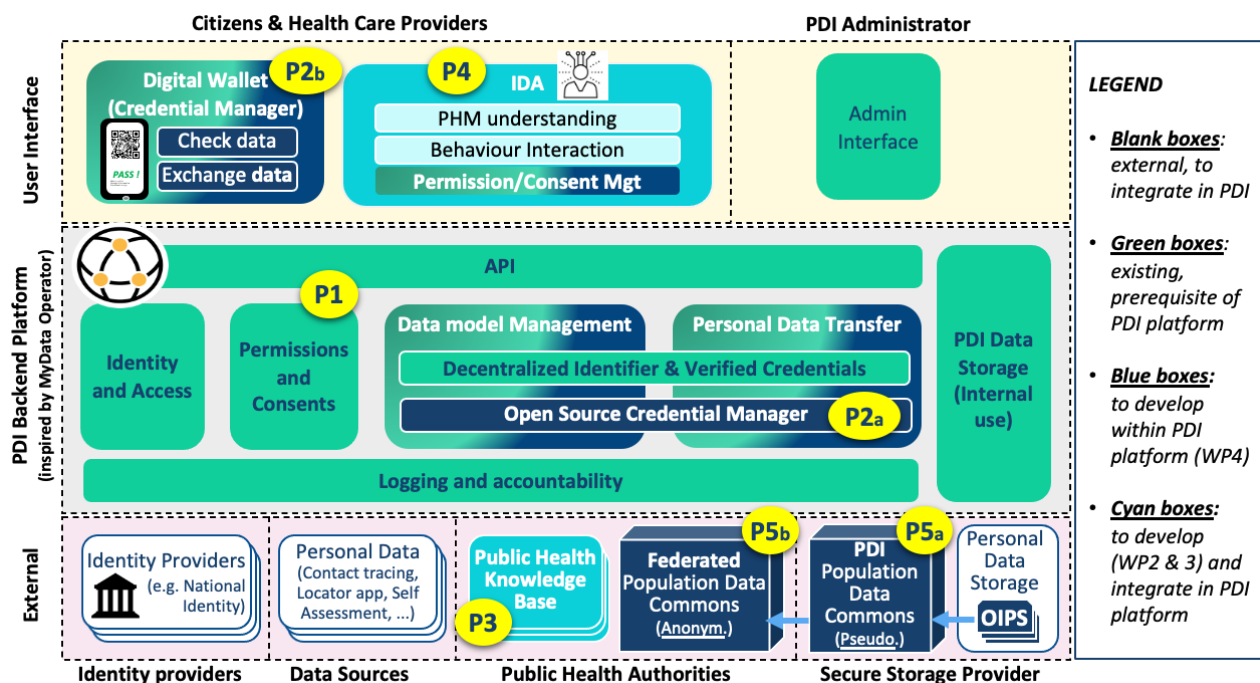
- clarify integration/ API between PDI and virtual assistant

OPEN

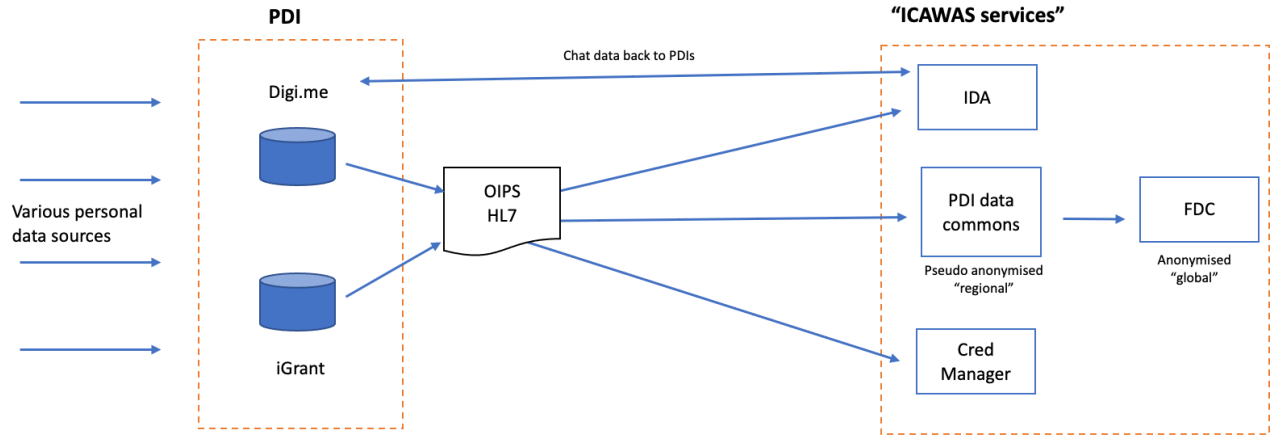
- (Dixon). Follow up with Lucy on opportunity to have support from board on M4P
- (Isabelle) Fujitsu presentation - **key messages** (Isabelle to prepare slides afterwards) => DELAYED ?
 - For employees of Fujitsu, in Europe and elsewhere. Several different presentations; AI ethics, AI Governance etc.
- (Frederik) Definition & Onboarding to M4P: updated charter ??, 1h basic welcome and updating

Agenda

- architecture of M4P/ ICAWAS - and clarify components require personal data access (outbreak IPS, data commons, credentials, integration with virtual assistant and KB) in addition to MyData operator services.



DISCUSSION



- 1) Clarity on who is responsible for each of the key "ICAWAS services".
- 2) Given the existing technology, what might the user journey look like?
- 3) How will each of the "ICAWAS" services interact with each other and the PDIs?
 - What are the key data flows (to / from where, direction, push/pull, etc.)?
 - Transport mechanisms
 - Standards
 - Etc..
- 4) The key being to understand who is integrating with what and broadly what the roles and effort might be

Wednesday 16th February - 14:00 - 15:00

Present: Dixon, Isabelle

Apologies: Fredrik

Highlights:

- Seen very quick scale up and scale down of restrictions over the last month in several countries (eg. .no and .dk)

Action Points:

- (Dixon). Follow up with Lucy on opportunity to have support from board on M4P
- (Isabelle) Fujitsu presentation - **key messages** (Isabelle to prepare slides afterwards) => DELAYED ?
 - For employees of Fujitsu, in Europe and elsewhere. Several different presentations; AI ethics, AI Governance etc.
- (Frederik) Definition & Onboarding to M4P: updated charter ??, 1h basic welcome and updating
- KPI related to end of pandemic - can we contribute to this (question from Christoph - see [\[ref\]](#)) => no resources to work on this

Agenda

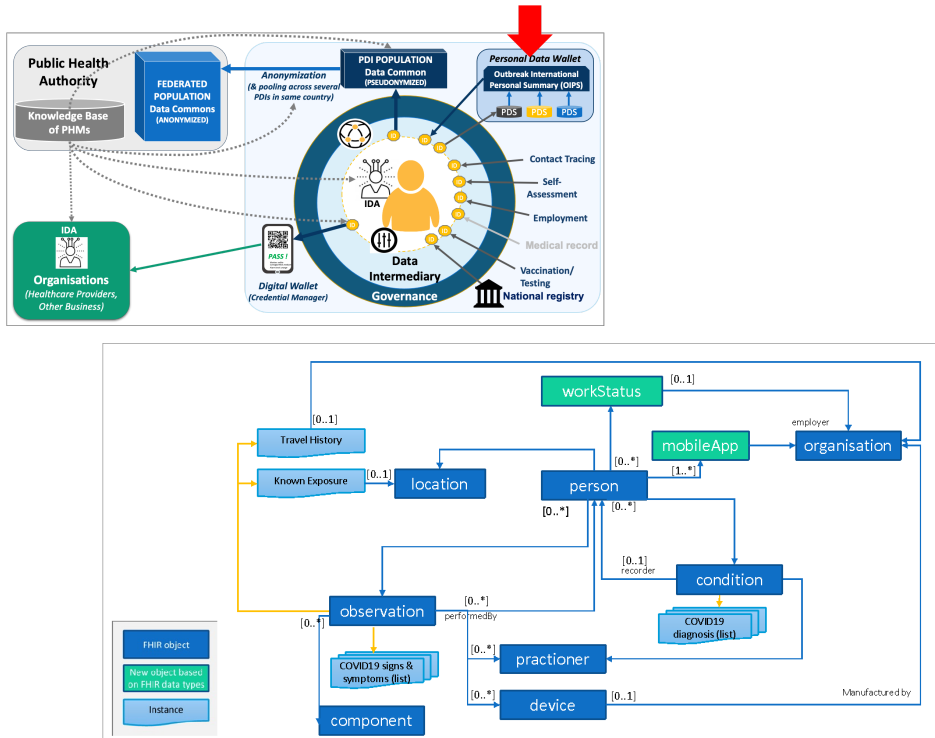
- Clarify actions from last meetings
- 2 other topics from Horizon Europe project: OIPS & credential manager

DISCUSSION

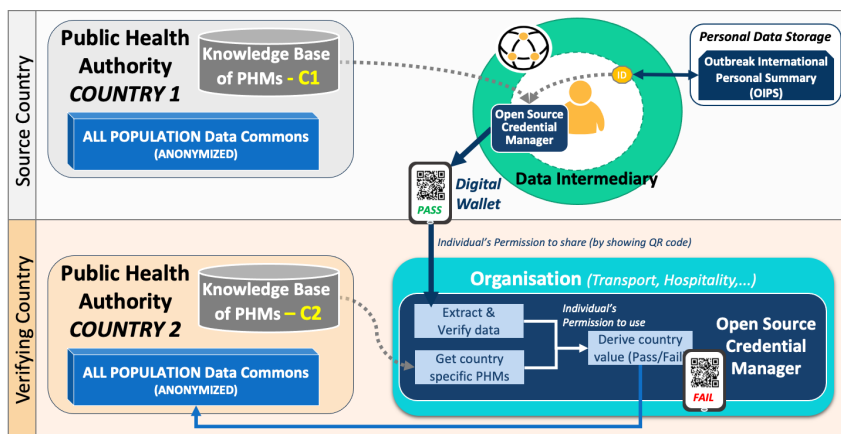
- Support from MyData on M4P from the board: how to reach citizens to support ICAWAS ... contact between Dixon and Lucy Yang.
Lucy Yang will evaluate possibility. Dixon will follow-up with her

NOT DISCUSSED - FOR NEXT TIME

1. Outbreak individual profile - on top of HL7 IPS [\[ref\]](#) => **OUTBREAK Individual Personal Summary**



2. Credential manager - if we have validation rules (e.g. PCR negatif and proof of 3 vaccines OR contact tracing negatif (+ data ; the complexity of interoperability decreases dramatically. How to make sure we have interoperable rules AND data. We have some assumptions - would be nice to validate/discuss them with the group



Wednesday 3 February 2022 - 14:00 - 15:00

Present: Fredrik, Dixon, Davide

Apologies: Isabelle,

Highlights:

- Seen very quick scale up and scale down of restrictions over the last month in several countries (eg. .no and .dk)

Action Points:

- (Isabelle for mid February) - Fujitsu presentation

Agenda/Discussion

- Definition & Onboarding to M4P
 - updated charter
 - 1h basic welcome and updating
- KPI related to end of pandemic - can we contribute to this (question from Christoph - see [\[ref\]](#))
 - Should we encourage WHO to ask for the mandate to also end a Pandemic?
 - Consequence -When the world is not in a Pandemic, Pandemic laws national do not apply
 - Conseq. -Countries need to update their Health/endemic laws and regulations, Nationally or locally. eg. Vaccination schemas and regulations dependent on local indemnity laws.
- Fujitsu presentation - key messages (Isabelle to prepare slides afterwards)
 - For employees of Fujitsu, in Europe and elsewhere. Several different presentations; AI ethics, AI Governance etc.

Wednesday 19 January 2022 - 14:00 - 15:00

Present: Isabelle, Sterling, Dixon, Victor, Dan, Fredrik, Lotta, Lal

Apologies: Davide,

Highlights:

- different operators have different ways to implement requirements
- architecture is a must: business/data architecture must be common, technical architecture will be specific for each operator
- working with (interoperable/standardised) machine-consumable rules enables to waive the need for interoperable standards on credentials/pass - what is needed is interoperable data sets that can be interpreted in each region

Action Points:

- (Isabelle) follow-up on Africa partnership (whenever becomes concrete, liaise with Sterling)
- (Isabelle) finalise WP4 for ICAWAS

Agenda

- Short update from Global majority meeting (potential for collaboration with Africa and Asia on M4P and Horizon Europe project)
- Main topic - interoperability needs from MyData operators in the context of M4P/ ICAWAS [[ref](#)]
 - Intro: ICAWAS, Prerequisites for PDIs, Problems to be solved
 - Point of view of each PDI on problem to be solved
 - Discussion on Common approach

Discussion

Update from meeting with Global majority team

- **Marcelle** will check on contact (potential in Cameroon) - meeting today with Luc Bertrand Bibog with intro on M4P
 - interested in the concept- need to check with MoH next steps
 - hurdles: no national identifier, trust of citizens, limited digital data
- **Jay** checking on potential contacts in different countries (see minutes of meeting from Jan 14)

Discussion on interoperability needs for PDIs

SelfInnovation - Sterling

- SSI is important
- Full anonymization of All population data commons -
 - open to fraud if not open for check
 - 3 levels - foundational/ semantic/ structural
- Semantic interoperability
 - health pass in US has 8 variables with different clearance

DIGI.me

- **Dan:** agreed on principles - architecture critical to define (agree on push versus pull for data); integration of data done through orchestration layers
- **Rupert:** emphasis on identity (nothing wrong to add identity attribute to PDS)
 - data might be stored in different DB that the users has access to in its PDS => yes - this is something out of scope and assumed to be already managed within PDI
 - why do we want to share with identity => triangulation / linkage of data within outbreak data profile.

Fredrik - IPS - take the IPD code from SNOMED / LOINC

iGrant.io - Lal

OK on principles - already discussed many times within M4P
interoperability need to align with **a specific protocol ???**

Need to have security

- Potential of incorrect processing by PDI ... how to ensure common anonymization techniques as well
- SECURITY - only as good as the source data are reliable: NHS came with solution with different levels of integrity ... local, region, countries...

Identity management

- no identity management as a player but link/integration with identity management providers => can link/consume different identifiers such as eIDAS in Europe

- SelfInnovation compliant to local identity management - compliant with identity management in more than 100 countries (though in some African countries there is no national identifier..)

CREDENTIALS MANAGER

- Verified credentials - machine readable credentials
 - e.g. vaccination - different vaccines in different countries ... PHMs must have as well regulatory knowledge on the type of vaccines
 - credentials are checked against data & rules : data and rules must be verified
- CREDENTIALS MANAGER - across countries
 - we need a common standard ??? probably not - just PASS/FAIL as different countries will set different rules - and issue their own credentials -
 - issue: different rules for different level of jurisdiction

POST MINUTES NOTES - to be done as part of WP4

1. Architecture
 - a. Business & Data Architecture : common (interoperability requirement, aggregation/anonymization specification)
 - b. Technical Architecture for testing: specific per PDI
2. Adaptation of specific app (translation):
 - a. Self Assessment (MyData4Life ?)
 - b. other ??
3. Development of Credential Manager
 - a. requirement
 - b. development
4. Configuration of each PDI for testing
 - a. integration of identified data sources
 - b. generation of outbreak individual data profile
 - c. integration of all personal ODP in Pseudonimized PDI Data Commons,
 - d. integration of segmentation rules from PHM and segmentation of individuals
 - e. anonymization of data from Data Commons and transfer to National one
 - f. integration of IPDA
5. Development of "national" Data Commons and segmentation
6. Deployment of each PDI and support during testing

When it comes to the aggregation algorithm (aggregation entail anonymity) - nodes in this federation they run the analyses in a secured container and produce the aggregated result that is available for the community responding the specific query (a number of nodes in the federation). All this process is formalised via algorithms that are public, so anyone could eventually download and deploy to test for example whether the process is fully compliant with the legal bases - [here](#)

PHIRI Federated Research Infrastructure (FRI) -

- D7.1 Small-scale prototype of PHIRI federated infrastructure - [\[ref\]](#)
- Pilot - Common Data MOdel - [\[ref\]](#)

Wednesday 14 January 2022 - 11:00 - 12:00

(Isabelle/Jay)

Present: Isabelle, Jay Sharma

Agenda/Objectives

following intro of M4P at Global Majority channel (thank you Dixon !), discuss potential for collaboration on M4P and on the Horizon Europe project (ICAWAS) in Asia and Africa

Discussion (highlights)

- Presentation of ICAWAS project (based on M4P work) - [[ref](#)]
 - Key message: if we want to ensure behavioural changes in citizens, it is not enough to work on advocacy - what is key is to build an enabling environment in an multi-stakeholder partnership
- SDG
 - provides a common framework to build alliances. Jay NGO is focusing on SDG17 (partnership) as we need collaboration for social changes (it is only through meaningful collaboration that we can achieve transformation changes) .
 - Pandemic is a problem for SDG as it will slow down progress

Actions

- Potential collaboration on ICAWAS
 - **Jay** to Identify Citizens/ HCPs group in Asia/Africa that would be interested in collaborating on the Horizon project (possibility to have an outreach committee with financial support to participate to workshops)
 - **Jay** to identify missing concepts in the overall M4P approach and messaging based on personal experience with authorities in the UK and NGO in Asia
- Potential collaboration and funding in following areas - contact to be taken by **Jay**. If interest to be followed by a presentation on potential for collaboration with **Isabelle** (and other members of M4P who are interested)
 - Uganda - Human rights organisation with socio-political focus (personal data, civil liberties, surveillance, legal protection etc)

- Kenya - national scope, local communities with a 'data for development' focus
- Malaysia - academics (a healthy aging & wellbeing centre in university) with international scope
- Vietnam - part of a global nutrition initiative to save lives, prevent illness, and ensure healthy growth of mothers and children.

Wednesday 5 January 2022 - 14:00 - 15:00

Present: Isabelle, Sterling, Dixon, Davide, Fredrik

Apologies:

Decision:

Action Points

- Dixon to invite Isabelle to next Global Majority meeting (DONE)
- Sterling to come back with details on details with African hospital to participate to Horizon Europe (DONE)
- Isabelle to propose some date + objective + agenda / **early March** on Fujitsu
- Isabelle to prepare agenda for meeting on interoperability (use definition from EU interoperability framework as a reference [[ref](#)]) (DONE)
- Isabelle to resubmit white paper (Data policy)

Agenda

- Discuss potentially for collaboration with Africa (Horizon Europe proposal)
- Updates on actions points from last meeting
 - Data trust Initiative proposal - rejected (rationale to be provided)
 - Horizon Europe
 - paper to be resubmitted (by end of last year_)
- Onboarding process to a TG, specifically to M4P/ FAQ with principles, rules & recommendations, including our arguments (Fredrik)????

Discussion

Sterling - meet an African hospital tomorrow.

- Two level of interactions with users
 - Organisation level - digital conversational assistant to identify applicable rules for organisation (no needed to have personal data)
 - Patient/ citizens - interaction through personal digital assistant / need interaction on personal data through PDI
- Hospital in Africa can be a full partner if they want - what is important is commitment to delivery

Dixon will meet next week with Charlie on GLOBAL MAJORITY meeting (meeting with Africa, Asian people to see how we can expand on MyData in these regions) - 6 pm Japan time.

Presentation to Fujitsu

- needs to be related to SDG; something that they can support as a solution provider (Personal Data Management/Data Store, Digital Assistant ?,.....)
- 45 min presentation/ 15 min Q&A
- example of what could be presented [[ref](#)]

Preparation on interoperability

- Need to define the different components of interoperability (technical(health passport technology), semantic(data), business/process (use cases))
- Sterling
 - data interoperability & standardisation
 - requirements -
 - identification/ authentication
 - preferences for sharing
 - technical creation based on interoperability: similar functionalities
 - business similar roadmap
- Dixon
 - users from different services and systems should be able to share data across PDIs interchangeably (portability)
 - when sharing data - should have the same schema
- Davide
 - data interoperability/standardisation (format, structure)...
- Isabelle -
 - data +
 - sanity pass interoperability
 - technology (e.g. blockchain ..) - this may be much bigger than M4P
 - type of vaccines (e.g. Chinese vaccine is not accepted anywhere like Pfizer or Moderna,...=> need to have a matrix
 - what does it means
 - yes/no based on a specific regulation

- o yes/no + data that can be checked to confirm agreement with current location regulation

<u>TripsGuard</u>	Travel Restrictions Quarantine Info Advisories Mask Requirements Open to Tourism Restaurants Open Open Public Transportation	https://www.tripsguard.com/	\$1999/year
<u>Travelbans</u>	Travel Restrictions Quarantine Info Airlines	https://travelbans.org/api/	\$99.99/ mth
<u>iata.org</u>	COVID19 Travel Restrictions	https://www.iata.org/en/programs/ops-infra/covid-19-ais-restrictions/	
<u>Lumo</u>	Advisories COVID19 Quarantine Info	https://www.thinklumo.com/news/lumos-covid-19-api-is-now-free	Open
<u>COVID19 API</u>	COVID19	https://covid19api.com/	\$0-100/mth
<u>Sitata</u>	Entry Requirements Advisories Airlines Airports Alerts COVID19 Diseases	https://www.sitata.com/en/developers	\$199 per first 1000 requests then price decreases
<u>Travel Perk</u>	Travel Restrictions	https://www.travelperk.com/travel-solutions/travel-restrictions/	Open Endpoints, Pay for full access
<u>Amadeus</u>	Local Guidelines Entry Requirements Caseloads Travel Restrictions	https://developers.amadeus.com/blog/-introducing-amadeus-covid-19-travel-restrictions-api	Pay as you go

Wednesday 8 December 2021 - 14:00 - 15:00

Present: Isabelle, Fredrik, Sterling, Dixon

Apologies:

Decision:

Action Points

- Dixon to send example from M4Children and aNG presentation to Fujitsu (DONE)
- Dixon - to invite Eric and Charlie at 2: 30 CET in 2 week for the M4P meetings (5th January) - discuss Horizon Europe with Africa (DONE)
- Dixon to guide us through requirements for presentation to Fujitsu (Feb/March)
- Isabelle - send message from Siensano/ Belgian to Fredrik to send to Swedish authorities (DONE, DONE)
- Isabelle to resubmit paper (JMIR, Data & Policy ?)
- Sterling to discuss potential for M4P deployment in Africa (discussion as well on the 5th)
- ALL : what should be a proper onboarding process to a TG, specifically to M4P

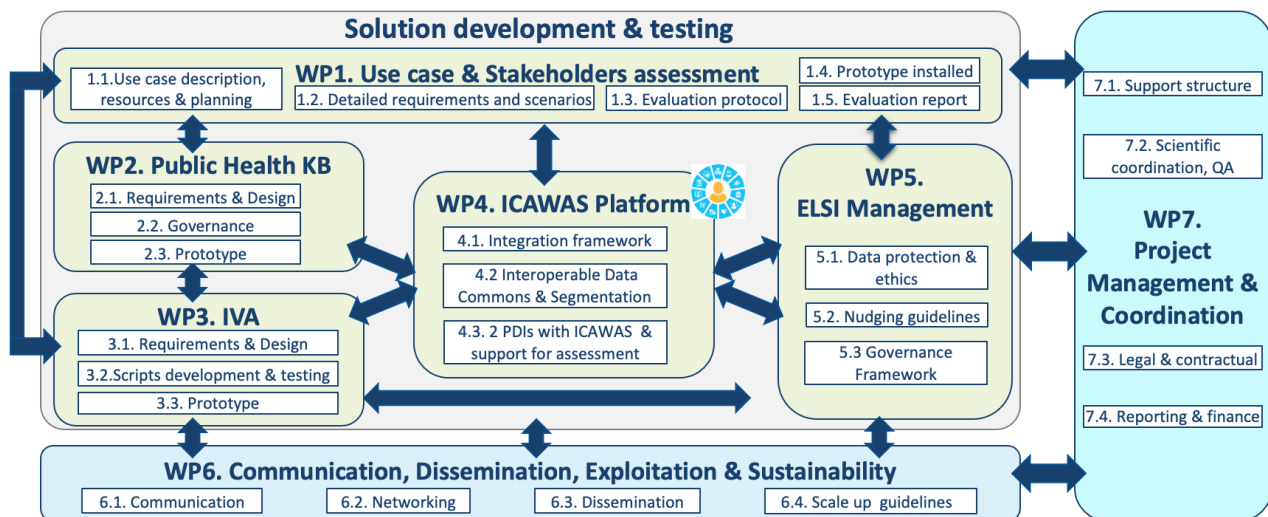
Agenda

- Updates on actions points from last meeting
- Update
 - Data trust Initiative proposal - submitted (answer this week ?)
 - Horizon Europe
 - Swedish M4P activities
 - paper submitted - to be resubmitted (by end of the year_)
- FAQ with principles, rules & recommendations, including our arguments (Fredrik)

Discussion

- Updates on actions points
 - Fujitsu MyData4Children presentation to Fujitsu
 - 77 people registered (33 joined because of technical problems / from 7 different locations ; they learned about MyData global
 - in january presentation from aNG

- M4P - to be scheduled in February/early March (conditions for acceptance: introduce topic, rough agenda,..)
- Fredrik -
 - Sweden - release of Covid vaccination pass / 10.000 complaints mainly on the fact that this was only on the vaccination and should include as well testing (full pass sanitaire)
 - Meeting with a Digital Agency in Sweden based on iGrant and introducing M4P... to be followed.
 - eHealth agency in Sweden (but run from the region)
 - feedback on meeting 1st December in Stockholm with "digital agencies" for crises
 - Update
- Data trust Initiative proposal - submitted (answer this week ?)
- Paper submitted - to be resubmitted
 - by end of the year to JMIR?
 - (Benoit Loeillet) something more related to policy than Health. It could be interesting to check for "Data & Policy" journal
- Horizon Europe - Draft WP of proposal Horizon Europe (mid December)
 - WP1 - how to reach "Mr average citizen"
 - cities are not the solution
 - Africa is in a different situation as they have low vaccine access



- **Sterling:** contact Charlie (Africa), discuss M4P for Horizon Europe in Africa.
- **WP 4 - discussion 19th January** of the 3 MyData operators involve in HE (iGrant.io, DIGI.me, SelfInnovation) - discussing interoperability and Data Commons

- integration framework data sources/ standardization data models
 - data commons (standardization) - what it is use within same countries and across countries
 - credentials format
 - identity management
- FAQ with principles, rules & recommendations, including our arguments
 - One starting point is the fact that one should not allow Pass-Sanitaire as only one ground. I should be 3 and it must be at least 2. Forced vaccination like in .at should not be allowed or at least never be intended to be used in practice. etc and so on.
 - MDG has a declaration but there is still a need to clarify different opinions on how this is implemented in the different TGs.
 - It should be easily accessible to everybody to know how different we are in M4P - and how we are doing different things
 - need an "onboarding process" or guidelines + roadmap ... how can somebody new who wants to join M4P can get up to speed ? Would be the same problem for other TG.... should that be in the TG charter ?
 - What should be included in the "onboarding process/ guidelines"
 - what is our mission/vision
 - how are we different from other groups doing something similar; where do we align/ are the same
 - what we are doing precisely
 - roadmap - where are we
 - how/where can contribute - contributing guidelines & requirements for people who want to contribute (how "my project" could align with the activity) ; categories of contributing

Japanese used chatbot to support health data

Wednesday 24 November 2021 - 14:00 - 15:00

Present: Isabelle, Dixon, Sterling

Apologies: Fredrik

Decision:

Action Points

- **(OLD) Dixon** identify a time slot when we could present M4P to Fujitsu (if early January)... following presentations from MyData4Children and aNG
- **(OLD) Fredrik** - feedback on meeting 1st December in Stockholm with "digital agencies" for crises
- **(OLD) Isabelle** - draft WP of proposal Horizon Europe (will be for mid December)
- **Isabelle** - share link on the proposal to the Data Trust Initiative [[ref](#)]
- **Dixon** - to invite Eric and Charlie at 2: 30 CET in 2 week for the M4P meetings
- **Sterling:** contact Charlie (Africa), discuss M4P for Horizon Europe in Africa.
- **Isabelle** invite **presentation 19th January** of the 3 MyData operators involve in HE (iGrant.io, DIGI.me, SelfInnovation) - discussing interoperability and Data Commons

Agenda

- Alignment with SDG [[ref](#)]:
- Update on paper submitted (Lancet digital health)
- Update on Data trust Initiative proposal - submitted
- M4P - Horizon Europe and collaboration with Smart Cities

Discussion

- Alignment with SDG [[ref](#)]:
 - **SDG 3 Good health** - mobility in a health crisis, avoid contagion...
 - **SDG 4 Education:** enabling role + also about educating people in a changing environment
 - **(SDG 5. Decent work & economic growth)** - enabling role
 - **SDG 9** Industry, innovation & infrastructure
 - **SDG17. Partnership** for the goal , international community - strategic partnership to reach global influence (WHO, CDC, eCDC, Smart cities)

- Update on paper submitted (Lancet digital health) - **rejected**.
- Update on Data trust Initiative proposal - submitted, decision in 2 weeks.
- M4P - Horizon Europe and collaboration with Smart Cities
 - discussion with FING / France + AMS + Helsinki
 - discussion with ECHAlliance - Karo
 - Africa (Sterling) - met with an interesting organisation about deployment and doing further research .
 - Japan (Dixon) - not clear who should be contacted ; they would be a drive for a market for personal data stores. Drop it for Horizon Europe (may be a change with the Fujitsu meeting in January - thought it will be more global based)
 - Are authorities paternalistic and autocratic and do not see the value/need to change and involve citizens
 - up to us to explain properly
 - explain to authorities they need to have more powerful system
 - citizens are not really to use the system from authorities because they do not trust it (need to be understandable, what it is and why it is needed)
 - Can we do without public health authorities ? we can keep working with academics and then push authorities to deploy
- M4P - as of January: workshop with concrete prototype
 - start with iGrant.io, DIGI.me, SelfInnovation (also part of Horizon Europe)
 - objective is how to achieve interoperability across MyData operators building on the use case of M4P
 - 5 min intro M4P – objective and needed for (data) interoperability
 - 30 min - each participant (10 min each) : intro / what exist (e.g. identity, digital pass, consent, self app..) of interest for the M4P use case
 - 20 min - discussion: how to leverage the work of each other, how can we work together (to implement MyData principles and declaration)
 - 5 min – conclusion/ next steps

Wednesday 10 November 2021 - 14:00 - 15:00

Present: Isabelle, Fredrik, Dixon, Davide, Sterling

Apologies:

Decision

- It is OK for anybody to use all the material from M4P, provided it is specified in the acknowledgement that M4P is the source. Also it is always nice to receive feedback on the material and comments on how to improve

Action Points

- **Fredrik** - final reading of the paper before submission
- **Isabelle** (for next meeting) to identify SDG call related to M4P - to elicit interest by Fujitsu ; to be proposed and confirmed by the group at next meeting
- **Dixon** identify a time slot when we could present M4P to Fujitsu (if possible early January time frame)
- **Isabelle / Fredrik** - check with Teemu on discussion with Deloitte next week on
- **Fredrik** - feedback on meeting 1st December in Stockholm with "digital agencies" for crises
- **Isabelle** - draft WP of proposal (will be for mid December)
- **Sterling** check connection with people that could help promote M4P (from Deloitte)

Agenda

- update on the paper to be submitted (Lancet digital health)
- Data trust Initiative proposal - what is it, partners shortlisted, impact for M4P
- Horizon Europe and collaboration -
 - (1) status,
 - (2) discussion with Teemu and Karo on MyData participation and role ,
 - (3) partners - including Japan (Dixon) and Africa (Sterling)

Discussion

- **Paper for submission**

- title "Pandemic management requires a citizen enabled, rapidly scalable, infectious disease surveillance & alert system.
- objective (if we are accepted !) : get some good solid noise to get funding
- **Data Trust initiative proposal - we were short listed ..**
 - **Who.** Managed by Univ of Cambridge and Birmingham ("bottom up data trust")
 - **Objective:** Explore what needs to be done to set up and operate Data Trusts => M4P is a "Data Trust on demand" i.e. what needs to be done to set it up in case of Pandemics
 - **Partners:** iGrant.io, Isabelle/b!loba, Andreas Häger (lawyer and Cystic Fibrosis patient association)
 - **deadline** 25th Nov - Start in January (if approved)
- **Horizon Europe project**
 - Status - contacting partners
 - Discussion with Teermu and Karo on role of MyData -no decision need to further discuss Amsterdam
 - Partners - extension to other countries : would be nice to involved them early January when we start to have an idea on the consortium and more details on WP

(answer from PMO on potential funding)

 - *# USA is eligible to participate and usually also to receive funding in Health topics, however, we should discuss if this is really necessary/advisable from a strategic point of view . It usually depends on the role and involvement of the US partner and how, where and from whom the results will be owned/exploited in the end (impact for Europe?).*
 - *# most African partners are also usually eligible to participate and receive funding – no strategical objections.*
 - *# Japan is a bit more difficult..*
 - *In case of “pandemic preparedness” participation it should be possible according to [Japan | European Commission \(europa.eu\)](#) and [ec_rtd_loi-eu-jp.pdf \(europa.eu\)](#) but I still do not find how funding is to be organized in that case. Usually this has to be organized locally, and the partners usually know the process and contact persons very well. If this is a critical issue, I can check in more depth.*
 - *EURICE just submitted a proposal with a Japanese partner (Fujifilm). They did not want to include any funding for them in that proposal, and even do not plan to apply for funding locally. They “just” wanted to safeguard access and ownership*

to/of the results. During the process we discussed adding the European branch as partner instead of the Japanese one, but decided not to go for that in the end. Fujitsu has a German subsidiary – maybe that could be also an option here?

- **DIXON: I am starting to get acquainted with the Sustainability Unit that drives several SDG Goals (<https://global-delivery-responsible-business.global.fujitsu.com/>). It would be nice to get a short online blog about what we want Fujitsu to do and I can share to the SDG Enablers.**

Dixon : Japan - is a different market, very slow - for instance digital passports are still not there. What is important to make them move forward are the SDG ... **Fujitsu is mainly interested in the SDG...** - Which kind of SDG would M4P support.

November 26th - Dixon will hold a workshop within Fujitsu related to MyData; there will be more and more related to different TG !

Sterling

USA might be less likely than Africa - still a lot of non vaccinated people, the only way that it is going to happen in the USA if this is regulated ... or some benefits that would incentivize (e.g. related to health insurance premium...)

Africa - might be more interested ! Deploying a project related to data wallet/ health passport; funding is not much a requirement - **more a collaboration / standardization that would be shared with EU**.

One person working is in Kenya .. (1% vaccination, people could not access to vaccine); working in an epidemiological clinical - where there are the most vulnerable/ at risk.

Fredrik - may have some contact in Africa - UNCD ?

ALL

- What is key is to train people so that they understand / authorities are not transparent - Education is at 2 levels: (1) education of the citizens and (2) education of the decision makers ...
Education or political will ! (example in EU and in US).... it needs to be neutral
- Action: Fredrik - invited to digital agencies for crises (meeting the 1st December) - feedback ...
- Problems is the NPI KB/medical directions - VA should be more easy ?

- We should specify the "paperwork" - with the M4P "stamp" - around 3 direction
 - Government/ authorities
 - R&D/ Science
 - Business / promoting the market contact
- Use our material - acknowledge back

Wednesday, 13 October 2021 - 14:00 - 15:00

Present: Isabelle, Dixon

Apologies:

Action Points

- Action - Snearling to forward paper on segmentation - DONE
- Action - Snearling to set up a meeting with Isabelle to bring up to speed to the work we are doing - DONE
- Action - check time of the meeting - if needed
- Action - check with Teemu on Mydata collaboration
- Action - all to check document potential partners - but need to limit to max 14 under EU budget, other continents to be checked....

Agenda

- Update on meeting with the city of Lyon ([see slide enclosed](#))
- Joint discussion with Cities at the AMS meeting mid November (see agenda above). Who is interested to participate ?
- Way forward for Horizon Europe project [\[ref\]](#) - invitation letter, consortium member, role of this tea/mMyData

Discussion

- **Meeting Metropole of Lyon**
 - meeting with Ines (who presented at H3), Hanthalie (CDO - but did not join) and Benoit Loeillet
 - High interest on the following aspects
 - possibility to build on what they are working currently around selfData
 - addition of another services
 - working with different cities
 - interoperability of data operators/ intermediaires
- **Workshop AMS.** The idea discussed with [@Ansku Tuomainen](#) is to have 2 workshop with/for cities - including one related to pandemics.
 - TITLE: "Needs and role of (smart) cities in pandemic management, from avoidance to control, to preserve safe and optimal mobility for and by citizens".
 - TOPICS of DISCUSSION
 - lessons learned from the COVID19

- what do cities need to help manage/avoid/control a new/expected pandemic
- how to engage with citizens and empower them
- how to collaborate with authorities/decision makers to provide data/information and collaborate on defining clear instructions
- how to engage with private sector
- **Horizon Europe project**
 - extension to other countries
 - with City of Tokyo + Fujitsu/Personnium (important to have Fujitsu for interoperability aspects, we could have as well DIGI.me as they are active in Japan if needed)
 - with US - no / too difficult
 - with some country in the Middle East or in Africa - to be confirmed by Snearling
 - digital pass would not be limited only to vaccines - we need different types of credentials ;
 - GHP may be only focused on vaccines (and too much proprietary)
 - we cannot have only one solution on pass - we need to have interoperable solution
 - Consortium

MyData as coordinator - great organisation for policy / guidelines but might not be strong enough in terms of project coordination and they have some specific agenda items ; also very EU focus for the moment

Wednesday, 29 September 2021 - 14:00 - 15:00

Present:, Isabelle, Dixon

Apologies:

Action Points

-

Agenda

- Status:
 - GHPC, white paper, Data Trust proposal, other funding

- discussion public authorities/ Infarmed
- MyData Community event ?
- Brainstorming: why should cities be interested to work on a pilot with us
 - initiating discussion with Lyon; need to check potential for Ghent, AMS, Oulu...
 - need to clarify what would be the scope of a pilot and what would be the benefit for them ? (they are fundamentally very much “passive” as much as citizen in the current situation)

Discussion

- Cities - what is in it for them ?
- JAPAN
 - local authorities have their own budget to support the companies (e.g. only allow 20% of the working population to go to the office - but no way to track this with digital platform)
 - Note: in Japan, a lot of the burden is put on companies (e.g. vaccination, control number of employees going to work) - there is little support from the authorities - some financing, no system to trace
 - Authorities will combine SSN with every single data from bank + public sector + health.... => need to enforce the MyData principles
 - process
 - Cities express interest (how to lobby local authorities ? how to check if they are interested)
 - Companies propose solutions (what would be the right price)
 - City will pay
 - Nobody wants to be an operator as there is no money to make. Banks are less and less interested in single transaction (do not see/ understand the value of selling population level data - with consent of individuals)
 - Best approach in Japan is to have a strong proposal by a technology company - AND there has been success already demonstrated in another city

Wednesday, 15 September 2021 - 14:00 - 15:00

Present: Davide, Fredrik, Isabelle Dixon

Apologies:

Action Points

- Fredrik will move forward with GHPC - M4P logo

Agenda

- Tried Huddle
- GHPC: Wait until next meeting to endorse
- Confirm approach for coming 6 months: build credibility with authorities
- Status report
 - Tweeting - status ?
 - EU4Health - Fredrik/ Isabelle
 - White paper : Isabelle to finalize based on comments
 - Funding
 - Fujitsu => Isabelle to follow up with Dixon in September
 - DataTrust proposal => Isabelle following up with iGrant

PARKING LOT (possible to close some of them ??)

- *reach to Data Hubs - follow up on contact* - - **CLOSE**
- *Communication to Public Health Orgs (Isabelle) + meeting WHO GoDataMyData + contact Hessie J* - **CURRENT FOCUS**
- *status BrightHive (Iain)* - **CLOSE**
- *Webinars - first one on M4P (Isabelle) => October (agreed with Sille)*
=> **to be delayed November/December (need more authorities on board)**

Discussion

- GHPC: ENDORSED !
 - send M4P
 - need to build a common message on what it means: health pass are difficult - we need to continue to explore, at least GHP has a roadmap - happy to contribute/support/use.
 - negative : no constraints - in case they fail not so good for us
 - positive: as good as it gets in terms of Health Pass

- Confirm approach for coming 6 months: **build credibility with authorities**
 - Initial contact with INFARMED
 - What is in it for you ?
 - How can I contribute around PDS and MyData - as a citizen !
 - Ensure transparency - ensure people are not manipulated as a citizen (need to understand why we need to get a vaccine - right information to citizen, protect right)
 - the next time - we cannot be at the same level we are today ; technologies will be quite advanced => need to make sure we can use them => need to push the agenda of preparedness - the entire system needs / need more data literacy (contact tracing and proximity tracing is not the same thing..)
- Status report
 - Tweeting - status... => everybody should tweet for themselves mentioning M4P - more focus on building personal contacts
 - EU4Health - Fredrik/ Isabelle => **need to set up a consortium for EU project (Eu4Health or Horizon Europe - deadline- end OCTober/ early November)**
 - partner operators:
 - iGrant (Lal, Lotta - including Davide, DIGI.me (Rupert),
 - *potential: Meecom (Katrina) in collaboration with Hedera Hashgraph (3rd generation ledger)*
 - **Graig - check rom Fredrik (Austria)**
 - Fujitsu - collaborating partner ?? to be clarified with Dixon (next cycle for decision will be in March) => Isabelle
 - Fredrik - either as a data source or as a consultant
 - Government: hack4Sweden will check at pass for everybody - may be potential partners
 - Academic : Oulu / Marritt and Oxford ???
 - **White paper** : Isabelle to finalize based on comments
 - Funding
 - Fujitsu => Isabelle to follow up with Dixon in September
 - DataTrust proposal => Isabelle following up with iGrant

Wednesday, 1st September.2021 - 14:30 - 15:00

Present:

Apologies: Isabelle

Present: Fredrik, Dixon

Action Points

- Tried Huddle
- Wait until next meeting to endorse GHPC.

Agenda

CLOSED

- Project charter extension - officially approved by the Board
- Funding : i4trust with OULU (DIH Finland)
=> after discussion with Marit (DIH in Finland/ Oulu) , decided to drop - not worth the effort

OPEN

- GHP participation (**Dixon, Fredrik**)
 - MyData Board not moving, we can do it as an official TG as M4P
 - Action: Fredrik to propose on next steps - it is our decision now !
 - We need to support this initiative as they have a roadmap towards a decentralized approach. The nations and many other initiatives do not.
 - We agree to “lend”/allow to publish them our mydata4pandemics logo. Until they have fulfilled their planned implementation deadline and requirements. Start by pushing before leaving.
 - It is not perfect but it is better than most and can become good without losing too many/any liberties.
- Tweeting: double followers from 36 to 72 in July - Dixon We are at 42 today so next 6 months we aim for 84.
- EU4Health action plan and funding potential - how do we approach [[ref](#)]
=> Isabelle to follow up
- Funding

- Fujitsu
=> Isabelle to follow up with Dixon in September
- DataTrust proposal
=> Isabelle following up with iGrant
- White paper
=> Isabelle to finalize based on comments

PARKING LOT

- *reach to Data Hubs - follow up on contact - **Isabelle***
- *Communication to Public Health Orgs (**Isabelle**) + meeting WHO GoDataMyData + contact Hessie J*
- *status BrightHive (**Iain**)*
- *Webinars - first one on M4P (**Isabelle**) => October (agreed with Silke)*
- *public Speaking at TED or the like*
- *Meecoo and Hedera Hashgraph work of interest to m4p*
- *We maybe too far ahead technically need to refocus on the data side of things.*

Discussion

- EU4Health action plan and funding potential [\[ref\]](#)
 - grants and procurement
 - many linked to member states/ authorities
 - need to clarify our strategy & collaboration with authorities
=> check how authorities are prepared:
 - interesting webinar: **COVID-19 response: How have international travel restrictions affected freedom of movement during the pandemic?** : available on [YouTube](#)
 - [TANJA SCHMIDT](#); DB from WHO [public health and social measure \(PHSM\)](#)
 - **"how are we going to tackle the next outbreak - during the first 6 months where there is NO Vaccine, no test, no treatment..? ... No answer..."**

Wednesday, 20 July 2021 - 14:00 - 15:00

Present: Isabelle, Iain Dixon

Apologies: Davide

Action Points

- NO MEETINGS in AUGUST - enjoy the break and come back with a lot of energy on September 1st !
- **DIXON** to send material from Fujitsu - Isabelle to check eligibility
- **Isabelle** to submit EU4Health feedback
- **Isabelle** to finalize TG charter & confirm with Sille if M4P can participate as M4P rather than MDG to GHP
- **Davide** to TWEET in August (we are at 38, still far from target of 72)

Agenda

- BREAK OF MEETINGS up to 1st September - OK
- Review comment to EU4Health before sending [\[ref\]](#)
- TG Charter [\[ref\]](#)
- Funding - check on i4trust with OULu (DIH Finland)- **Isabelle**
- EU4Health action plan and funding potential - how do we approach [\[ref\]](#)
- GHP participation as MyData - presentation to board (**Dixon, Fredrik**)
- Tweeting: double followers from 36 to 72 in July - July/Dixon (38 currently)
- Review Parking lot
 - reach to Data Hubs - follow up on contact - **Isabelle**
 - Hub Japan: [@ito_nao](#) [@Yuichi Ota](#) [@Nobuhiro](#)
 - Hub Greater Bay Area: [@Crystal So](#) [@King Cheung](#)
 - Hub Taiwan: [@Sherry](#) [@Tammy Yang](#)
 - Hub Korea: [@Chris](#)
 - Hub Asia: [@prustar](#) [@Try](#)
 - Hub Bangladesh: [@Galib](#)
 - (meeting 9 June) - Communication to Public Health Orgs (**Isabelle**) + meeting WHO GoDataMyData + contact HESSIE J
 - (meeting 12 May) - status BrightHive (**Iain**)
 - White paper - (**Iain**) - delayed up to Mid August
 - Webinars - first one on M4P (**Isabelle**) => September

Discussion

- Review comment to EU4Health done [\[ref\]](#)
- Funding - check on i4trust
 - contact taken with with OULu (DIH Finland)- no answer so far
 - a lot of paper works for 120 K to be distributed across 4 organisation... main value in pursuing the proposal is to refine our message
- Funding - Fujitsu grant (document from Dixon)

- Need to verify if we can apply - Dixon will send more details
- GHP participation as MyData - presentation to board (**Dixon, Fredrik**)
 - no update from Board
 - Paul Knowles is involved already - can we work through him ???
 - contact between Isabelle & Rupert (DIGI.me) - how can we show we build on the work on other when asking for funding (same comment in TG charter)
 - This is becoming too much administrative burden
=> CAN WE GO WITHOUT Board approval as M4P
Isabelle to check at TG leader
 -
 -
 -

PROPOSED TWEETS

- **#mydata - #covid -#eu4health- #empowercitizens**
Pandemic avoidance relies on citizens' empowerment; pandemic resolution relies on pharmaceutical intervention. The M4P group within MyData just submitted their point of view to the EU4Health consultation to further support the development of open-source, scalable, digital solution integrating different emerging technologies (contact tracing, health pass...) that can be rapidly deployed on top of Data Intermediaries and linked with by public health authorities KB, to effectively support citizens when new outbreak emerge [\[ref\]](#)
- **#mydata - #covid #pandemic-avoidance - #pandemic-preparedness - #empowercitizens**
***Pandemic preparedness** is based on collaboration between public health authorities' and researchers in academia and in pharmaceutical industry. It focuses on faster development of medical countermeasures and enable to solve a pandemic.
 Pandemic preparedness is needed but not sufficient, we need to **work pandemic avoidance**; this relies on citizens' empowerment*
- **#mydata - #covid #pandemic-avoidance - #pandemic-preparedness - #empowercitizens**
*Pandemic avoidance relies on citizens' empowerment; pandemic resolution relies on pharmaceutical intervention.
 There is currently a lot of focus on pandemic preparedness and faster development of medical countermeasures. This is not enough. What will we do differently if a new pathogen like COVID-19 come? Time to adapt test and treatment as well as to develop vaccine will always leave a window of time of 3 to 6 months during which a local outbreak can quickly become a pandemic. It took about 3 months for COVID to spread from Wuhan, China to the rest of the world.*
- **#mydata - #covid #pandemic-avoidance - #empowercitizens**
*· Pandemic avoidance relies on citizens' empowerment
 Current infectious diseases surveillance systems are based on anonymised data; they would benefit for personal data shared willingly and in trust through emerging Data Intermediaries*

Outcomes. M4P wants to develop open-source, scalable, digital solution integrating different emerging technologies (contact tracing, health pass...) that can be rapidly deployed on top of Data Intermediaries and linked with by public health authorities KB to empower citizen to share their data – based on up to data information - while providing valuable data to decision makers

- **#mydata - #covid - #empowercitizens**

Citizens have been the forgotten stakeholders in the COVID19 crisis; we need individual-centric data solution, driven by MyData principles to be better armed for current and forthcoming outbreaks
[\[ref\]](#)

- **#mydata - #covid #pandemic-resolution - #empowercitizens**

INFODEMICS ... misinformation in the context of PANDEMICS...

To solve this we need to ensure citizen get the right information - adapted to their level and context

Wednesday, 7th July 2021 - 14:00 - 15:00

Present: Isabelle,

Apologies: Dixon, Davide

No participant - no meeting... agenda postponed for next meeting

Agenda

- Review comment to EU4Health before sending [\[ref\]](#)
- EU4Health action plan and funding potential - how do we approach [\[ref\]](#)
- Funding - check on i4trust with OULu (DIH Finland)- **Isabelle**
- Updates
 - TG charter - follow up on approval with Silke next (**Isabelle**)
 - GHP participation as MyData - presentation to board (**Dixon, Fredrik**)
 - reach to Data Hubs to present myData NL hubs - follow up on contact - **Isabelle**
- Review Parking lot
 - Tweeting: double followers from 36 to 72 in July - July/Dixon, August/Davide
 - (meeting 9 June) - Communication to Public Health Orgs (**Isabelle**) + meeting WHO GoDataMyData + contact HESSIE J
 - (meeting 12 May) - status BrightHive (**Iain**)
 - White paper - (**Iain**) - delayed up to Mid August
 - Webinars - first one on M4P (**Isabelle**) => September