



# GÉANT Special Interest Group on Digital Health Data

Perspective on Sensitive Data Handling from the  
SIG-DHD and the community of NRENs

EGI 2024 Conference

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October 1, 2024  
Lecce, Italy

Public (PU)

1. The SIG-DHD Digital Health Data of the GÉANT Community Programme
2. Survey on eHealth 2024 for NRENs : main outcomes, also in relation to TREs
3. Baseline of new service concepts (GN5-2 project)

I won't list ongoing, individual initiatives and projects by NRENs:

See for example the recent webinar for NRENs on TREs:

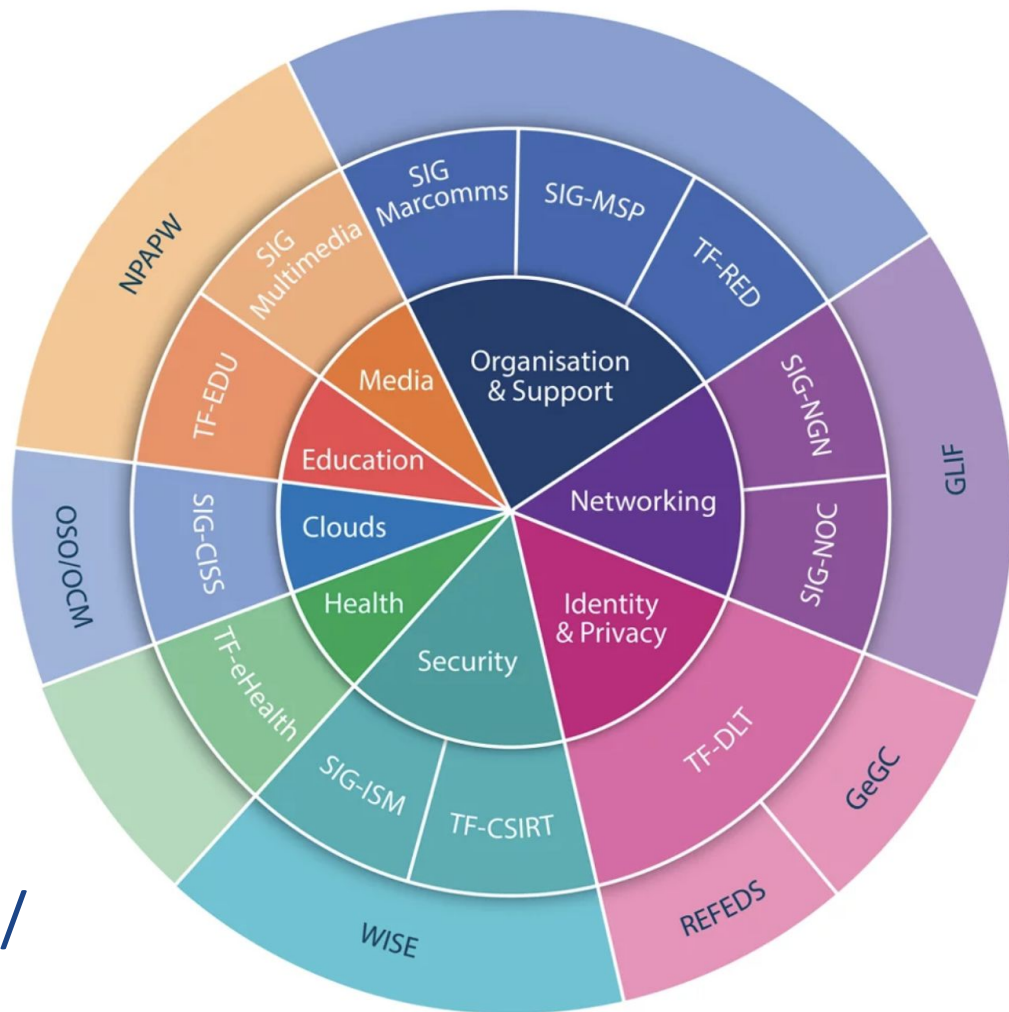
<https://events.geant.org/event/1700/>

referring to initiatives and projects at CSC, SURF, JISC, SWITCH

Video recording on <https://geant.app.box.com/s/s423cezkvx99y9x5jdcwohdxxy5kcwfjp>

# The GÉANT Community Programme

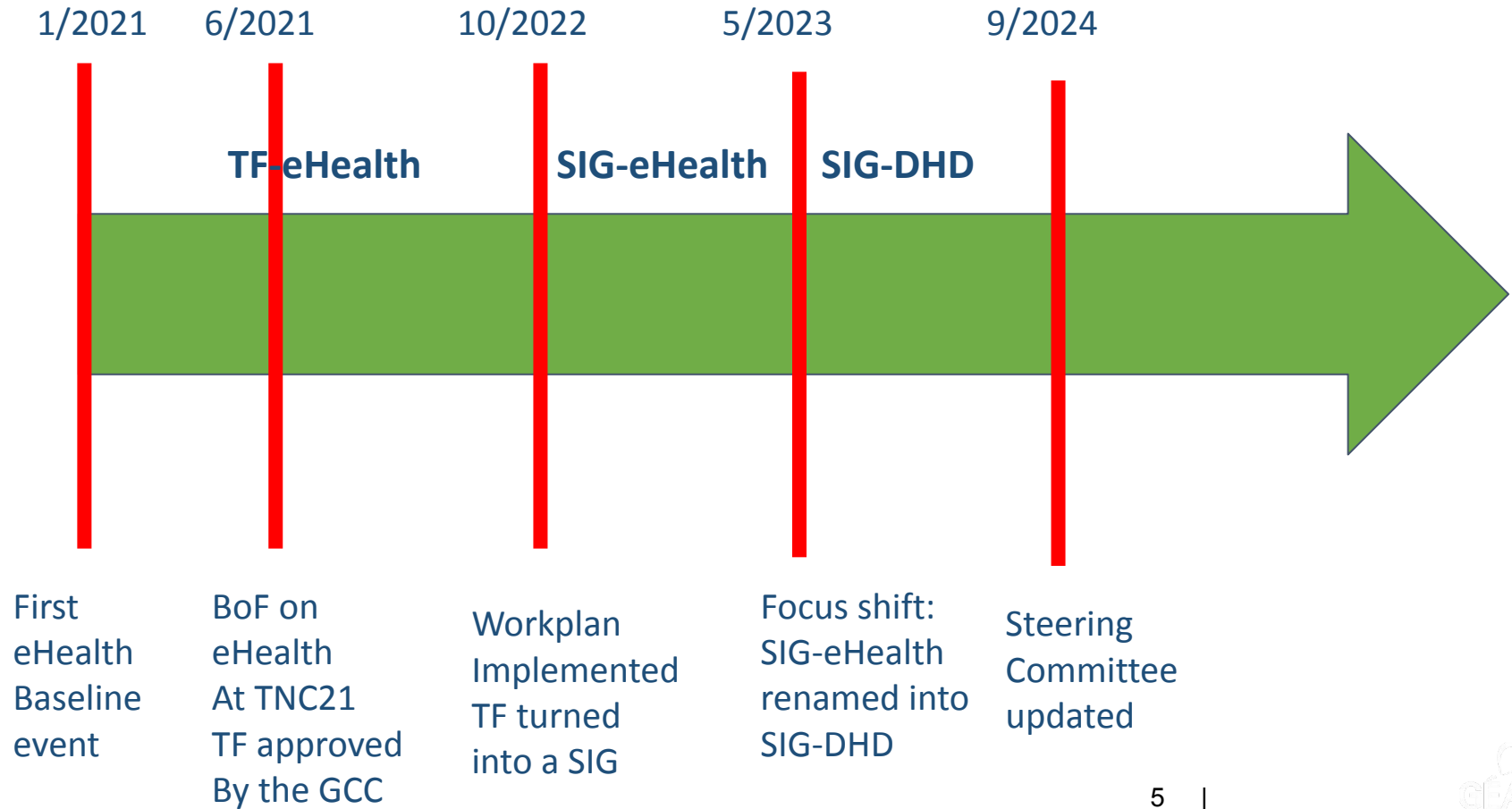
- **Brings the NRENs and Research and Education Community together** to tackle common challenges
- Main goal is to **exchange experiences, best practices, share hands-on expertise** in various domains involving the NRENs, their services and their connected community of users
- Implemented through **Special Interest Groups** and **Task Forces**

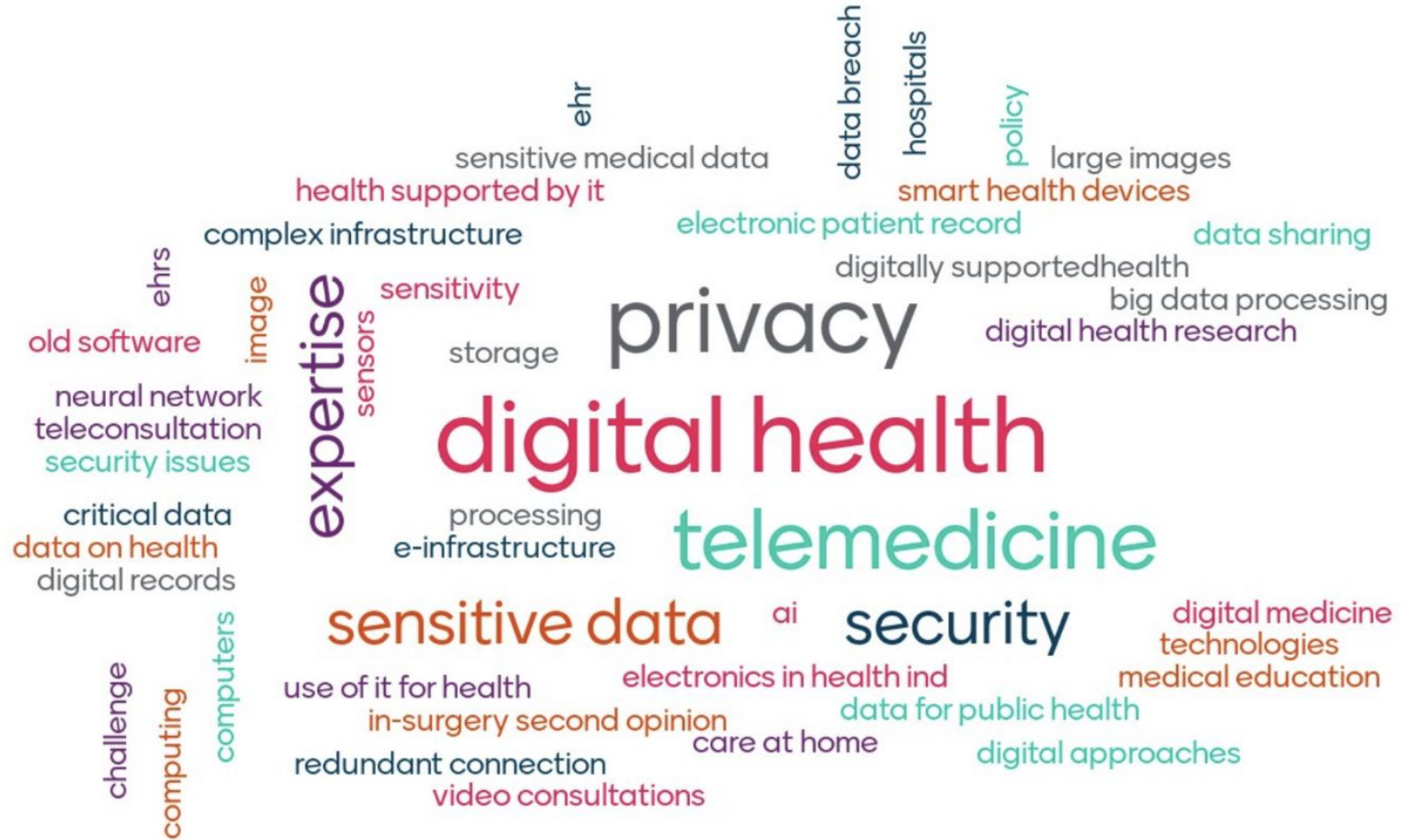


<https://community.geant.org/>

- Approved by the **GÉANT Community Programme** Committee, June 30, 2021
  - for a first initial year of work
  - Following two main community events (Jan 27, June 25 in 2021)
- With the **following mandate from NRENs:**
  - **to gather NRENs' efforts on eHealth support**
  - **exploit synergies**
  - **exchange best practices**
  - **seek specific collaborations with Health related projects**
- Goal for the TF is to **implement the work plan** and include additional work items if needed
- The **approved TF work plan** is available on
  - <https://bit.ly/ehealth-tf-workplan>

# How did things start and develop within the **GÉANT Community** ?





# Outcome and take-home messages from the Community at the first eHealth baselining event

- **Cloud, AAI, Security, Data Access policies** are very relevant domains to this community, overall
- **Artificial Intelligence and ML** applied to medical data sets are key technologies requiring the NRENs community to provide support for
- **NRENs well off to provide privacy preserving/secure services to research eHealth institutions**
  - Starting from storage and data sharing services
  - Liaising with the activities carried out within the Community Cloud task
- There is a **common need to acquire additional information on latest EU directives/communications** and promoted new concepts on eHealth
  - [EU eHealth Dataspace](#)
- Key areas where support at the policy level is required and developments are needed identified in
  - Data Access policies
  - Enforcement of standards and FAIR data approach
  - Trusted research environments
  - Evangelization to Hospitals and their staff
- Consensus on **common interest to know more about funding opportunities** for the community



## Provided Deliverables by the eHealth Task Force

1. The **Gap analysis document** highlighted the areas where NRENs see collaboration opportunities  
<https://wiki.geant.org/display/EHE/eHealth+Gap+Analysis>
2. The **training on Security and Privacy for eHealth** was attended by ~25 persons, who have also been able to contribute hands-on work in an interactive session. <https://events.geant.org/event/1205/>
3. The final deliverable reports on **available services and key projects** within the NRENs community to support eHealth  
<https://wiki.geant.org/display/EHE/Overview+of+services+and+projects+supporting+eHealth>



- **Dissect the problem** of supporting eHealth in its natural domains
  - Infrastructure Interoperability
  - Ethical Issues
  - Regulatory matters
  - Business related
- Acquire information on the exact **status of national eHealth initiatives** in each EU country, including the legal aspects/frameworks
- Push for the adoption and the enforcement of **standards allowing interoperability**
- **Training, Training, Training !**
- **Liaise** with the national eHealth initiatives and large international collaboration in eHealth

- **Liaise with the EC and inform our eHealth community** connected institutions about new project calls, EC regulations, EC communications
- Provide input to the community discussions on how to improve support for eHealth
- **Liaise with national eHealth initiatives**
  - Identifying collaboration domains (Network, infrastructures, Storage Services, Cloud)
- **Provide Security Trainings for the community** to ensure tools, processes, DCs, LANs are secure
- **Primary use of Health Data and Telemedicine:**
  - Provide high bandwidth and enable ubiquitous teleconsulting, diagnosis, cure
- **Secondary use of Health Data for Research:**
  - **Push for the adoption of our open community standards** (e.g. AAI, AAI-a-a-S)
    - Ensure FAIR access to research data - avoiding vendor lock-in
  - Provide eHealth specific services (e.g. anonymization, secure data transfer..)
  - Provide support to the infrastructure for secondary usage of electronic health data
    - Trusted Research Environments / Secure Processing Environments
  - (EHDS)
  - Liaise with other key initiatives in Europe (e.g. EuroHPC JU)

## Suggested focus areas for a SIG on eHealth

- EHDS: What is the role that existing eInfrastructures and research communities will play in **MyHealth@EU** and **HealthData@EU** ?
- EHDS: **Secure Processing Environments and Trusted Research Environments**
- **EOSC** and the **Common European Data Spaces**
- EC regulations like DA, DGA, AI act
- How should our community **relate to the national eHealth Initiatives** to ensure the community of eHealth users gets all required support ?
- Share experiences on pilots on **Trust and Identity, Storage services, Cloud** focusing on supporting the eHealth Community
- **Showcase success stories** and share experiences on providing access to compute resources (**Cloud, HPC, HTC**) for **AI, ML**
  - Keep the eHealth User Community well linked to HPC community/EuroHPC JU



## Results of the **eHealth Survey for NRENs 2024** (27 respondents)

Survey URL: <https://www.surveymonkey.com/r/2RVW3MJ>

Side notes URL:  
[bit.ly/eH-survey-side-notes](https://bit.ly/eH-survey-side-notes)

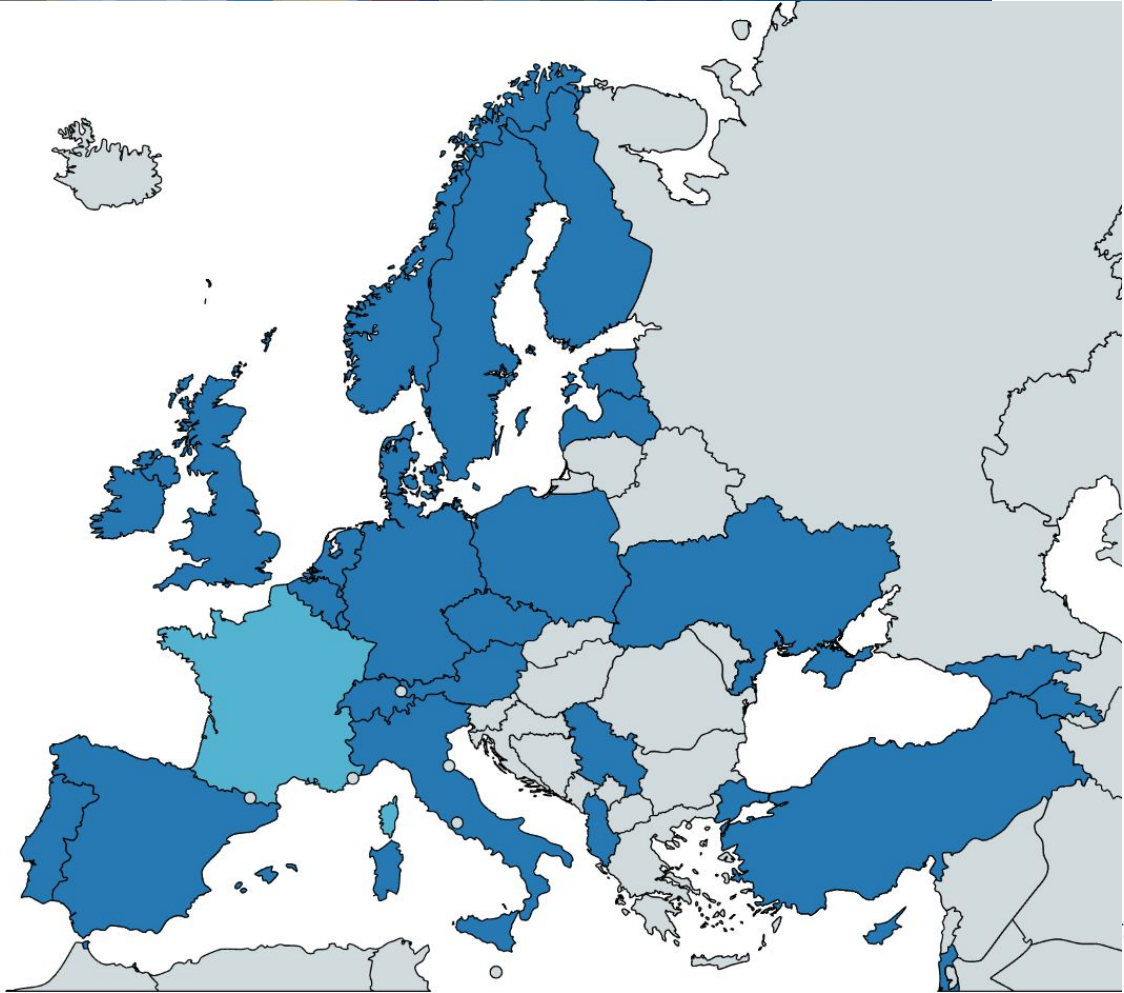
## Goals and scope for the 2024 eHealth Survey for NRENs

- **Help understanding the landscape around eHealth and managing Digital Health Data**
- **Underlying question is: is it time, do we have the resources, time and will to step up our efforts on specifically targeting the Health Community, possibly spawning something beyond the SIG ?**
- **How relevant is Health and how required is the management of sensitive data / medical data within our Community ?**
- **How much awareness is there about the latest regulatory processes about Health, starting from the proposal of the European Health Data Space ?**
- **Is it “time to act” , also in liaising with key, flagship EU initiatives (e.g. Health Data Hub, THEDAS..)**

# 27 NRENs provided an answer

## NRENs eHealth Survey 2024

- Answer provided
- Response pending



## Three main survey sections:

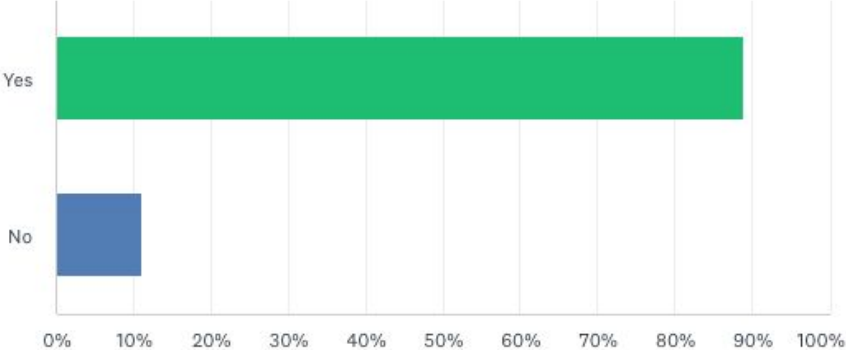
- **Current level of support to the eHealth community and related trends (Q 1-10)**
- **EU regulatory landscape, the EC, and the desired role of NRENs in the domain of Digital Health Data (Q11-12)**
- **Should NRENs collectively engage more? (Q13-24)**



# Question 1

Do you currently connect (provide NREN connectivity to) Health institutions (Hospitals, Research-Hospitals, Medical departments in the Universities, Nationally-relevant Health Institutes) ?

Answered: 27 Skipped: 0

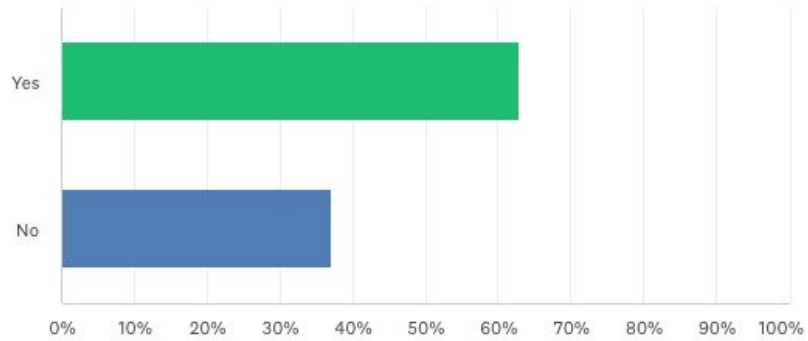


ANSWER CHOICES	RESPONSES
Yes	88.89% 24
No	11.11% 3
<b>TOTAL</b>	<b>27</b>

# Question 2

Are you currently providing the Digital Health community with specific, tailored services - directly provided by you (e.g. Cloud Storage and/or Computing resources for sensitive data, or Cloud-based AAI services, Security-related services )?

Answered: 27 Skipped: 0

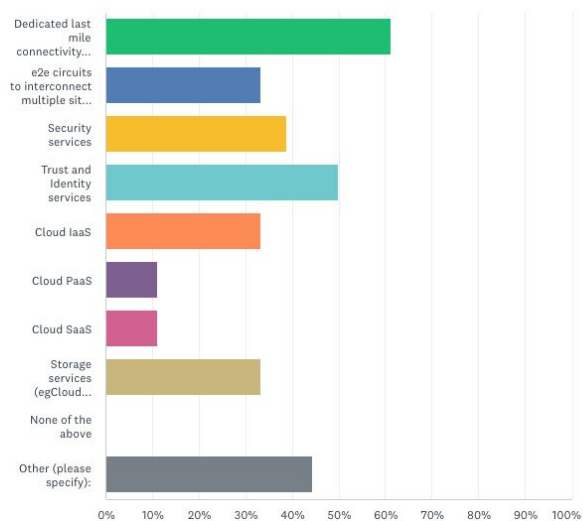


ANSWER CHOICES	RESPONSES	
Yes	62.96%	17
No	37.04%	10
<b>TOTAL</b>		<b>27</b>

# Question 3

If you answered 'YES' to the previous question (n.2) , please specify what specific services you are providing to the Health Institutions and users community:

Answered: 18 Skipped: 9

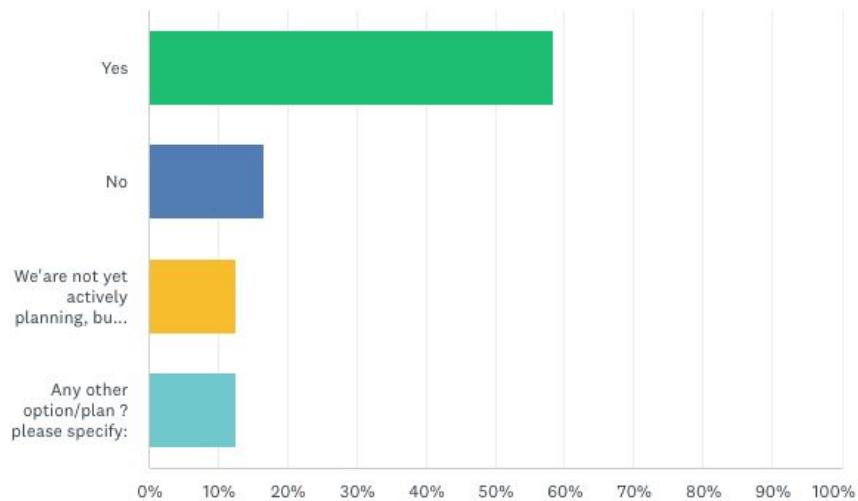


ANSWER CHOICES	RESPONSES
▼ Dedicated last mile connectivity services (e.g. redundant end-site connection link, ..)	61.11% 11
▼ e2e circuits to interconnect multiple sites within the NREN network	33.33% 6
▼ Security services	38.89% 7
▼ Trust and Identity services	50.00% 9
▼ Cloud IaaS	33.33% 6
▼ Cloud PaaS	11.11% 2
▼ Cloud SaaS	11.11% 2
▼ Storage services (egCloud Storage, Sync&Share..)	33.33% 6
▼ None of the above	0.00% 0
▼ Other (please specify):	Responses 44.44% 8
<b>Total Respondents: 18</b>	

# Question 4

## Are you planning to do so in the next 1-3 years ?

Answered: 24 Skipped: 3

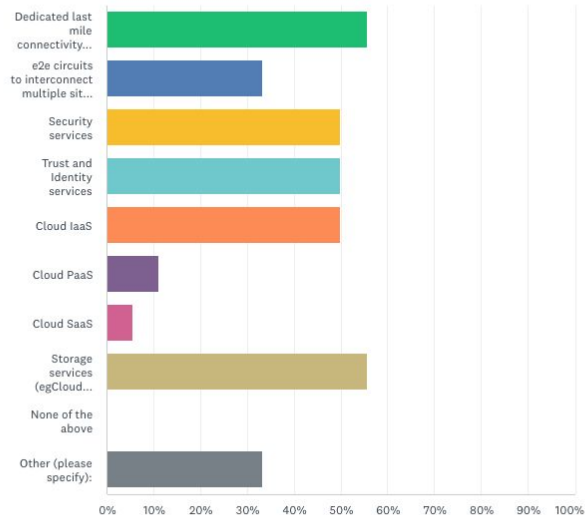


ANSWER CHOICES	RESPONSES	
▼ Yes	58.33%	14
▼ No	16.67%	4
▼ We are not yet actively planning, but we're considering to do so	12.50%	3
▼ Any other option/plan? please specify:	<a href="#">Responses</a> 12.50%	3
<b>TOTAL</b>		<b>24</b>

# Question 5

If you answered 'YES' to the previous question (n.4) , please specify what specific services will you provide your user community with next ?

Answered: 18 Skipped: 9

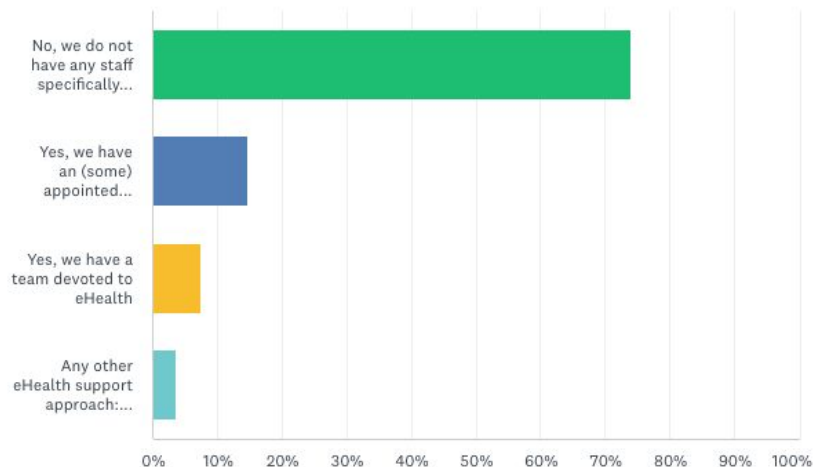


ANSWER CHOICES	RESPONSES	
▼ Dedicated last mile connectivity services (e.g. redundant end-site connection link, ..)	55.56%	10
▼ e2e circuits to interconnect multiple sites within the NREN network	33.33%	6
▼ Security services	50.00%	9
▼ Trust and Identity services	50.00%	9
▼ Cloud IaaS	50.00%	9
▼ Cloud PaaS	11.11%	2
▼ Cloud SaaS	5.56%	1
▼ Storage services (egCloud Storage, Sync&Share..)	55.56%	10
▼ None of the above	0.00%	0
▼ Other (please specify):	Responses 33.33%	6
<b>Total Respondents: 18</b>		

## Question 6

Do you have - within the NREN - a department, a team, a working group or any other form of structured support - specifically dedicated to the domain of Digital Health Data and/or eHealth?

Answered: 27 Skipped: 0

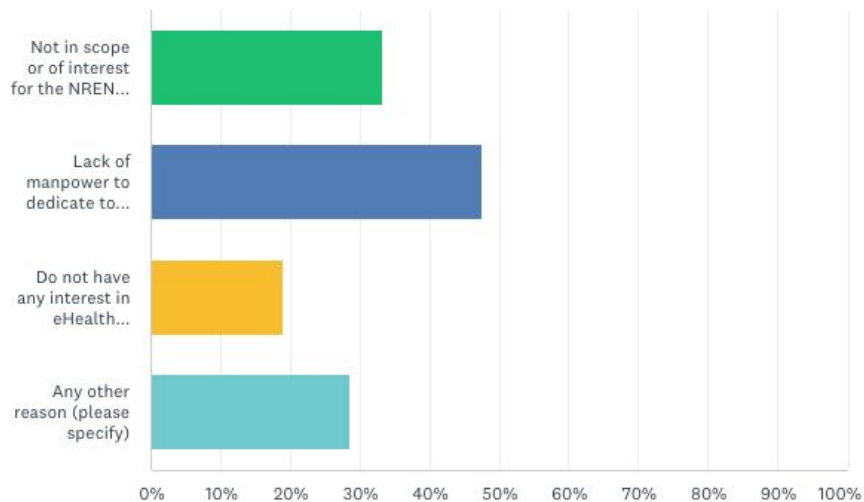


ANSWER CHOICES	RESPONSES	
▼ No, we do not have any staff specifically dealing with eHealth	74.07%	20
▼ Yes, we have an (some) appointed person(s)	14.81%	4
▼ Yes, we have a team devoted to eHealth	7.41%	2
▼ Any other eHealth support approach: please specify	Responses 3.70%	1
<b>TOTAL</b>		<b>27</b>

## Question 7

If you answered 'No' to the previous question (n.6), please tell us why you do not have a team specific dealing with eHealth:

Answered: 21 Skipped: 6



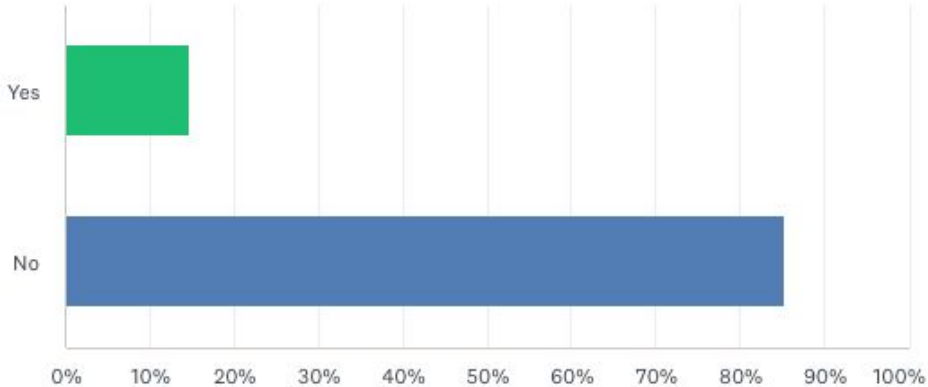
ANSWER CHOICES	RESPONSES
▼ Not in scope or of interest for the NREN mission and goals	33.33% 7
▼ Lack of manpower to dedicate to this potentially interesting domain	47.62% 10
▼ Do not have any interest in eHealth specifically	19.05% 4
▼ Any other reason (please specify)	Responses 28.57% 6
<b>Total Respondents: 21</b>	



# Question 8

Do you have an appointed staff member to join the SIG-Digital Health Data (SIG-DHD) activities (formerly called TF-eHealth) ?

Answered: 27 Skipped: 0



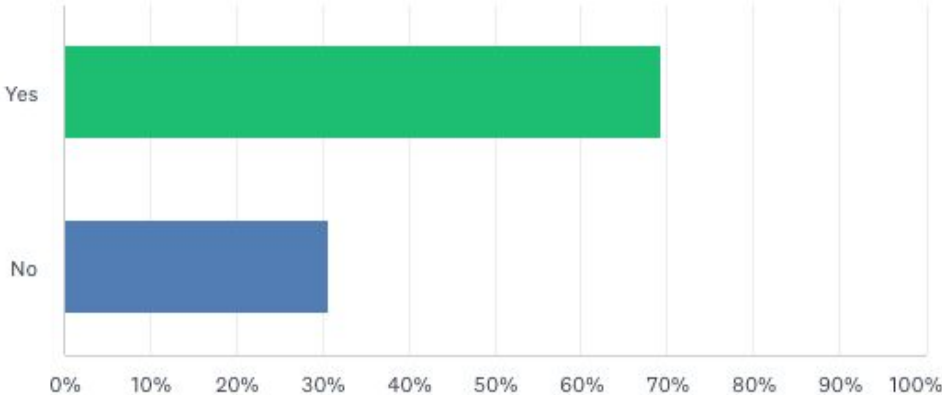
ANSWER CHOICES	RESPONSES
Yes	14.81% 4
No	85.19% 23
<b>TOTAL</b>	<b>27</b>

[Comments \(14\)](#)

# Question 9

Would you like to see your involvement in the domain of Digital Health growing in the next 2-4 years ?

Answered: 26 Skipped: 1

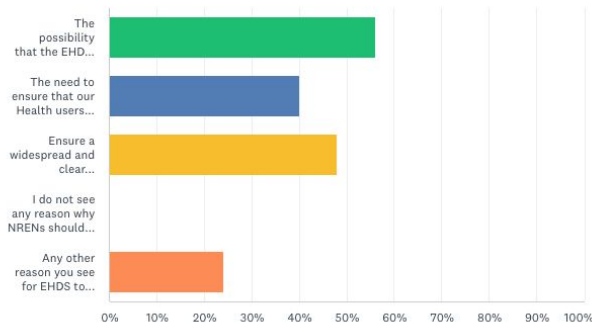


ANSWER CHOICES	RESPONSES
Yes	69.23% 18
No	30.77% 8
<b>TOTAL</b>	<b>26</b>

# Question 11

The EC is planning and designing the European Health Data Space (EHDS) as a health specific ecosystem comprised of rules, common standards and practices, infrastructures and a governance framework. This aims at Empowering individuals through increased digital access to and control of their electronic personal health data, and fostering a genuine single market for electronic health record systems (primary use of data) Providing a consistent, trustworthy and efficient set-up for the use of health data for research, innovation, policy-making and regulatory activities (secondary use of data) Do you think NRENs should be concerned by (or involved in) the design and establishment of the EHDS, because of the following reasons:

Answered: 25 Skipped: 2

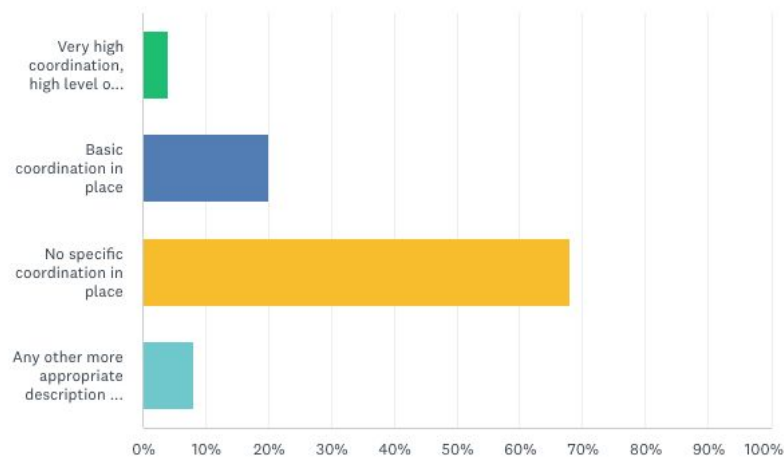


ANSWER CHOICES	RESPONSES
<input type="checkbox"/> The possibility that the EHDS will be designed based on standards on access policies, data transfer and management protocols, user authentication and authorization) that will turn out to be non compliant or not interoperable with the already existing standards in our R&E community	56.00% 14
<input type="checkbox"/> The need to ensure that our Health users community will be prepared, proactively informed and aware of the implied changes (for researchers and site IT administrators) by EHDS getting endorsed and operational within the EU member states (e.g. required certifications, data access policy, data discovery and data curation, ..)	40.00% 10
<input type="checkbox"/> Ensure a widespread and clear understanding of the implications of EHDS for the NRENs as providers of services to their user community ?	48.00% 12
<input type="checkbox"/> I do not see any reason why NRENs should be dealing with or concerned by the establishment of the European Health Data Space	0.00% 0
<input type="checkbox"/> Any other reason you see for EHDS to impact on the R&E ecosystem supported by GÉANT and the NRENs ?	<a href="#">Responses</a> 24.00% 6
<b>Total Respondents: 25</b>	

# Question 12

What is the level of contact and coordination you have in place with the National Contact Point for eHealth (NCPeH) in the context of the eHealth Digital Service Infrastructure (eHDSI, myHealth@EU) and, more in general, with the National Health Initiatives in your country ?

Answered: 25 Skipped: 2

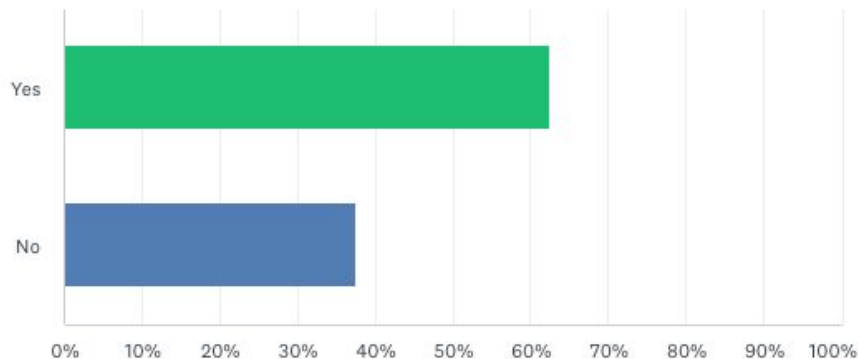


ANSWER CHOICES	RESPONSES
▼ Very high coordination, high level of awareness of the governmental, national plans on eHealth (e.g. technical roadmaps, adopted solutions, implied dissemination towards users..)	4.00% 1
▼ Basic coordination in place	20.00% 5
▼ No specific coordination in place	68.00% 17
▼ Any other more appropriate description of the level of awareness and coordination you'd want to use here: <a href="#">Responses</a>	8.00% 2
<b>TOTAL</b>	<b>25</b>

## Question 13

Do you see as your task/role - as NREN - to aim at providing Cloud services (Computing, Storage) or other above-the-net services to manage sensitive data, and to provide Secure Processing Environments / Trust Research Environments for your Health user community (either directly or on behalf of the National Health Initiative/Health Data Access Bodies) ?

Answered: 24 Skipped: 3

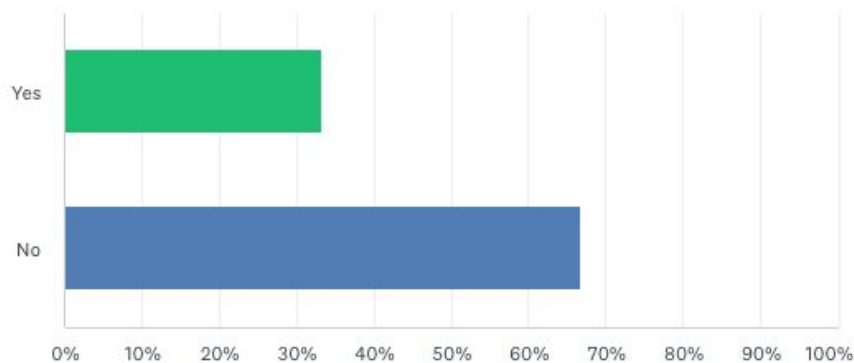


ANSWER CHOICES	RESPONSES
▼ Yes	62.50% 15
▼ No	37.50% 9
<b>TOTAL</b>	<b>24</b>

## Question 14

Do you see as your task/role - as NREN - to aim at evangelising the Health User Community about the impact of EHDS, and its implications on the management of data, on data access policies, on provided services to the user community and the end-users side required changes (e.g. new/different ways of authenticating and being authorised to access resources/datasets..)

Answered: 24 Skipped: 3



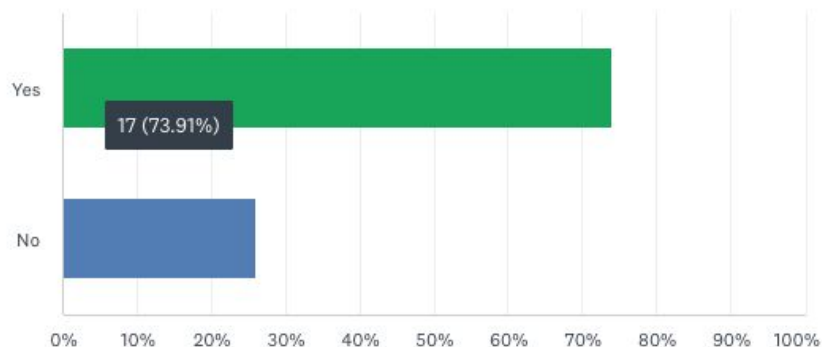
ANSWER CHOICES	RESPONSES	
Yes	33.33%	8
No	66.67%	16
<b>TOTAL</b>		<b>24</b>



## Question 15

Should GEANT and the NREN proactively act and lobby towards the key actors in the EHDS ecosystem, to ensure the services we're currently providing to our communities will be able to interoperate with the solutions currently being designed for the EHDS2 ("HealthData@EU" - Health Data Space for the Secondary use of Health Data (e.g. Research) - liaising for example with the HealthData@EU pilot project: <https://ehds2pilot.eu/> ) ?

Answered: 23 Skipped: 4



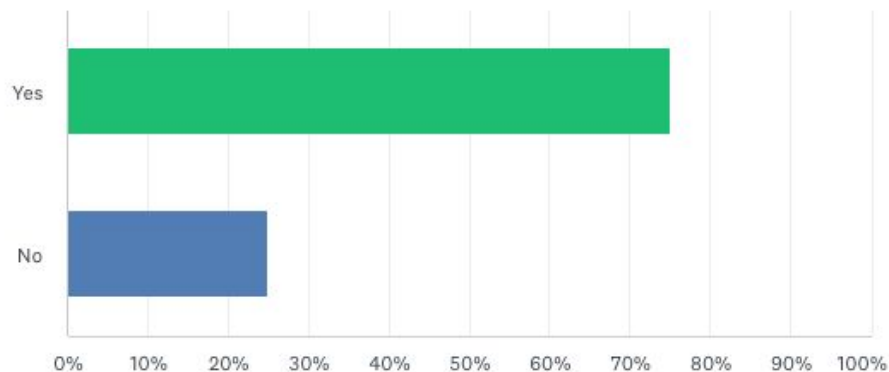
ANSWER CHOICES	RESPONSES	
▼ Yes	73.91%	17
▼ No	26.09%	6
<b>TOTAL</b>		<b>23</b>



## Question 16

Would you welcome an action within the SIG-Digital Health Data aimed at introducing NRENs to each other in the domain of Digital Health, with the possible further outcome of jointly responding to Horizon Europe/Digital Europe/EU4Health/etc. calls for EU-funded project proposals ?

Answered: 24 Skipped: 3

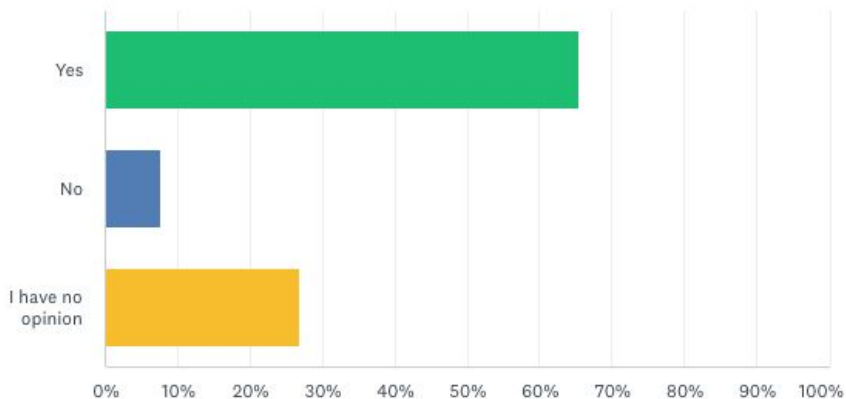


ANSWER CHOICES	RESPONSES
▼ Yes	75.00% 18
▼ No	25.00% 6
<b>TOTAL</b>	<b>24</b>

## Question 17

EHDS is one of the 14 defined Common European Data Spaces (CEDS), which will be a part of the EU Strategy for data. Would you welcome any community task aimed at understanding how the CEDS will interoperate and how their integration with the EOSC will work (in particular, more specifically, how the EHDS will) ?

Answered: 26 Skipped: 1

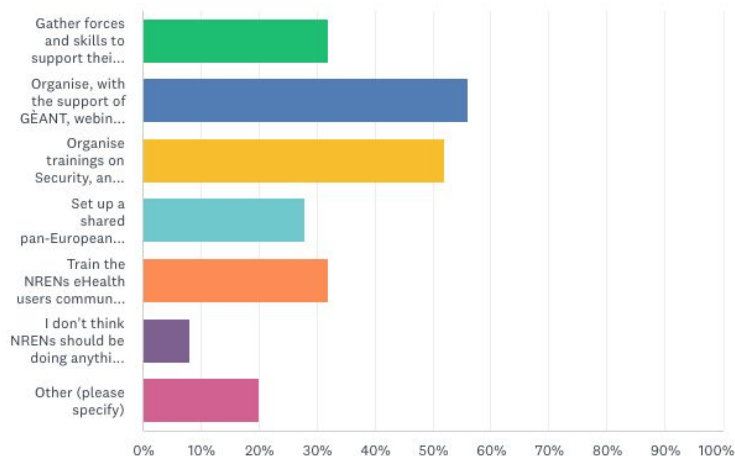


ANSWER CHOICES	RESPONSES
▼ Yes	65.38% 17
▼ No	7.69% 2
▼ I have no opinion	26.92% 7
<b>TOTAL</b>	<b>26</b>

# Question 18

## What do you think NRENs could do together in the domain of eHealth ?

Answered: 25 Skipped: 2



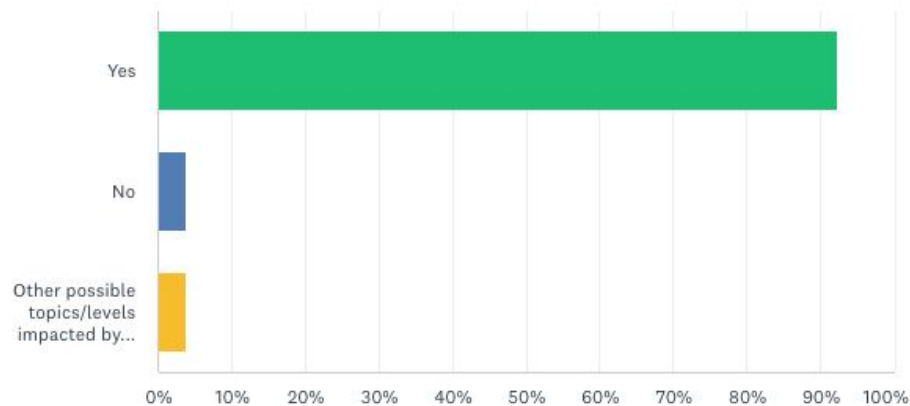
ANSWER CHOICES	RESPONSES
▼ Gather forces and skills to support their eHealth user communities to submit project proposals on eHealth and Digital Health Data management ?	32.00% 8
▼ Organise, with the support of GÉANT, webinars on key aspects related to supporting the eHealth user community, also in relation with the forthcoming new regulation (EHDS) ?	56.00% 14
▼ Organise trainings on Security, and on the technologies to handle medical and sensitive data, on anonymization and pseudo-anonymization techniques and tools, on securing the IT infrastructure to make it ready to handle sensitive data ?	52.00% 13
▼ Set up a shared pan-European testbed available to all GÉANT NRENs to directly experiment with the management of sensitive data for eHealth ?	28.00% 7
▼ Train the NRENs eHealth users community on the European Health Data Space ?	32.00% 8
▼ I don't think NRENs should be doing anything together, collectively, in the domain of eHealth and Digital Health Data	8.00% 2
▼ Other (please specify) <a href="#">Responses</a>	20.00% 5

Total Respondents: 25

## Question 19

More generally speaking, should the SIG further disseminate to the NRENs about the latest developments on the EHDS and its implications possibly impacting the NRENs at all levels (e.g. on Cloud, AAI, network, security services - and at the policy level) ?

Answered: 26 Skipped: 1

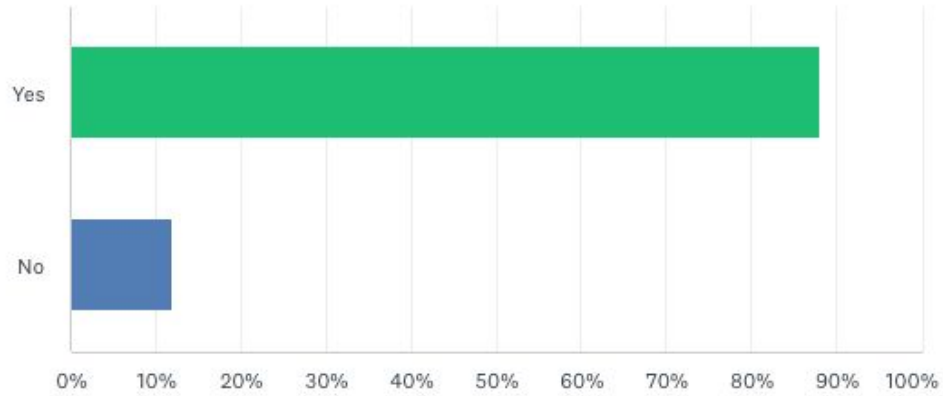


ANSWER CHOICES	RESPONSES
▼ Yes	92.31% 24
▼ No	3.85% 1
▼ Other possible topics/levels impacted by EHDS (please specify)	<a href="#">Responses</a> 3.85% 1
<b>TOTAL</b>	<b>26</b>

# Question 20

Should NRENs coordinate more with each other to jointly defined actions to be carried out collectively?

Answered: 25 Skipped: 2

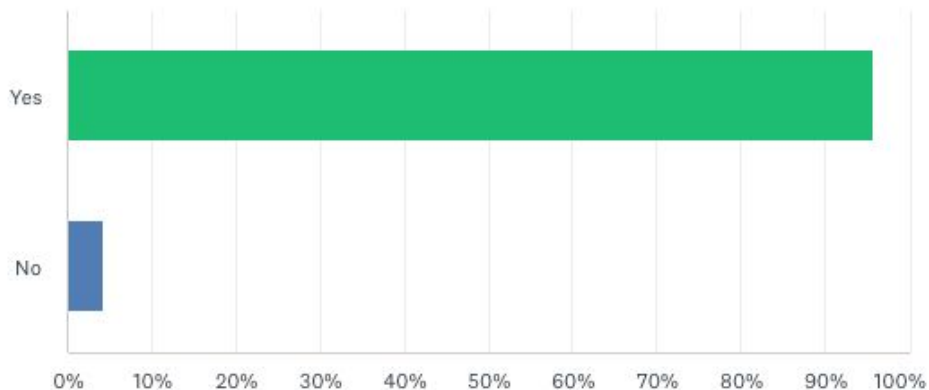


ANSWER CHOICES	RESPONSES
Yes	88.00% 22
No	12.00% 3
<b>TOTAL</b>	<b>25</b>

## Question 21

Should the SIG further disseminate to the NRENs about the latest developments on the EHDS and its implications impacting the NRENs at all levels ?

Answered: 23 Skipped: 4



ANSWER CHOICES	RESPONSES	
▼ Yes	95.65%	22
▼ No	4.35%	1
<b>TOTAL</b>		<b>23</b>

Research  
**data-set transfer  
service** on-top of  
network

**Common PaaS cloud  
middleware** for  
integrated Trusted  
Research

Pan-European  
Sovereign research  
data **object-storage**

## Data transfer infrastructure for mid-range to large transfers

Supporting Research Infrastructures & Data Repositories, interfacing with HPC

Enabling seamless dataset management  
(moving on from bits and files)

Overcoming challenges in point-to-point data transfers

Optimising exploitation of network infrastructure

Maximising the network performance perceived by users



## Unified Platform-as-a-Service middleware for Virtual/Trusted research environment

Integrates NREN services (T&I, security)

Deployable on any infrastructure cloud (commercial and community)

Provides Virtual/Trusted Research Environment functionality to end-users

# Pan-European sovereign object-storage infrastructure for research data (archives)

Unified hardware platform, collectively procured

Simple object-storage interfaces

Enables temporary and flexible use of non-sovereign platforms

Ensures data safety with a copy in a sovereign solution

Capitalises on scale efficiencies and collective procurement capability

- A natural evolution of the forthcoming Research Dataset transfer network could be the provisioning of TREs and SPEs via a dedicated slice of this infrastructure, aimed at complying with stricter privacy and security constraints
- No implementation plans available yet - room for work in GN5-2 starting 1.1.2025



# Thank You

[www.geant.org](http://www.geant.org)



Co-funded by  
the European Union