Who is the customer in data re-use?



1

Many Not-For-Profit [NFP] groups ruin their business models when they focus on selling to the wrong person. Income drops, fingers are pointed, panic ensues."

"The **Customer** [of an NFP]: This is the **person with influence over the decision**, either because they're paying for it, or because they can persuade whoever is paying. They make an active choice to support you, so we need to delight them.

The **End User** [of an NFP]: The **person who ends up experiencing** your product or service.

The **Beneficiary** [of an NFP]: The **person whose life improves** because of your product or service."

https://isaacjeffries.com/blog/2016/3/1/customers-end-users-and-beneficiaries



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- Is it worth distinguishing CUSTOMERS, END USERS and BENEFICIARIES if looking for ways to strengthen trust (as well as funding, financing and legal environment)?
- Is it a risk for policy makers if their attention falls on the beneficiary (instead of the customer or the end-user)?
- Who are the customers, end users and beneficiaries of handling big data in health within the existing EU regulatory framework to ease the uptake of innovative usage of data across the healthcare sector for the benefits of society, individuals and performance of Member States health systems?
- Can end-user be more important than the person with a direct influence over the decision who is paying the bill or approving confidentiality, security and accessibility?
- How to develop digital health literacy of customers, end users and beneficiaries to strengthen empowerment and adherence to data sharing and re-use?
- What is the product/service exactly, and who is producing/providing it?



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HEALTH DATA and BIG DATA SERVICE INFRASTRUCTURE/SPACE			
Stakeholders	CUSTOMERS	END USERS	BENEFICIARIES
PATIENTS			
FAMILIES			
EMPLOYERS			
INSURANCE ORGs			
PUBLIC INSURANCE			
GRANT DONORS			
CARE PROVIDERS			
PROFESSIONALS			
RESEARCHERS			
DATA PROTECTION			
MED/MED.D. AGENCIES			
POLICY MAKERS			
INDUSTRY/INNOVATORS			



Work Package 5 – Innovative Use of Health data VIRTUAL WORKSHOPS ON COMMON GOVERNANCE PRINCIPLES FOR THE RE-USE OF HEALTH DATA - DAY 2. Public Health and Research, Wednesday, 24 June 2020