Ethel Symposium: Looking forwards: towards an EHDS enabling infrastructure

Do research need to get data directly from people?
Norman Sabbah, TTSA

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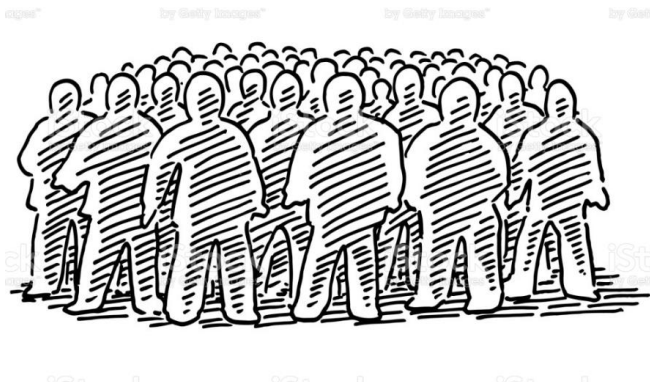the European Union

SITES ARE OVERWHELMED …

- Increased number of studies
- Lack of awareness of all studies on site
- Spread of study information across various supports
- Complexity of selection criteria
- Many HCP* not involved in the research activities
- Time prioritization: practice vs research

* HCP : Health Care Provider

…. HENCE RECRUITMENT DELAYS OCCUR

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HOWEVER, PATIENTS ARE OUT THERE

BUT ONLY **0,2%** **OF THEM***
ARE BEING REFERRED TO A STUDY

THE CURRENT SOLUTION LANDSCAPE

Historical databases

- Past clinical trials records
- Electronic Medical Records (EMR)
- Market data

Lack of data accuracy :
- Outdated data
- Competition not considered
- No HCP involvement

Promotional efforts

- Advertisements and selecting call centers
- Patient engagement materials
- Patient advocacy groups
- Social media

Increased workload for HCP :
- Referal of non relevant patient
- First patient selection not done by investigators

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BUT THE RECRUITMENT CHALLENGE REMAINS MAJOR

xShare project

Explore Business use cases in which the EEHRxF and the xShare Button demonstrate value for clinical research **with a patient-centric approach**

3 BUCs detailed
- *Patient's prescreening*
- *Study feasibility*
- *Study support*

→ BUC situation simulation

BUC : Patient pre-screening

Paul is willing to know if a CT is compatible with their health condition

Paul IPS

37 yo
Active CD
Under Azathioprine
Interolerant to Infliximab
Iron deficiency Anemia

PHR
EEHRxF
data

Data Sharing

Prescreening Tool' questionnaire

Results on the PHR :

80% of compatibility with FAST Ongoing in Hospitals Paris, Lille and Lyon

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BUC : Patient pre-screening

Share EHR Xchange Format

Results on the PHR :

80% of compatibility with FAST Ongoing in **Paris**, Rennes and Lyon

PHR EEHRxF data

Data Sharing to **Paris' hospital**

Critical prescreening information validation through additional questions

FAST requires 3 additional colonoscopies

H

On-site visit

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Let's go for a demo !

Paul is eligible and agrees to signs the ICF and is included in the FAST study in Paris' hospital.

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Any questions?

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