



# Collaborating with Patients and Next of Kin: Towards a Culture of Equal Partnership

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Nordic Biobank Conference 2022

# Conflict of interest

No known conflicts of interest.



# Culture of Equal Partnership Core Team



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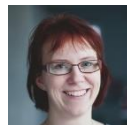
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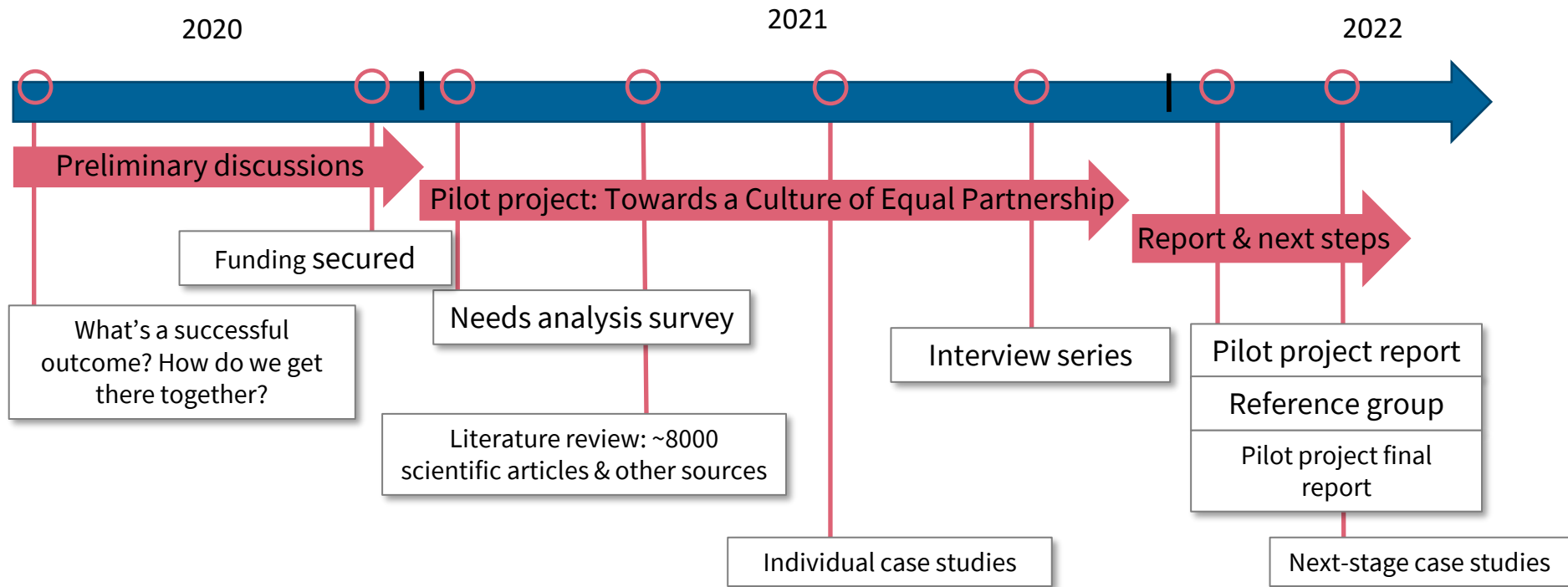


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The network against cancer



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Patient researcher

# Project timeline 2020-2022



# Positive outcomes of equal partnerships

## Equal partnerships...

- build trust, both in partnership initiatives and in the system as a whole
- contribute to efficiency, quality and patient safety
- give a better overview of the full scope of the healthcare process
- contribute more perspectives – and as a consequence more potential solutions to challenging problems
- lead to better healthcare economy
- contribute to improved study protocols
- help us measure results better
- make it easier to recruit study participants
- increase the individual's commitment to their own care process
- boost public interest in and support for research
- lead to a wider dissemination of research results
- contribute to a better quality of research
- improve chances of research funding

...so with all these positive outcomes in mind, why don't we see more successful partnerships in healthcare and the life sciences?

# Obstacles on the way to equal patient and next of kin partnerships

- No culture regarding the involvement of patients in innovation, health care, clinical studies, research and development
- No standard for involving patients in design, planning, implementation and evaluation of prevention, treatment, clinical studies and rehabilitation
- No governmental structures on patient involvement in research and health care, no reimbursement structure and no long-term strategies
- Few or no tools for addressing representation and power imbalances in partnerships
- No culture of dissemination of positive and negative outcomes

...but it can be done!

# A positive real-life example

A government working group

- listened to patient advocates – implemented **co-creation** as a working method
- patient and professional expertise were **valued equally**
- involved the patients in **design, implementation, and evaluation** of the project
- **clear goals and evaluation criteria** were formulated, involving everyone in the process

## The result:

Everyone worked together for mutual understanding and a strengthened partnership, which was much more positive for both patients and healthcare professionals - it also led to significantly increased efficiency – which in its turn leads to better results and reduced costs.

# Equal Partnerships: the report



Topics addressed in the report:

- What are the potentially positive outcomes of partnership initiatives?
- Why do some potential partners, like clinicians and researchers, hesitate when it comes to partnering?
- What are the most common challenges faced and mistakes made in patient and next of kin partnerships?
- What can be done to overcome those challenges and avoid those traps?

Questions we have been getting frequently:

- Starting small and building up towards better partnerships little by little. Can it be done? (Yes.)
- Is there a checklist for that ? (Yes, go to page 34.)
- Are there any guides to other resources if we want to learn more about the patient and next of kin partnership field? (Yes, check out appendix 6 and 7.)
- What do all these acronyms mean anyway? (There are so many! But appendix 5 will hopefully help.)



# Equal Partnerships: the limitations

The individuals in our reference group raised many interesting points that were beyond the scope of this report, but that have been included as topics for further discussion in an appendix.

We hope we will be able to dive deeper and to address at least some of these issues in the upcoming discussion with all of you here today.

Catharina Barkman (Forum för Health Policy), Britta Berglund (Riksförbundet Sällsynta diagnoser), Anna Blommengren (Karolinska universitetssjukhuset), Mats Brömmels (Karolinska Institutet) Helena Conning (Nätverket mot cancer), Kristina Gustafsson Bonnier (Riksförbundet Sällsynta diagnoser), Sonja Eaker (Biobank Sverige), Roger Henriksson (Umeå universitet), Eva Jolly (Karolinska Comprehensive Cancer Center), Siri Kautsky (RCC Stockholm Gotland), Dag Larsson (Lif), Karin Lilja (Swelife), Frida Lundmark (Lif), Lisbeth Löpare Johansson (Sveriges kommuner och regioner), Anna Martling (Karolinska Institutet), Karin Mellström (Barncancerfonden Stockholm Gotland), Anna Nilsson Vindefjärd (Forska!Sverige), Peter Nordström (Swelife), Lars Palmqvist (Göteborgs universitet), John Stewart (Nätverket mot cancer)

We also want to take this opportunity to thank the members of the reference group, who were so generous with their time and expertise.





# Thank you!

A digital copy of the report can be downloaded via the QR code on the right.

You're also very welcome to grab a paper copy! They're available here in F3, and at Biobank Sweden's booth.

If you're interested in the forthcoming English version of the report, please e-mail Anna Clareborn, so she can add you to the list.

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