Final Conference

Annex 2: Our Daily Digital Health …

is everyone ready?

Version v1.0

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## Change History

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1. Introduction

1.1 Purpose of this document

This document provides details of the United4Health final conference which took place over a day and a half, on the 19\textsuperscript{th} and 20\textsuperscript{th} January 2016, with the opportunity to speak in a more informal setting taking place over a three-hour networking dinner on the evening of 20\textsuperscript{th} January.

1.2 Overview

The conference’s main messages were that United4Health has been about “Keeping the patient safer, healthier and more empowered” so that now “Telehealth is here. It is happening!”

The two days offered plenty of opportunity for higher-level and policy messages to be passed. Yet, they were also full of real-life experiences shared by numerous deployment sites. At least nine United4Health sites presented their practical experiences on subjects as diverse as stakeholder engagement, patient acceptance, organisational transformation, workforce adoption, health/information technology infrastructure, and electronic health records.
2. Summary of discussions

The conference included five plenary sessions and two breakout sessions of three streams each.

The plenary sessions focused on topics such as:

- Transforming the patient experience in Europe.
- Upscaling telehealth – the need for policy engagement.
- Lessons learned on accelerating healthcare transformation at scale.

Wider subject-matter plenary sessions included:

- Infrastructures as an enabler.
- Scaling up digital health innovations.
- Healthcare anywhere and the Internet of Everything.

Throughout the conference, there was not only plenty of conversation, dialogue and networking, but documentation too.

![Photo 1: There was plenty of information circulating at the event](image)

Note: Close to 50 speakers addressed the conference. The content of many of the presentations are mentioned directly in this short report. Due, however, to the many parallel sessions that occurred throughout the conference and the need to respect limited space in this report, not all speakers or presentations are detailed here.

2.1 Day 1 – Transforming the patient experience and leveraging of the benefits of eHealth in Europe

Introduced by United4Health project coordinator/EHTEL President, Prof. George Crooks and EHTEL secretary general, Mr Marc Lange, the first day of the conference plunged quickly into an exploration of the experiences of United4Health patients on three of the telehealth-using sites.

To set the scene, Dr Panos Stafylas, United4Health medical coordinator of HIM SA, laid out the comprehensive work that United4Health – as a study of deployment
United4Health has undertaken to explore the implications of telehealth use for patients in each of three areas of chronic conditions. As a consequence, United4Health is able to lay out a seven-step approach to telehealth deployment, ranging from innovating to adopting in real life.

More than 10,000 patients have been involved in the United4Health initiative, with some 1.5 million days of follow-up and around 80,000 contacts with physicians. The project has been able to process all the resulting data within a 40-day period. Some of its first indicators are that hospitalisation rates are being reduced; some 90+% of patients are showing substantial satisfaction rates, and, in particular condition areas, there have been reductions in several conditions (e.g., in patients with diabetes, there are reductions in glycated haemoglobin i.e., HbA1c).

Most interestingly, it appears that as a result of the United4Health project, many of the project sites are now going to enhance and expand their use of telehealth use in the months and years to come. Hence, scaling-up is working!

Throughout the morning, the conference audience heard from by three specialist clinicians – Dr Hugh Brown on COPD; Dr Sandeep Thekkepat on diabetes; and cardiologist, Dr Miren Nekane Muga.

Photo 2: Panellists speaking on transforming the patient experience in Europe

This plenary session was closely associated with a follow-up break-out session on the ways in which telehealth enables improved patient self-management and care at which presentations were made by Dr George Dafoulas, Ms Claire Hurlin and Mr Lukás Roubik. Here, the presentations in both the plenary and associated break-out session are merged.

COPD is the third most common cause of death in Wales and the second most common reason for admission to hospital in England, announced Dr Hugh Brown. The Welsh Hywel Dda pilot resulted in beneficial reductions of the numbers of days that patients were hospitalised and overall saved costs. The major lesson learned was about process: not to introduce the telehealth support at the moment of discharge from hospital.

In parts of Wales, connectivity is difficult – there is not even a 2G system, and no WiFi noted Ms Claire Hurlin of Hywel Dda, Wales. Hence, the authority reverted to using the phone. The best system on offer for use with its patients was Florence
(‘Flo’), a simple messaging service which enables reminders to be sent\(^1\). Using this system “puts the patients back in control of their everyday lives.” Overall, the key message is about: “Helping you live your life your way.”

Dr Sandeep Thekkepat – whose ‘handle’ is ‘Dr Insulin’ – described the upcoming diabetes pandemic: some 642 million people globally are expected to experience the disease by 2040. He outlined the use that is being made in Scotland of the SCI-Diabetes system\(^2\) and MyDiabetesMyWay.\(^3\) Scotland’s use of these applications has led to far greater patient control of their own conditions. The positive results could, for example, ultimately lead to as many as 43% fewer limb amputations.\(^4\) Telehealth-supported diabetes care has become firmly part of routine care in the country. As Dr Thekkepat concluded, “We are now able to make important sensible decisions, and frequently.”

Also on diabetes, Dr George Dafoulas of Trikala, Greece, reminded the audience that: “Diabetes is a disease that you mostly have to face alone in your own home; you visit your own doctor sometimes and specialists, like diabetologists, even fewer times. In Greece, we have been trying to reduce unnecessary visits to clinicians.” Dr Dafoulas pointed out that the most difficult challenge for the Greek United4Health pilot was, not procuring and running the technology, but making it part of ordinary care. The reason for this: there was no appropriate care model, care flow or management structure in place when the initiative started.

The in-depth telehealth initiative on cardiac conditions that has taken place in the Basque Country, enabled the Kronikgune site represented by Dr Nekane Muga, to conclude that it resulted in “an improvement in patient health, in patient satisfaction, and in the health services. In addition, there were also improvements in patient empowerment and adherence, and in anticipatory care.” For the Basque Country, this was particularly an area where patient satisfaction was very high.

The positive experiences of chronic heart failure services at Olomouc hospital’s supported by telehealth in Northwest Moravia in the Czech Republic were presented by Mr Lukáš Roubík. The Olomouc experience has acted as an encouragement to explore telehealth services in the future for a wide range of other conditions such as COPD, sleep apnoea, and even risky pregnancies.

Throughout the session, many conference participants asked questions. Many of these are summarised later in this report under the heading “Core subjects of interest to attendees”.

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\(^3\) http://www.mydiabetesmyway.scot.nhs.uk, last accessed 27\(^{th}\) January 2016.

2.2 Day 1 – Other morning sessions

Two other, parallel, breakout sessions concentrated on: leveraging the benefits of telehealth in Europe, and tackling technology barriers (interoperability and legislation). Facilitated respectively by Dr Panos Stafylas and Mrs Elinaz Mahdavy, they deep-dived into the challenges surrounding evaluation, infrastructure, interoperability and regulation. These sessions were particularly good for focusing in-depth on project outcomes and for showing how the project results relate to the project publications. Just like the plenary and panel sessions, these breakouts were full of interaction and dialogue.

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Joint Symposium

2.3 Day 1 - Seamless connected health and scaling up digital health innovations

The United4Health focus of the conference was complemented by two afternoon plenary sessions, aiming at positioning telehealth and United4Health in a broader picture, the EHTEL one. The first of the two sessions concentrated on the need for adequate platforms and infrastructure to support telehealth. The second explored how digital health innovation can be scaled up more precisely.

Introducing the importance of infrastructures and their role in supporting seamless connected health, three presentations were given by a local Brussels official, a Member State civil servant, and a health service provider. Future expectations with regard to what the Connecting Europe Facility (CEF) may have to offer Europeans in terms of infrastructure, interoperability and cross-border healthcare communication was described by Mr Tapani Piha of the European Commission. Dr Andreas Grode of gematik, Germany described the concrete work of a series of initiatives made by European Member States to build some of the core and generic services that are forming the building blocks of the CEF. Currently, four further projects are continuing this work, including VALUeHEALTH, which explores future business models in the field of eHealth (including telehealth) services.

A specific insight into how Luxembourg is building a national platform that will help to connect patients with their electronic health records was offered by Mr Samuel Danhardt of the country’s Agence eSanté. Dr Hadas Lewy of Maccabi Healthcare Services in Israel, one of the country’s main healthcare providers described the innovative efforts made to create a universal telehealth platform, completely, with phone centre, to support people who are chronically ill.

Photo 5: Panellists speaking on scaling up digital health innovations

Having got the infrastructure in place, what else can be done to ensure that digital health innovations can shift to scale? Two interesting insights were offered by telehealth leaders from the National Centre for Health and Welfare in Finland and the Technology Enabled Care and Digital Innovation Division of the Scottish Government. Dr Päivi Hämäläinen placed her emphasis on nationwide electronic health record and other services for patients need to be operationalised with a

country’s policy framework. Dr Margaret Whoriskey, MBE, then offered a fascinating insights into lessons learned when managing service transformation from both a personal and an organisational perspective.

2.4 **Day 1 – United4Health policy messages**

To complete the first day of the conference, Prof. George Crooks introduced United4Health’s three key policy messages around:

- Ensuring a policy environment that promotes and supports telehealth deployment.
- Seeking national consistency with local adaptation.
- Empowering patients, carers and healthcare professionals to take full advantage of eHealth.

The project makes six specific recommendations to policy-makers at European level, by emphasising the importance of regulatory environments, scalable deployment programmes, cross-fertilisation, evaluation methodologies and the role to be played by appropriate policy fora. All of these are available in a succinct United4Health report entitled *Upscaling Telehealth – the need for policy engagement.*

Representatives of two stakeholder associations, AGE Platform Europe and the Assembly of European Regions (AER), that had contributed to United4Health’s user policy advisory board, then reflected on these key policy messages.

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Ms Anne-Sophie Parent of AGE Platform Europe announced firmly that on policy, “We are with you; we hope to be able to go with you; we can join you!” before highlighting AGE’s own way of supporting active and healthy living environments for citizens. Through a Covenant of Demographic Change, launched in December 2015, AGE pays close attention to the experiences of elderly people in local settings, towns and cities, and regions.8

Ms Agneta Granström, politician from the region of Norrbotten in northern Sweden and chair of AER’s eHealth network, supported the United4Health policy messages particularly around local adaptation and empowerment. She also emphasised the importance of available national, regional and local infrastructure: “We need infrastructure. We need broadband, and we need mobile connectivity.” To leverage the benefits from constructive initiatives like United4Health, she proposed that: “We now have the opportunity! In Europe, we should take the opportunity to be the frontrunner for eHealth services, outside of hospitals too.”

2.5 Day 2 – Lessons learned on accelerating healthcare transformation at scale

The conference began on its second day with a focus on the lessons learned by United4Health. These are located in the project deliverable D3.8 on Guidelines for Procuring and Implementing Telehealth.9 The session was led by Dr Rachelle Kaye of the Association Internationale de la Mutualité.

Photo 7: Lessons learned session chair, Rachelle Kaye, leads the discussion

Among the main messages of the session were:

- Patients come first.
- Co-production means that patients become more pro-active participants in their own health.
- Self-efficacy enables patients to have the confidence to understand their own condition.
- It’s all about people and processes.

• As in Norway, it is possible to move ‘from the stone age to the 21st century’ in just three years.
• In Scotland, in terms of accelerating toward scale, we would not be at this stage without United4Health.
• Technology design needs to evolve: adopting a co-design approach is important with increased and early patient involvement.
• Last but not least, no pain no gain.

2.6 Day 2 – Interactive Lessons Learned: Parallel Digital Poster Sessions

While poster sessions are most well known in academic conferences when research outcomes are presented by research teams, in this final conference the United4Health project consortium innovated by introducing the notion of digital poster presentations made by the people on-the-ground who implemented and experienced these telehealth initiatives. Up to four electronic posters were presented in each interactive session over coffee/brunch. Each session was animated by a facilitator, and the three speakers from the morning’s first plenary session acted as resource persons for further insights and information.

Photo 8: The digital poster presentation from Galicia

Three sessions emphasised the project’s lessons learned around the topics of:
• Stakeholder engagement and patient acceptance.
• Organisational transformation and workforce adoption.
• Health-IT integration with local/regional electronic health record infrastructures.
These three sessions were among the most lively debate and dialogue experiences of the two days, with much practical information shared.

2.7 Day 2 – Future-proofing telehealth

As a tradition in EHTEL symposia, the conference ended with an insightful, future-proofing session that explored the implications of the Internet of Things for the next generation of healthcare.

Chair, Mr Mario Romao of Intel Corporation, painted a picture of many new technologies that can already work in health and care (including public health) and which are now already available in retail stores: sensors, electronic fitness products, and drones. From the Internet of Things, the shift will be to the Internet of Everything.

Four speakers looked at the different, new and innovative ways in which healthcare could and should be provided anywhere, in many geographic areas, in society.

Mr Elijah Charles of Intel in the United Kingdom spoke about “riding on the datum”, exploring data from integrated systems, communication between systems, and messaging so as to be able to undertake effective planning for patient flows in hospitals and clinics and between primary care and secondary care institutions. His conclusion was that healthcare institutions are not yet making the most of the potentially huge amount of data that is available to them.

Two of the panel speakers drew attention to the importance of future data and devices for people with diabetes.

Mr Claus F. Nielsen of DELTA, Denmark – a self-confessed ‘gadget boy’ – drew from the experiences of his young son who has diabetes type I, a condition that affects 25,000 Danish children. Using equipment to help measure vital signs with regularity can enable a son to measure his health status, and a father to have piece of mind even when miles away from home. Many new forms of equipment are available, including those being supported with the help of pharmaceutical companies. For example, Continua’s personal connected health alliance is working to generate greater awareness, availability and access to plug-and-play personal health technologies.10 Mr Nielsen’s tip was to look to Scandinavia “because that is

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where it is happening”, and his encouragement to all was to “come and visit us in Denmark, Norway, Finland, and Sweden.”

Yet diabetes, especially diabetes type II, is a huge problem worldwide, as Dr Petra Wilson of the IDF pointed out. In Europe, perhaps one out of every 11 people have diabetes; in the United Arab Emirates, for example, it is however one out of every four. She particularly criticised health care data silos. Every person with diabetes spends much of his or her time in self-management: up to 8755 hours a year. For this reason, obtaining more data about one’s condition can help the individual, but at the same time it can assist healthcare professionals to do a better job and health care systems to manage the coming tidal wave of chronic conditions much more effectively. Some data protection and privacy issues remain to be resolved, however.

The view from the pharmaceutical sector on data regulation was articulated by Mr Brendan Barnes, who represented the European Federation of Pharmaceutical Industries and associations (EFPIA). EFPIA welcomes the new agreement on General Data Protection Regulation. The pharmaceutical industry is most interested in using de-identified data. Areas to be explored would include a platform for continuing dialogue among the diverse stakeholders in the field, and the construction of a regulatory framework that will both enable further drugs research while still helping to build trust.

Photo 10: Panellists on healthcare anywhere and the Internet of Everything react to audience input

Commenting on these shifts in direction on data privacy and data regulations, chair, Mr Mario Romao of Intel Corporation commented in conclusion of the session: “Everyone will need to ‘re-load’ what privacy means in the future perhaps at both the national or at the regional level.”

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2.8 **Day 2 – Closing conference messages**

Among the two days' major and repeated messages\(^\text{13}\) were:

- Telehealth should not be seen as an add-on or complementary to ordinary healthcare, but as genuinely part of routine care.
- Telehealth is only a tool. What is being changed is empowerment!
- Technologies are changing very fast. So the technology should be kept simple. It is also worthwhile watching the technologies of the future.\(^\text{14}\)

Several of these issues emerged also on the close to 40 Twitter messages that were sent or re-tweeted during the two conference days.\(^\text{15}\)

Here is a sample of the short Twitter messages sent by conference attendees. They draw attention to some of the conference highlights:

- “There’s clear evidence that telehealth can reduce hospitalisation for chronic patients”. Mr John Crawford, IBM.
- “Telehealth enables improved self-management and care”. Dr Simona Abbro, UPMC, Italy.
- “It’s the care pathway that is crucial.” Dr Sandeep Thekkepat, NHS Lanarkshire, Scotland.
- “The key message for success in patient/stakeholder engagement - communicate, communicate!” Ms Kathleen Maguire, NHS Ayrshire & Arran, Scotland.
- “Only recently has Healthcare ICT focused on benefitting the individual and not the organisation.” Prof. George Crooks, NHS24, Scotland.

And, last but certainly not least:

- “There’s no eHealth without eID.” Dr Andreas Grode, gematik, Germany.

Overall, the main message emerging from this intensive, communicative United4Health final conference is well summed up in Prof. George Crooks' own closing words:

> “Evidence has shown that successful transformational change on a large scale requires not only bottom up willingness to change but also top down policy support.”

Involving not only health authorities and their policy-makers but many local, grassroots 'doers', the United4Health consortium and its project sites have every intention to continue this two-way journey into a new health and care future.

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\(^\text{14}\) For example, the King’s Fund in the United Kingdom has recently explored eight technologies, including smart phones, that are likely to change the future of health care: [http://www.kingsfund.org.uk/publications/articles/eight-technologies-will-change-health-and-care](http://www.kingsfund.org.uk/publications/articles/eight-technologies-will-change-health-and-care), last accessed 27\(^{\text{th}}\) January 2016.

\(^\text{15}\) [https://twitter.com/u4h_ec](https://twitter.com/u4h_ec), last accessed 27\(^{\text{th}}\) January 2016.
3. **Conclusions – Core subjects of interest to attendees**

Several of the discussions that arose during the two days related to the difficulties and risks of using particular research methods and as to whether pockets of organisational resistance actually remain.

![Photo 11: More audience members contribute to the discussions](image)

Firstly, clearly, there are considerable challenges that face United4Health and other large-scale pilots when trying to compare and contrast their results. This has to do with not only the wide variety of different sites but also the number of criteria that they are examining (such as clinical, organisational and socio-economic issues). On the one hand, the project consortium is confident about its ability to present substantial clinical research results using large datasets. On the other hand, for change managers and behaviourist and social science researchers, it would be more appropriate and effective to use action research methods rather than using very formal large-scale data collection (see the United4Health policy messages).  

Secondly, representatives in attendance from patient organisations, such as the International Diabetes Federation (IDF) and the European Allergy and Airways Diseases Patients Associations (EFA) were especially interested in whether there had been either any physician or patient resistance to deploying telehealth. The United4Health sites reported a mixture of results. Yet it was ultimately evident that the sites had resolved the challenges of getting doctors, nurses, and patients involved in the whole deployment process through using a number of creative methods. One project partner emphasised that: "United4Health has been acting as a real catalyst to support the organisational changes needed."

Thirdly, therefore, United4Health, for example, come up with a very simple diagram that helps those involved in telehealth deployment to illustrate just how care flows are shifting. Several of these can be seen in a brochure produced by the project on care service models.  

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Using simple, circular, traffic-light colour charts helps healthcare authorities and healthcare professionals to understand the situation quickly. They can also give persuasive, agile briefings to higher-level policy-makers – including a ten-minute pitch given recently to the new mayor of the city of Athens. “You start to have the impression that a picture is worth a thousand words!” commented International Federation for Integrated Care (IFIC)/HIM SA, Ms Leo Lewis.

**Ambition**

The overall aim for implementing telehealth into the care management programme for patients living with Type 2 diabetes who monitor their blood glucose levels, was to support the individual patient’s endeavours to self-manage and lead a lifestyle to reduce their risk of developing diabetes-related complications.

**Photo 12: A picture is worth a thousand words!**

The day ended with its focus on policy messages, and current and future policy directions were certainly among the topics raised during the conference dinner that followed.