



Meeting minutes of 1st JADECARE Stakeholder Forum

“Implementation of digitally enabled integrated person-centred care – Needs and Solutions“

Meeting Title:	1 st JADECARE Stakeholder Forum	Meeting Date and time:	10 th November 2021, 10:00 to 13:30 CET
Meeting Type:	Stakeholder Forum	Meeting Location:	Online by Zoom Meeting
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Distribution	participants by email, presentations-pdfs attached		

JADECARE (Joint Action on implementation of Digitally Enabled integrated person-centred **CARE**) will contribute to innovative, efficient and sustainable health systems through providing expertise to assist European countries in undertaking health system reforms. It will enable national authorities to benefit from efficient solutions in digitally enabled integrated person-centred care.

The main objectives are to reinforce the capacity of health authorities to successfully address important aspects of health system transformation, in particular the transition to digitally-enabled, integrated, person-centred care and to support the best practice transfer from the systems of “Early Adopters” to the ones of the “Next Adopters”. This Joint action involves the Competent Authorities of 16 Member States and 29 Affiliated Entities.

The Stakeholder Forums of JADECARE are intended to facilitate the exchange of experience and the networking between the organizations participating in JADECARE and relevant external Stakeholders, including health system representatives, researchers and academia interested in collaborating with the JA to discuss the current status of the local implementation plans of best practices, emerging problems, further ideas and solutions. In addition, key health care industries/developers are invited to contribute on how to enhance the competitiveness of EU industry to create economic growth opportunities.

In the 1st JADECARE Stakeholder Forum potential needs and opportunities of health care systems related to the transfer and implementation of digitally-enabled person-centred care were identified and compiled. The expertise, knowledge, experience and opinions of the active participants to enrich and improve the local implementation plans of JADECARE were given as follows.

Minutes of 1st JADECARE Stakeholder Forum

Moderating: Martina Rimmel (Bavarian Health and Food Safety Authority, LGL, Germany)
Expert speaker – presentation, (pdf of presentation attached)
<p>Julia Palma (EIT Health, Spain): “Challenges of Implementation of digitally enabled integrated person-centred care”</p> <p>Questions, answers and remarks in the chat reconfirmed that a person-centred approach is required, based on a need-driven approach to define and understand what the needs of the persons with diseases (comorbidities, needs due to the disease, different conditions and situations) are, similar to the European blueprint for the digital transformation of health and care designing a person-centred approach. In addition learning communities and targets for different initiatives should focus on participants’ organizations, patients, society at large (citizens, the population in general, patients and children). At the same time they should be encouraged and empowered to share their real needs, to speak up, to self-provide and actively contribute in</p>



their health, to build the capacity to become an actor, from a multidisciplinary view to account for clinical outcomes, social-economic determinants, needs at psychological levels and the patients' situations.

JADECARE –the Joint Action – presentation, (pdf of presentation attached)

Esteban de Manuel Keenoy (*Kronikune Institute for Health Services Research, KG, Spain*):

General presentation of JADECARE (Background, identified needs, goals, implementation strategy)

Questions and remarks in the chat acknowledged this to be a huge programme of work attempting transfer of good practices at this scale. Service integration then implies to different extent interdisciplinarity and an impact on professional roles/perceived identity in the organizations from siloed/individual to team approach.

JADECARE Original Good Practices (oGP) and their Core Features– presentation, (pdf of presentation attached)

Jon Txarramendieta (*KG, Spain*):

- **Basque Health Strategy in Ageing and Chronicity: Integrated Care (Basque Country)**

Josep Roca (*IDIBAPS, Spain*):

- **Catalan open innovation hub on ICT-supported integrated care services for chronic patients (Catalonia)**

Manfred Zahorka (*Optimedis, Germany*)

- **The OptiMedis Model of Population-based integrated care (Germany)**

Morten Sønderskov Frydensberg, (*RSD, Denmark*):

- **Digital roadmap towards an integrated health care sector (South Denmark, RSD)**

Questions and remarks in chat remarked the huge menu for all those in the field who will implement the oGP and the workload, emphasizing that implementation leadership will be key and challenging.

JADECARE Next Adopters Local Good Practices/Local Action Plans – presentation, (pdf of presentation attached),

Paolo Michelutti (*AGENAS, Italy*):

Local Good Practices/Local Action Plans for implementation developed by Next Adopters

Questions and answers regarding chat referred to whether there are other tools for patient clarification/risk stratification that have been used by oGPs beyond the ACG system from Johns Hopkins?

Josep Roca answered, that JADECARE has two roles in this area: a common strategy for the deployment of risk assessment and a specific tools assessment such as GMA or Adjusted Morbidity Groups for risk assessment. GMA compiles an open, flexible algorithm in different kinds of models like logistical regions, machine learning etc. This allows to generate assessment of risk and predictions for health risk at population level for health policy purposes, for clinical decision support, for case finding, etc.

Martina Rimmele introduced the roundtable part of the Stakeholder Forum and showed on a slide the first question to be addressed by the experts:

Panel discussion

1. Regarding JADECARE:

Where do you see the greatest opportunities and what are the greatest challenges for the digitally enabled integrated person-centred care in the near future (5 years)?

Which of those challenges do you envision to be tackled within JADECARE? Do you have ideas/ suggestions for improvement of implementation plans according to your experience/knowledge?



Statements of panellist experts

Antoni Dedeu (*WHO, Europe*):

A national or at least subnational strategy on digital health aligned with a governance model leading to endorsement and political willingness of decision makers is crucial to ensure the sustainability of the JADECARE project so as to avoid “pilotitis”, meaning the design and execution of many resources with wasting piloting actions that in the end are not rolled-out and do not give sustainable results. Such a sustainable strategy needs a broad view in terms of an all- systems strategy in digital health, incorporating other health plans in different regions. JADECARE has taken into account necessary contextualisation approaches for the regions and participating examples and health environments. As integrated care goes beyond the borders of health systems, the term “digital determinants of health” could contribute to the concept of JADECARE involving different actors from different levels cross-sectorally. A further opportunity and a challenge as well would be to understand the digitally-enabled person-centred solutions as digital public goods. In this respect, it is relevant to address less developed countries regarding the implementation of health technologies, resources, education, human capacity and financial investment in accordance of what is appropriate in their environment.

Donna Henderson (*TEC, Scotland*):

In terms of transferring a good practice, contextualization on a local level and adaptation is critical as is done in JADECARE. As an opportunity, the COVID-Pandemic has shown that the ways of delivering health and care services need to be and can be changed. Digital solutions should be embraced, but must demonstrate their usefulness also in the space of other emerging pressure points, like the management of waiting lists for routine scheduled care. This is a pressure point which is creating even more issues in the system elsewhere, if not managed with digital solutions. Other opportunities concern the environmental impact that evolves from enabling more ways to keep appointments by digital services without the need for travelling, as well as the increased investment interest of large industry or technology partners in the health domain. This increased interest can make technology developments faster, the developed digital tools more affordable and accessible and allows a better choice of digital tools within the health and care services.

The main challenges are digital health skills and literacy (of workforce and citizens) and effective change management to embed digital ways of working.

Marc Lange (*EHTEL, EU*):

An additional huge challenge is the implementation leadership for both the JADECARE-Project and for the Next Adopters, because the Next Adopters have very much work to do in transferring the Good Practices. This demands the right leadership skills, but also the right understanding of the connections between everyone. It is essential that the good implementation work performed here is properly connected to the governance in place in the regions of the Member States, and that the digital determinants, other environmental determinants and the organizing contexts are also addressed, in order to avoid the aforementioned “pilotitis” and to scale up successful Good practices.

In the chat a further opportunity was highlighted, being now, with the COVID-experience, the right momentum toward digitally enabled integrated person-centred care, since the policy makers and relevant stakeholders are less reluctant to experiment with new changes in their daily practice. The greatest challenges in JADECARE can also be identified as the different policy readiness and maturity levels but also the lacking interoperability standards and the need for a harmonized EU policy legislation or at least EU directives that would promote the oGPs of JADECARE in a consistent way throughout the EU.

It was agreed that it is important to take into account that (large scale) implementing takes time and needs continuity of engagement. It also relies on political commitment, but also on the intermediate and top management. Also, Large scale implementation needs a number of interconnected horizontal activities to build capacity (administrative, technological, etc.). Local ecosystems for innovation may represent powerful enablers to facilitate implementation over time.



Julia Palma (*EIT Health, Spain*):

There are additional challenges in JADECARE caused by the differences between the governance levels of different regions, but also the difficulty of handling both at the same time: A change concerning the implementation of novel things and the management of the existing business. This can be a huge hindrance for health care systems in the context of capacity overload. Overcoming this problem requires a smart strategy for parallel procedures. The pandemic generated a drive against the inertia of established conditions and institutions, so open innovation, entrepreneurship and initiatives can be fostered to get to a more agile mindset that is needed to do the changes in parallel to the more established actions of health provision.

Donna Henderson agreed in the chat on the important point about promoting entrepreneurial skills within the health and care workforce - Health is Wealth. It needs high-level endorsement of this approach. NHS Scotland has set up Scottish Health Innovations Ltd (SHIL) to support innovations in healthcare and encourages staff to bring their ideas to life. So this link this might be of interest: <https://www.shil.co.uk/who-we-are>.

Martina Rimmele picked up from the chat the point of the importance of functioning leadership for effective implementation. She mentioned that in the structure of JADECARE, Transfer Work Packages are implemented, closely led by experts from the oGPs, following-up and interacting with the Next Adopters to support them to establish the implementation. Also, JADECARE established Policy Board meetings enabling direct interaction with politicians in the context of the national levels of the countries.

Esteban de Manuel Keenoy added, that key aspects in JADECARE are the alignment of national policies and resources in the core of the local good practices and action plans to ensure sustainability, as well as the work of strong Next Adopters Working Groups. These involve local policy makers, executives of the health care systems, health care professionals and academics, analysing existent interventions and policies in their contexts.

Marc Lange emphasized in the chat that to take up the citizens needs in their context has an impact on how to answer to their needs, as can be addressed in the EIP on AHA personas work on this: https://ec.europa.eu/eip/ageing/blueprint_en.html

Martina Rimmele went into the next round of questions and introduced the next experts:

2. Regarding cross-sectoral collaboration:

What would be your suggestion how health and social services can better engage industry and academia to seek solutions to allow the transformation of healthcare systems into digitally enabled integrated person-centred care systems?

Where do you see the biggest opportunities for start-ups?

Statements of panellist experts:

Giovanni Gorgoni (*AReSS, Italy*)

Digital transformation in the health care sector and also in social or societal sector needs to embrace the people/patients' journey, organizational and operative processes regarding integrated practice units and in the last step, to connect these dots with technology. Those aspects should be embedded in an ecosystem strategy that enables a continuing dialogue between small and medium enterprises, universities, ICT players, pharmaceutical companies, and between private and public sector in order to build an ecosystem framework, which is guided by a cross-border leadership-concept. Start-ups are advised to pursue solutions to enhance and enable current remote contact systems with artificial intelligence ("conversational intelligence") that are designed for easy use, for autonomous devices, for urban spaces and connected community care, keeping it simple, taking digital illiteracy of patients into account.

Albert Alonso (*IFIC, Spain*)

To summarize a couple of suggestions around of how we can do better in terms of engaging industries and academia in order to develop solutions, two main ideas could be brought up: Technology, defined as the



functional component to integrated care, acting as a glue that joins together the different layers in order to achieve real integrated care, needs to be enriched through conversation to provide alignment and meaningfulness when it comes to engaging industries and academia in order to develop solutions. Furthermore, this conversation needs to allow and ensure organic growth, so it is necessary to keep complexity behind the scenes by using more intelligence behind the scenes and to be as simple as possible on the surface. Following this, the approach of “frugal innovation” could assist people to make everyday decisions and help to deliver better services that actually matter to the patient.

Donna Henderson added in the chat a definition: Frugal innovation - Through minimising the use of resources in development, production and delivery, or by leveraging them in new ways, frugal innovation results in dramatically lower-cost products and services. Successful frugal innovations are not only low cost, but outperform the alternative, and can be made available at large scale. Often, but not always, frugal innovations have an explicitly social mission. Please also see: <https://innovations.bmj.com/content/7/4/647>

Ivan Eržen (*NIJZ, Slovenia*)

Slovenia has been able to establish connections between all health care providers. They are connected, can exchange documents and results, can see what is happening with individual patients. Not only the health care providers, but also the patients themselves can see the documentation in their electronic health records. But it is highly important for a country to make clear decisions about the direction of the development and goals concerning digital health. A long-term national strategy should be established to connect and take into account the contexts of healthcare industry, academia and health care providers in order to agree with them on which direction they should and can develop their digital care solutions. Challenges regarding working processes, which need to be interoperable and unified between providers, must be faced together and should be tested properly to provide evidence. Only then health care providers and social services can accept and apply them and make health information and health care activities accessible also for the patients in their electronic personal health records.

Antonio Sarriá-Santamera (*Nazarbayev University, Kazakhstan*)

From a medical doctors' point of view, medical education now should be changed to prepare students for the necessary changes in the health care sector. But the driver should not be technology. Technology will facilitate changes, will facilitate for example the possibility to continuously monitor patients' glucose levels. The question is how to use technology in a way to treat patients better, to receive better outcomes for a patient. A system should always be developed in consideration of the specific characteristics of health care and its specific purpose. To improve different frames of a system, contextual elements like financing and literacy must also be considered. Improved value consists of improved outcome and cost.

Bernhard Gibis (*KBV, Germany*)

The challenge of introducing and implementing new technologies effectively is to know your own health system really well and then to find the tipping points to get a new technology inside the system. In Germany for instance, we have a social insurance system, and one of the specialties is that we have a benefit catalogue, a transparent list of services provided to patients, that a patient is entitled to receive. Digital tools, like the “Digitale Gesundheitsanwendungen”, digital health apps, have been newly integrated in the service list.

In order to introduce a new digital health process successfully, instead of merely focusing on technics, it is necessary to first identify the basic simple processes in place to generate health data and to deal with them in a medical practice, in a pharmacy, in a sick fund. It is necessary to listen to the voice of healthcare professionals from the beginning, since they are the ones who have to implement new digital tools, who have to adapt to and to take over the new tools. You need to have appropriate testing phases and have the prospective users approve new technologies before bringing in a new process nationwide.

A second aspect is the use of online health platforms, which must be carefully considered as the sensibility of health data needs a civil society way of thinking regarding the participation of industry as providers of such platforms. Platform technology mechanisms can be disruptive and should be applied in the field of the public health care sector.



Martina Rimmel went into the next round of questions and introduced the next experts:

3. Regarding use of data:

Where do you see the most relevant regulatory issues/conflictive points concerning the use of patient data that should be addressed by the healthcare systems in the near future?

Lars Hulbæk (*MedCom, Denmark*)

Legal advice by lawyers is needed to update legislation and support all developed digital opportunities of data sharing and cross-sector data exchange in order to meet the legal claims from the GDPR and the Medical Device Regulation. Technical services that provide aid in order to manage legal claims, registrations and access to health data according to the GDPR should also be considered from the perspective of citizens and should be kept simple. In Denmark some technical services to support citizens have been developed: “Treatment Relation Service” taking care of who is a priori allowed to access a citizens health data, “Consent Service” on a national level taking care on how can the citizen affect this, and how can they determine, who is allowed to access their health data, “MyLog Service” giving the patients the information on who has actually been looking at their health data.

It is also very important to have a national governance for mandatory user standards for data exchange and also for common infrastructure. But this should be balanced between central requirements from government and local degrees of freedom and innovation.

In the chat Lars Hulbæk added the link to the Danish eHealth Strategy 2018-2022

https://sundhedsdatastyrelsen.dk/-/media/sds/filer/strategi-og-projekter/strategi-digital-sundhed/digital-health-strategy-2018_2022.pdf

Dipak Kalra (*i-HD, EU*)

Five aspects should be considered regarding the use of patient data: First, digital innovations may lead to new data issues as new actors need to get the empowerment and also permissions to have access to personal, fully identified information. Secondly, digital innovation might be part of longitudinal continuity of care requiring the storage of health data, at best in integrated, holistic patient records. Thirdly, additional data for evaluation purposes are sometimes needed and need to be handled separately. Fourthly, the possible collection of additional data such as i.e., usability questionnaire surveys of a novel technology should be planned while it is still in the innovation space. Fifthly, the collected data has potential to be reused for longer-term downstream research. For each purpose, it must be made sure, that there is a legal basis meeting the demands of the GDPR, and JADECARE action implementers are sincerely advised to be aware of the different levels of data usage and therefore include those levels i.e., into the informed consent formats, transparent for all stakeholders, especially patients, so that the collection and processing of data is permitted to showcase its evidence and can therefore lead to transferable evidence.

Hrvoje Belani (*MoH, Croatia*)

In Croatia the central e-health platform and various e-health functionalities and services such as e-prescription and e-referrals have been established for more than ten years now nationwide, supported by the national e-Citizens platform when it comes to authenticating citizens to access their EHR data through the Health Portal. E-health must support the effective use of patient data and ensure people have the access to the necessary health services. Challenges are that legal frameworks lagging behind the corresponding technical solutions need to be synchronised and a sound legal framework of ethical guidelines for secondary use of data needs to be established. It is important to raise awareness and continually plan public communication on existing E-health services in order to enhance direct digital interaction pathways between patients and healthcare services or healthcare stakeholders.

The paper: “Building Sustainable Digital Health Services in Europe: lessons learned from the COVID-19 Pandemic” - eleven aspects on a strategic frame on e-health” is recommended:



[https://ec.europa.eu/reform-support/system/files/2021-06/Building%20Survivable%20eHealth Strategies.pdf](https://ec.europa.eu/reform-support/system/files/2021-06/Building%20Survivable%20eHealth%20Strategies.pdf)

Marc Lange remarked in the chat, that EHTEL views its point on engaging citizens to become an actor of patient-centred care to be also applicable in data sharing, with a citizen-centric data sharing approach complementing the more hospital-centric approach: <https://www.ehtel.eu/activities/ehtel-on-eu-affairs/ehtel-s-vision-of-european-health-data-space-priorities.html>

Manfred Zahorka added that the open notes initiative from the US might also be an interesting idea in involving patients in contributing to Health records <https://www.opennotes.org/>

Wrap up of Forum and Conclusions

Martina Rimmele thanked all of the participants for their valuable contributions and for these great new aspects that should be taken into account, and that JADECARE has in part already taken into account, and also for networking together on this years' JADECARE Stakeholder Forum's theme, that all participants share and want to take further.

Wrapping up, she hoped all have gotten a good idea of what JADECARE is about, what the aims and goals are, where JADECARE stands. In a year in another Stakeholder Forum the progress of JADECARE as well as proceedings in other digitally-enabled person-centred integrated care in the international agenda will be discussed again.

Greatest opportunities and challenges discussed today were:

- A national or international strategy, a governance strategy is very important to be able to sustain the efforts that are established with JADECARE.
- It has been highlighted that the contextualisation of the implementations/of the adaptations of the original good practices involved in JADECARE is very important, taken already into account to quite some extent in the project with different theoretical tools that have been implemented.
- To take environmental impacts into account in health system transformation endeavours was another challenge identified.
- The importance of leadership on many different levels has been pointed out, not only in the single Work Packages of JADECARE but also interacting internationally together, and also in bringing together academia and industry to have a joint ecosystem of digital system improvement and deployment. To bring that forward in a meaningful and target-oriented manner and to have a connection between the enhancement of current digital technologies and artificial intelligence advantages, conversational intelligence was advised to be used.
- The audience was reminded to administer Frugal innovation, minimising the use of resources in development, production and delivery and resulting in dramatically lower-cost products and services.
- It has been highlighted, that technology should not be the driver for digital innovation, but to keep the patients in the centre and be able to efficiently help the patient with digital tools to receive better outcomes for them, while empowering them as active participants. This should be made applicable also in everyday real physicians work, considering the different specifics in different countries and health systems.
- The importance of the different levels of data use has to be taken into account by JADECARE, i.e., to make sure to get the correct and adequately sufficient wording in the informed consents of patients, giving them transparency of what the data can be used for and should be used for, for the benefit of all participants.

Martina Rimmele hoped that all have been able to take something with them for themselves, and have hopefully been intrigued to follow JADECARE, via its website, via its social media (see below).



JADECARE will be working intensely further on, to make these implementations possible and durable.

Contact

For any questions or queries, please contact:

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