Ecosystem activation: methods used in XpanDH project for nurturing the European Electronic Health Record Exchange Format (EEHRxF) environment

Abstract/Summary:

The XpanDH project aims to activate and mature the European Electronic Health Records Exchange Format (EEHRxF) ecosystem by fostering digital health innovations and facilitating cross-border interoperability across the EU. Using a Network of Networks (X-Nets), XpanDH has advanced stakeholder collaboration in digital health, engaging diverse groups such as patients, healthcare professionals, and policymakers. The project employs co-creation methodologies to ensure participatory engagement and has established tools like X-Bundles and X-Bubbles to support the adoption of the EEHRxF. These efforts contribute to building a sustainable, scalable ecosystem that will continue through future initiatives such as xShare and Xt-EHR.

Key Points:

1. Network of Networks (X-Nets): XpanDH established 10 X-Nets representing various stakeholders across the digital health landscape, including patients, industry, hospitals, and regulators, to promote EEHRxF adoption and drive cross-border collaboration.

2. Co-Creation Approach: The project employed a participatory design methodology, engaging all stakeholders—patients, healthcare professionals, and developers—in co-creating digital health tools and services tailored to actual needs.

3. X-Bundles and X-Bubbles: XpanDH developed these interoperability assets to guide and simulate the adoption of EEHRxF. X-Bundles aggregate key artefacts supporting health data exchange, while X-Bubbles model real-world implementation scenarios.

4. Future Continuation: The project's outputs, including the X-Nets , will be integrated into the xShare and Xt-EHR projects, ensuring the long-term sustainability and scaling of the EEHRxF ecosystem across Europe.

Introduction

XpanDH – 'Expanding Digital Health Through a Pan-European EHRxF-Based Ecosystem'

XpanDH[i] is an ambitious project preparing and building capacity in individuals and organisations to be ready to use the European Electronic Health Records Exchange Format (EEHRxF) by establishing a pan-European effort through a Network of Networks approach (Martins et al., 2023). A short video introduction to the EEHRxF can watched here. The project pursues the main goal of maturing and accelerating a sustainable and scalable interoperability environment in Europe for digital health innovations based on the EEHRxF, involving both the supply and demand sides of healthcare provision. It aims to motivate, inspire and support multiple digital health actors involved in Europe to advance the concrete adoption of the EEHRxF. This involves developing guidance and field examples, aggregated in interoperability assets around the EEHRxF (so-called X-Bundles).

An ecosystem approach to digital health innovation and the creation of conditions for new cross- and intra-border interoperable environments around a proposed set of standards (the EEHRxF) is different from the EU cross-border initiatives so far, that have been mostly governmentally-lead. Understanding digital health as an ecosystem means accepting and/or fostering some emerging systemic properties:

i) Open innovation;

ii) Multiple leadership;

iii) Concepts over action plans;

iv) Governments and official entities as coordinators;

v) Industry and active end-users involvement; and

vi) Creation and animation of co-creation spaces;

XpanDH's ecosystem methodology was inspired partly by the PatientUp[ii] initiative and its collaborative approach, and the concept of health data activism[iii]. The XpanDH project's vision entails a participatory involvement from all relevant end-users, such as patients, formal and informal caregivers and healthcare and IT professionals, in the EEHRxF implementation, adoption and dissemination. In this vision, these groups are not merely passive recipients, or users of digital services aimed at improving health or healthcare. They are also not simply stakeholders to be consulted in a one-directional manner but are integral participants in the process.

In the project vision, these key stakeholders should receive access to health data and co-create the AEIOU (Accessible, Engaging, Interoperable, Operational and Useful) digital health tools of the future, proposed by XpanDH. This participatory design approach has 2

main implications: 1) all key stakeholders are actively involved in the co-creation of the EEHRxF ecosystem in all project phases 2) the consortium ensures the necessary flexibility and openness to manage potential changes and needs that arise from the co-creation, to ensure real acceptance (Bowen et al., 2013; Boyd et al., 2012; Thabrew et al., 2018).

Co-creation as a vector of ecosystem activation

Co-creation as a term was firstly introduced for marketing purposes in the design of new products and services in a collaborative way. Several authors and researchers have contributed to proposing various methodological approaches and models (De Koning et al, 2016).

It is a collaborative process where multiple stakeholders engage in the design and delivery of products or services, enhancing value within ecosystems (Eckhardt et al., 2021). It is not limited to science; it spans various sectors, promoting collaborative efforts that strengthen community engagement and innovation. In platform ecosystems, co-creation leads to increased sales and business performance for small vendors, highlighting the economic benefits of collaborative partnerships (Ceccagnoli et al., 2012). This approach fosters innovation and responsiveness to user needs, particularly in complex environments like healthcare (Indurti et al., 2023). Co-creation offers several advantages for ecosystem activation, including increased EU competitiveness in healthcare delivery and digital tool deployment as compared with competing regions.

Co-creation relies on active stakeholder engagement, which encompasses behavioural, cognitive, and emotional dimensions. This engagement leads to cooperation and collaboration, ultimately resulting in co-creation, which is essential for activating ecosystems (Viglia et al., 2023). In healthcare, involving diverse stakeholders—patients, providers, and policymakers—ensures that services are tailored to actual needs, enhancing overall effectiveness (Adlakha et al., 2020). While co-creation offers significant advantages, it can also present challenges, such as managing diverse stakeholder interests and ensuring effective communication. Balancing these dynamics is crucial for successful ecosystem activation. Using co-creation, the XpanDH method applied a democratic participatory strategy to growing the EEHRxF and the pan-European digital health ecosystem.

XpanDH made the creation, maintenance, and stimulation of an **EEHRxF Ecosystem** one of its main responsibilities. This approach is crucial for achieving a significant impact within the constraints of time and budget, particularly when building an EU-wide digital health ecosystem.

The X-Nets

XpanDH operates as both a **Network of Capacity**, helping organisations assess their readiness regarding the necessary interoperability assets for EEHRxF implementation, and a **Network of Action**, enabling large-scale and pan-European collaboration through the deployment of **X-Nets**.

The X-Nets represent an ensemble of networks created from EU or Member States organisations united by common interests and are active participants in the broader pan-European digital health landscape. With the goal of fostering a collaborative environment where different stakeholders can contribute to the evolution of digital health infrastructure throughout Europe, these networks are intended to promote the benefits and practicalities of adopting the EEHRxF. Stakeholders can collaborate across borders, capacities and stakeholder groups when they are brought together within the X-Nets, which promotes innovation and idea sharing.

The X-Nets where inspired by the Hospitals-on-FHIR[iv] effort, which was established in March 2022 with the goal of networking hospitals and healthcare professionals throughout Europe. Ten X-Nets have been promoted throughout the XpanDH project. Each network has an "activator" which manages its assembly, launch, and maintenance. As X-Nets mature, they have the potential to become increasingly independent, as demonstrated by the Hospitals-on-FHIR X-Net.

Ten X-Nets are part of XpanDH's approach, each focusing on a specific aspect of the healthcare ecosystem:

Table 1: List of XpanDH X-nets and its short description

X-Net	Description	N° of Gatherings
Biomedical research	Network of Researchers and Research collaboration initiatives in the life sciences and biomedical areas	1
Citizens and society	Network of citizen associations, consumer groups, and other representatives of civil society, including media	2
European Reference Networks (ERNs)	Network of all ERNs established and projects/initiatives in personalised medicine	1
Health Managers	Network of health management professionals and associations	3
Heath National and Regional authorities	Network of national and regional health authorities responsible for healthcare provision or oversight/planning healthcare	4

Hospitals-on-FHIR[1]	Network of organisations affiliated with the HL7 Europe Hospitals-on-FHIR initiative and interested parties	3
Innovation hubs	Network of partners of the innovations cycle (e.g. venture capital and innovation funds, incubators, innovation hubs)	1
Patient Associations	Network of patient associations	3
Professionals Associations	Network of health professionals' chambers, associations and unions, national and European	(1)
Industry	Network of digital health industry players (companies and associations, federations	6

X-Nets approach

The XpanDH project adopted a **systematic X-Net strategy**, acknowledging the diverse expertise, experiences, and expectations of stakeholders involved in digital health and health data exchanges. To ensure effective engagement, the X-Net outreach strategy was customised for each stakeholder group based on the following key points:

(a) **Type of Institutions Involved**: Identify typical institutions that form the core of each X-Net group, including both physical and legal entities. These institutions range from hospitals, research organisations, and patient associations to IT firms, government bodies, and regional health authorities and regulators, ensuring broad representation across the health data landscape.

(b) **Influence and Impact**: Recognise the varying levels of influence and impact that different stakeholder groups can exert on the digital health ecosystem. Some groups, such as **regulators** or **hospital networks**, play critical roles in decision-making processes, while others may be more focused on operational or advocacy functions, or be in a traditional position of receivers. Understanding each group's influence allows for targeted engagement strategies.

(c) **Barriers to Engagement**: A key element of the X-Net strategy is identifying and addressing potential **barriers to engagement**. These can include a lack of awareness, perceived complexity of the EEHRxF, or limited resources to adopt new technologies and/or create a framework for the upskilling of the future workforce on digital skills. By understanding these barriers, XpanDH can develop targeted solutions to mitigate them, such as offering training, simplifying processes, or demonstrating quick and mutually beneficial wins to encourage active participation.

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[1] Fast Healthcare Interoperability Resources

(d) **Stratification**: To further refine outreach efforts, some X-Nets such as the Patient Associations are broken down into specific **sub-groups** based on factors such as geographical region, operational focus, and organisational type when applicable. This stratification enables the project to address the unique needs and characteristics of different sub-groups within a larger stakeholder network, ensuring more precise and effective communication.

(e) **Concrete Benefits from XpanDH/EEHRxF**: Provide each stakeholder group with a clear outline of the tangible benefits and added value that participation in XpanDH and the adoption of EEHRxF offer. Whether through enhanced interoperability, improved patient care, or streamlined research opportunities, stakeholders are explained how the X-Net and the EEHRxF can meet their specific needs.

(f) **Engagement with own Community**: X-Nets are encouraged to interact within their own **community networks** by leveraging established communication channels and producing relevant content tailored to their audience. Whether through webinars, newsletters, or collaborative forums, the X-Nets aim to engage stakeholders in ways that resonate with their organisational culture and sector-specific challenges.

(g) **Specific Engagement Methods for X-Net**: Each X-Net agitator utilizes tailored **engagement methods** based on the characteristics of the group and the intended outcomes. For example, patient associations might require advocacy-driven, participatory approaches, while regulatory bodies may focus on compliance and governance-oriented engagements. The rationale for these methods is grounded in the stakeholders' role within the ecosystem and their potential to drive adoption of EEHRxF.

(h) **Relations to Other X-Nets**: The X-Nets are not isolated entities. Their **relations to other X-Nets** are carefully considered, as collaboration across networks can amplify their collective impact. For instance, the **Hospitals-on-FHIR** network may work closely with the **Professionals Associations** and **Biomedical Research** groups to align clinical data sharing with research objectives. In this line of thought, various multi-stakeholder focus group workshops have been organised online that brought together multiple representatives of each X-Net, making different stakeholder groups join forces. These "Network of X-Nets" efforts culminate in a presential meeting taking place in November 2024 in Brussels.

(i) **(Potential) Members**: Each X-Net has a defined set of **current and envisioned members**, with participation spanning a broad range of organisations across Europe. Regular updates are made to this membership list to reflect new partnerships, emerging stakeholders, and ongoing initiatives that align with the objectives of XpanDH, in order to continuously enable X-Nets to grow in numbers.

Dynamics and preliminary findings from the XpanDH X-Nets

The X-Nets collaborate through online and in-person workshops. They stimulate the ecosystem via newsletters and LinkedIn . X-Nets are resource networks that may be engaged in a variety of ways, such as inviting stakeholders to events or setting up consultations. Examples are workshops held at prestigious conferences like the *Madeira Digital Transformation Week[v]* or the *EHMA annual conference[vi]*, where many stakeholders convene to deliberate on the most recent advancements in the field of digital health and beyond. To ensure cross-collaboration and representation, X-Nets also convene multi-stakeholder focus group sessions. The Brussels event, which takes place in November soon after the Second EEHRxF Expert Summit, is a significant example of this kind of cooperation. It will bring together representatives from all X-Nets for an in-person strategic summit aimed at promoting deeper integration and strategic planning among the networks.

The X-Nets have fostered a collaborative environment for diverse stakeholders across the digital health spectrum. The Citizens and Society X-Net sparked debates on individual and civil rights and EHDS (European Health Data Space) regulation, while the ERNs X-Net gathered nearly all European Reference Networks, generating interest in EEHRxF for rare diseases. Health Managers and Health Authorities X-Nets played key roles in disseminating updates, refining strategies, and aligning policies on digital health. Hospitals-on-FHIR focused on FHIR standard implementation in around 70 hospitals across five countries, and Innovation Hubs promoted awareness of EEHRxF's potential for innovation. The Patient Associations X-Net tailored its approach to a Member State to overcome language barriers (events in French, German and Portuguese), and the Industry X-Net contributed to the co-development of XpanDH's Readiness Model, ensuring industry alignment with EEHRxF adoption. Collectively, these networks drive ecosystem activation and collaboration for the digital health future.

Looking ahead

XpanDH has taken on the task of initiating the EEHRxF ecosystem stimulation. These activities have been carried out following meticulous planning and strategy development, and they will continue until the project's official closure at the end of 2024. It is important to emphasise that, despite different maturity levels across certain initiatives, they all have a bigger scope and goal than just XpanDH: a longer-term vision. Because they were intended to be concrete, these functional networks are better equipped to continue without the project's specific infrastructure. To ingrain the XpanDH-activated ecosystem into the larger European digital health ecosystem setting, we conduct extra alignment and handover operations. The X-Nets will be transferred to and maintained inside the European legacy project "xShare" (*Expanding the European EHRxF to share and effectively use health data within the EHDS;* Project: 101136734 — HORIZON-HLTH-2023-IND-06) . The "Xt-EHR" joint action (*Extended EHR@EU Data Space for Primary Use*; Project: 101128085 — EU4H-2022-

JA-IBA), a second project centred on policy ecosystems, will receive the outputs from the Community of Doers. More specifically, the Xt-EHR Joint Action will prepare implementation guides, technical specifications, and a conformity assessment framework for the adoption of the EEHRxF at a European Level, effectively informing policy, regulatory, and practical facets of the format's advances.

In relation to the EEHRxF, co-creation has proven to be an effective strategy for ecosystem activation. Through the XpanDH project, the X-Nets (Network of Networks) have been established and fostered, demonstrating the potential for co-creation to support the development and implementation of the EEHRxF, a cornerstone of the European Commission's digitalisation agenda[vii]. With the help of X-Nets and the Community of Doers, the EEHRxF X-Nets is thriving and has the potential to expand by multiple orders of magnitude, becoming a sustainable part of the digital health ecosystem. Through its dedicated focus on the EEHRxF, XpanDH is contributing to a more integrated and interoperable healthcare system, ultimately enhancing patient care and facilitating efficient cross-border health data management within the EU. In order to guarantee that the X-Nets may expand and become more beneficial to the advancement of the EEHRxF and EHDS, sufficient supporting activities and direction will be further needed, including taking control of the current structures and providing additional supporting sources. These activities shall be assumed by the current and further Digital Health projects (such as xShare and Xt-EHR) ensuring that all ecosystem actors have voice in the co-creation and implementation of the EEHRxF. Achieving, in this way, a higher quality digital health services to the users, Health professionals, and patients.

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