Communication Strategies for Rare Diseases - Norway aiming for AI and chatbots

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Norwegian National Advisory Unit on Rare Disorders

Norwegian National Advisory Unit on Rare Disorders work for better quality of services, empowering patients, making rare disorders more visible in society, ensuring easier access to knowledge and services, and strengthening collaborations of professionals. We also work towards more effective use of resources. Innovation in communications play a central role in getting there.

The advisory unit consist of nine national Centres of Expertise on rare disorders where patients, their families and professionals can seek help and advice. The centres cover ca 700 rare disorders today. This means that some target groups <u>need more information and advise finding help</u>.

Recent inquiries show that especially young people hesitate to call our national help line for rare disorders, and that chat functions and online services are emerging. More precise and reliable sources are needed to help people finding correct information and advise. Our experience from service design proves it is time to focus on artificial intelligence and chatbots in supporting - not replacing - human advise.

Reliable and updated information on rare disorders

Our target groups range from people with a rare disease to society, politicians etc. Better health care, empowerment, relevant research and good decisions depend on good information. This is crucial for all target groups of Norwegian National Advisory Unit on Rare Disorders:

Patiens - often referred to as «users», or «usergroups» Politicians, pharm. industry, media, society in general Parents, siblings, family, other relatives Professionals, researchers, health care providers, expert groups, local health auth.

Collective trust, design & visual expression

Giving good advise depends on trust. Norway's highly educated and technically skilled youth have a very high degree of trust in their government and institutions (International democracy study, ICCS 2016).

Norwegian National Advisory Unit believe that search engines cannot replace a trustworthy governmental platform when it delivers internationally trusted, reliable, fast, up to date advise.

All health services in Norway use this symbol: A blue "cross" made of five dots, symbolising Norway's five health regions. Examples:



All national advisory units in Norway has five dots dark blue as logo element to show national mandate.

All logos: © Melkeveien AS, commissioned by Ministry of



South-Eastern Norway Regional Health Authority. All regional health authorities and state hospitals use dots of dark blue to show region.

Artificial Intelligence (AI)

What?

- "Artificial intelligence (AI) is intelligence demonstrated by machines» (Wikipedia)
- Watson from IBM is one example of AI in health services and diagnosis tools
- Al in chatbots are used in various messaging apps, for example on Facebook

Why?

- Al can help to structure vast amounts of information, faster and more reliable
- Al can keep score on research, recent developments and changes, up to date
- Al can provide "aided search" online, and simple chatbot dialogue, helping most target groups on their way, 24/7

How?

- Strategic national and international cooperation for sharing data & code lists
- Using national and international databases to educate AI in rare diseases
- Making chatbots for Norwegian hospital and governmental webpages, and on social media such as Facebook messenger

Timeline chatbot development

2016

2017

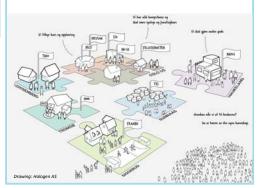
2018

2019

- Onboarding Innovation Center at Oslo University Hospital & Halogen AS
- Piloting service design project, youth surveys etc
- Learning from other health regions and tech businesses
- Setting up strategic cooperation with national bodies, businesses, researchers, care givers etc
- Strategic cooperation with national bodies (Helsenorge.no)
- Strategic cooperation with international bodies (Orpha.net)
- Estimate budgets and technical requirements
- Setting up project organization
- Funding granted
- Start up

Disorders and centres online today

Rare disorders and Norwegian centres in alphabetical order: http://Helsenorge.no/Sjeldnediagnoser



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