HAVE PATIENCE WITH “NO PATIENTS!”: TIPS FOR RECRUITING USERS FOR HEALTH UX

One of the rude shocks of a User Experience Researcher first working in healthcare is almost no access to the real users – the patients. It’s fair to say that my work in telehealth is nothing without users! So I’m sharing here some tips for gaining access to patients, gleaned from my 5 years of working in a healthcare setting and with Health Care Professionals (HCPs).

Firstly, patient access is a negotiated affair.

- It takes trust
- And trust takes time

When you first ask for patient access, there are all kinds of replies. But at its core is:

- We (the HCPs) are not ready
- Our organizational processes are not ready

What the real issue is, is that the HCPs in charge have never done this kind of work before, and they are understandably risk averse whenever it comes to any kind of patient contact.

WHAT DO YOU DO?

1. **Accept it**
    1. have patience when there are no patients
        - it takes time for them to trust you
        - being pushy will merely raise shields
    2. do one or two projects with no patients first
        - when using patient proxy data, the quality of your user experience data will naturally be compromised
        - advise the stakeholders in advance
        - and keep these initial projects short and low-risk/low-cost so that everybody gets to dip their toes in without the water boiling over.

2. **Realize that even when the HCPs you liaise with seem ready, they aren't really ready**

    1. with time and trust, you may be given some patient access
    2. this is not a time for celebrating yet, as often this access will still be highly constrained

        - *"you can interview patients, but you can't observe them!"*
        - *"you can give them test kits, but they can't actually use them!"*

    3. have patience and let the data speak for itself
        1. get good/convincing data with what access you *do* have
        2. show the truth
        3. gain trust when stakeholders realize this information is really *really* useful

3. **When they are ready cooperate with them at all times to ensure that existing protocols and guidelines are still being met**
    1. do consent forms
    2. observe any and all guidelines HCPs may place on you. Even adhoc ones, because HCPs are also learning as they go.
    3. store data securely – there is no such thing as a simple data leak in healthcare

> ***FINAL NOTE: CREATING PATIENT ADVOCACY GROUPS MAY HELP CUT THROUGH SOME OF THESE BARRIERS MORE EFFICIENTLY, BUT THAT REQUIRES A BASIC TRUST AND EXPERIENCE WITH PATIENT VOICE THAT HAS TO BE EXPERIENCED BY THE HEALTHCARE ORGANIZATION FIRST.***

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