How can data be better utilized in the future of women's health?

Aarhus University, Health – PhD workshop 2024

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"Denmark has some of the world's best and most detailed health data as a result of our long tradition of recording and journalizing the Danes' diagnostic and treatment programs.

There is great potential in utilizing this data to create better and more effective treatments, better clinical trials, and to add more value to both patients and our community overall."
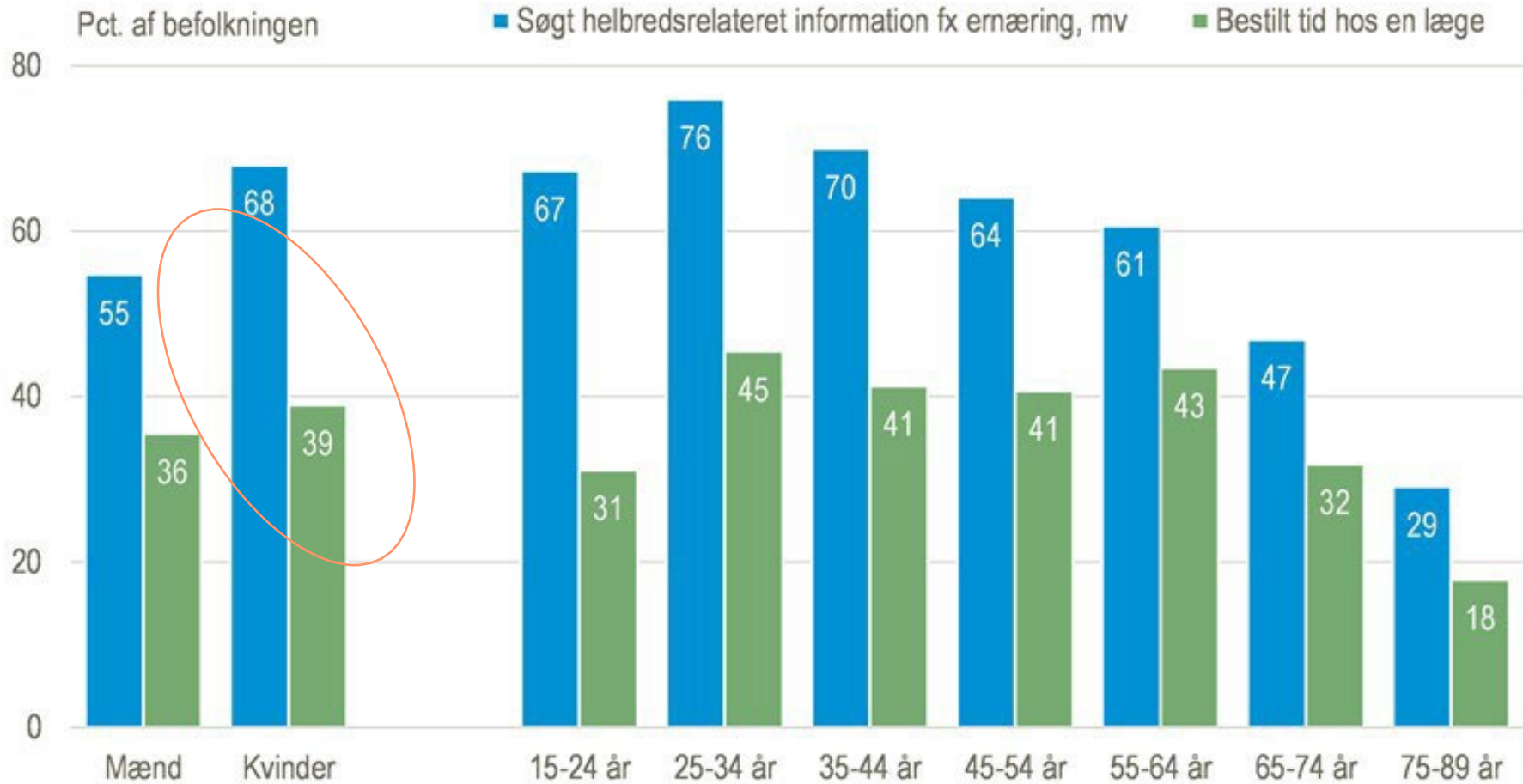
Challenge outline and background

Women's role in healthcare

- Women, who are still the main caregivers in the majority of families, have a leading role in healthcare decisions for both themselves and their families. Oftentimes, they are their families' chief medical officers, making 90% of the health care decisions, and also their communities' care-givers with over 70% of healthcare workers being women. Unfortunately, they are also the ones that experience a high gap in healthcare access. Therefore, they need to be equipped with the adequate knowledge and tools to satisfy their multiple roles as decision makers and, at times, patients. But health systems around the world—no matter how advanced—are failing women.

- Every woman should feel empowered to have an active and informed role in her own health care decisions, from prevention through to treatment.

- Healthcare is not one-size-fits-all. We can aspire to provide every woman with personalised healthcare — tailored not just to their clinical characteristics, but also to their personal preferences, priorities, as well as societal considerations.

Data and womens health
Especially women use the internet for health-related issues

Sundhedsrelateret internetbrug. 2016

Pct. af befolkningen   ■ Søgt helbredsrelateret information fx ernæring, mv   ■ Bestilt tid hos en læge

|	Mænd	Kvinder	15-24 år	25-34 år	35-44 år	45-54 år	55-64 år	65-74 år	75-89 år
Søgt helbredsrelateret information	55	68	67	76	70	64	61	47	29
Bestilt tid hos en læge	36	39	31	45	41	41	43	32	18

elvie

Women have never been more in control of their own health and as a result, there has never been more available data about them.

The rise of wearable technology, Femtech and at-home health solutions have offered us all unprecedented ways to understand and manage our health. Every day, five million people download a health app.

There is huge potential in data collected from digital platforms tracking women's health e.g. menstrual tracking apps, like Clue, at-home hormone tests like those designed by Thriva, fertility apps like Natural Cycles, new hardware and product innovations like those developed by Elvie and data used by companies like Niramini using AI and machine learning to detect early stage breast cancer.
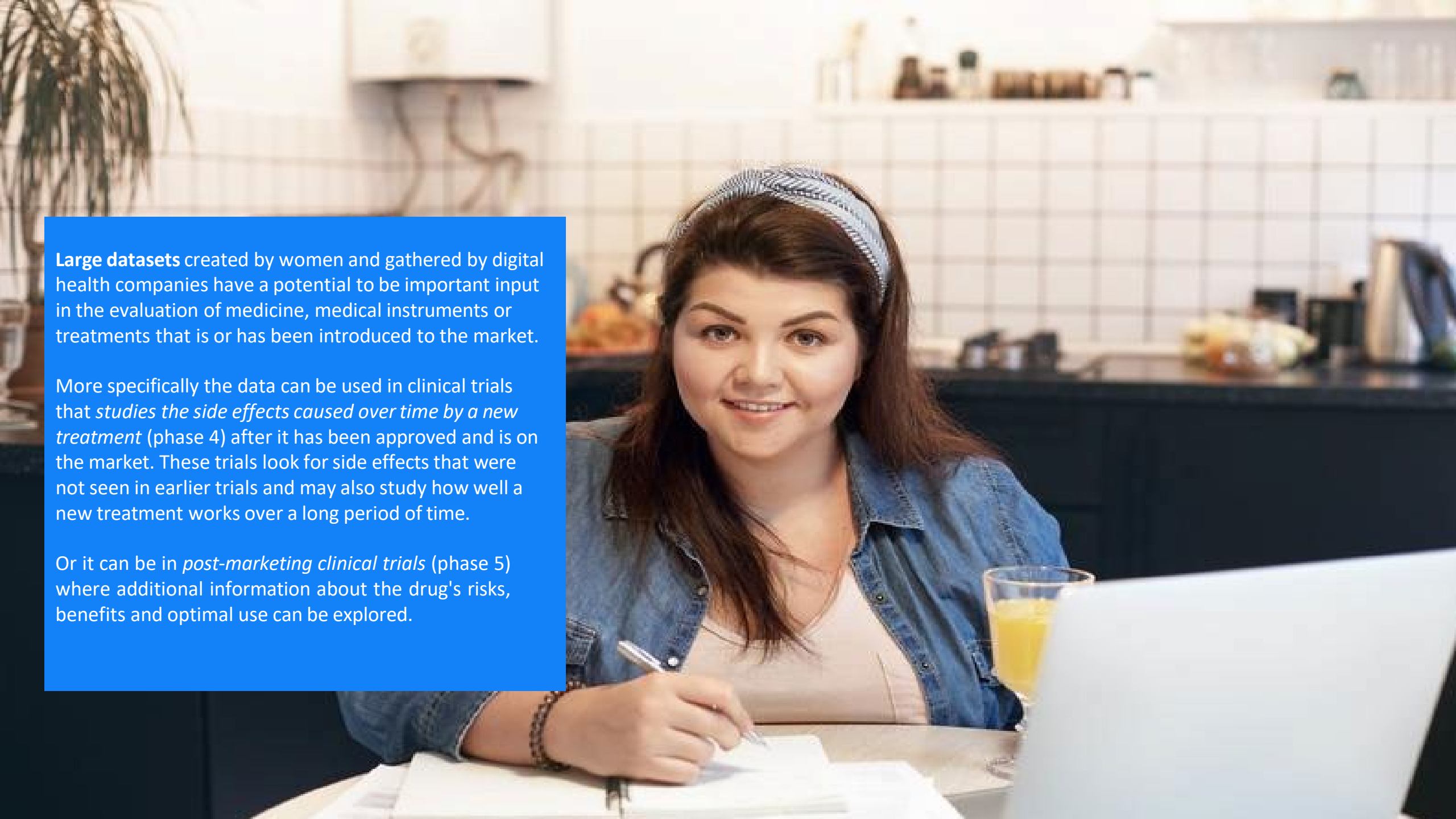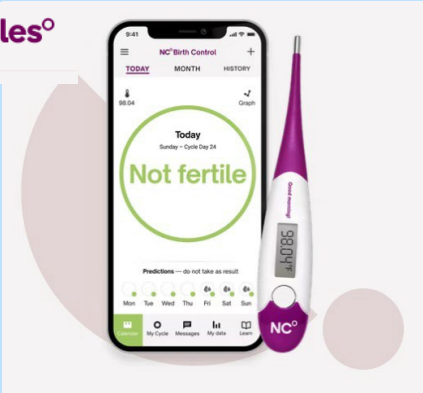

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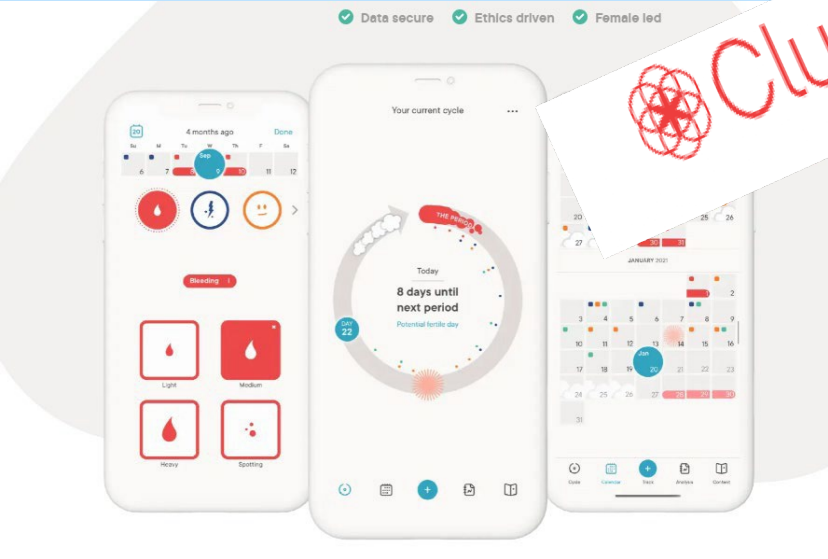
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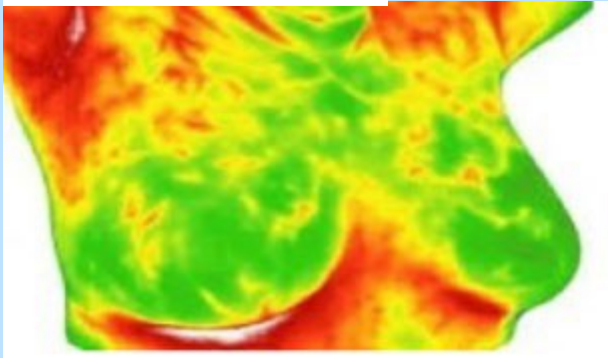
Natural Cycles°

Data and womens health

- In recent years we have started to see a move towards personalization in healthcare and, as part of that, a greater understanding of women's health. Powered by the rise in digital and proactive health, unlocking new opportunities to use data and Artificial Intelligence to improve healthcare for women across the world.

- Large datasets gathered by digital health companies, which are tapping into the proactive health trend, are proving critical for researchers understanding women's health and developing new treatments.

- This paves the way for new products or medicines and unlocks an opportunity for a truly preventative model of care, as clinicians will be able to use data and AI to determine which patients are most likely to be at risk from diseases before they materialize. Clinicians will be able to use data to determine which patients are most likely to be at risk from diseases and the focus of healthcare can shift from cure to prevention.

Source: https://www.med-technews.com/news/Digital-in-Healthcare-News/how-data-use-will-revolutionise-women%E2%80%99s-healthcare/

Large datasets created by women and gathered by digital health companies have a potential to be important input in the evaluation of medicine, medical instruments or treatments that is or has been introduced to the market.

More specifically the data can be used in clinical trials that *studies the side effects caused over time by a new treatment* (phase 4) after it has been approved and is on the market. These trials look for side effects that were not seen in earlier trials and may also study how well a new treatment works over a long period of time.

Or it can be in *post-marketing clinical trials* (phase 5) where additional information about the drug's risks, benefits and optimal use can be explored.

OSCAR – an example of how the Industry is working, in public-private partnerships, for better use of data
One-Stop-Shop for Clinical Research

- OSCAR is a public-private partnership project support by the Danish Innovation Fund. OSCAR is a platform that supports value-based health care by creating a sustainable business model for a One Stop Shop for Clinical Research that can facilitate experimental clinical research enriched with high quality Danish data and support usage of Real-World Evidence.

- OSCAR will develop, test and implement a Virtual Public Register (VPR) platform and document how this will create value for and excel the development of a sustainable health sector. VPR is an IT platform for collecting, anonymizing, linking, sharing and analyzing health data from public registers and data sources through Secure Multiparty Computation (SMC) encryption technology. With this platform, it becomes possible to create data analyses on a patient level efficiently, safely and confidentially.

- One outcome of the project is to test a model for enriching experimental clinical research with historic health data and patient-generated health data to enable usage of precision medicine in treatments

But there is still challenges…

Challenge statement

How can data be better utilized in the future of women's health?

The team may focus on one of these challenges:

- **Better use of women's health data for diagnoses and treatments**
How could we enable early diagnosis and better treatment outcomes by use of self-reported health data?

- **Better use of women's health data for Clinical Trials**
How can data collected by women in women health tools be used for better detection of unintended side effects of medical treatments and solutions (Phase 4/5 Clinical Trials)?

- **Tools and measurers**
What kind of tools would be useful in collecting and utilizing self-reported data, and how can the quality of self-reported data be investigated and verified?

- **How can we accelerate trust in data sharing ?**
How can we accelerate trust in data sharing and motivate individual citizens to share more of their data with projects, organizations and institutions with legitimate interests in this data - and thereby help create valuable insights and solve critical societal challenges?

- **Political recommendations**
What kind of structural changes should be implemented to increase the use of self-reported data?

The pitch can describe elements like

1. What is the solution? Who is the target group for the solution?

2. What kind of health data is needed for the solution? *(self-reported and registry data)*

3. Is the data needed for the solution already available, or is there a need for additional data?

4. Scalability and potential effect of the idea?

Additional reading

Additional reading and background information

DATA for GOOD Foundation is a Danish not-for-profit organization that promotes individual data rights and equip citizens with digital tools that allow them to exercise their right to data portability and make more data available for common good purposes.

https://dataforgoodfoundation.com/

The shared vision of the **OSCAR project** is to create a sustainable platform for better use of Danish health data in partnership with private companies and public organizations. The platform will ensure better access to health data in a secure manner that preserve personal data privacy protection.

https://www.oscar-project.com/

List of top 100 women and **solutions in femtech**

https://medium.com/women-of-wearables/top-100-women-in-fem-tech-and-health-tech-34eccf021053

Roche is committed to women's health at every stage of her life.

https://www.roche.com/solutions/focus-areas/womens-health/

Doing now what patients need next