

# How 'public interest' is defined in practice - an interview project

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Precision Medicine / Genomic data platforms around the world

Many platforms apply public interest criterion

# Public interest is poorly defined in platform policies

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- Multi-interpretable concept
- Ethics committees reported fearing misrepresenting what is in the public interest
- In need of more clarity, transparency and guidance
- Owen & Ballantyne (2020) describe public interest to take into considerations beyond health and the positive and negative consequences of research



*Is research aiming to predict educational attainment  
based on genomic data in the public interest?*

*Is sharing national breast cancer screening data with  
a foreign company that develops screening software in the public interest?*

# Data Access Committees (DACs)

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+  
Our  
Future  
Health



# How is public interest defined in practice by DACs?

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- Who is involved in deciding what research is in the public interest?
- What considerations are taken into account?



*21 interviews with DAC members*

# Who decides?

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A.



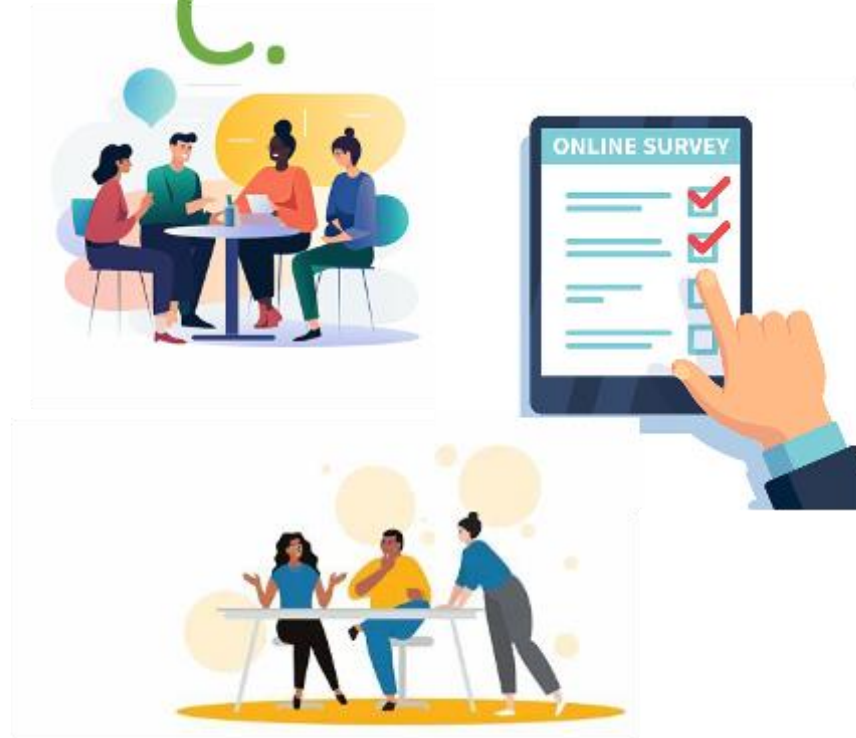
Scientific  
Experts

B.



Scientific, legal  
and ethics experts  
and public  
representatives

C.



Input from  
research  
on public  
perspectives

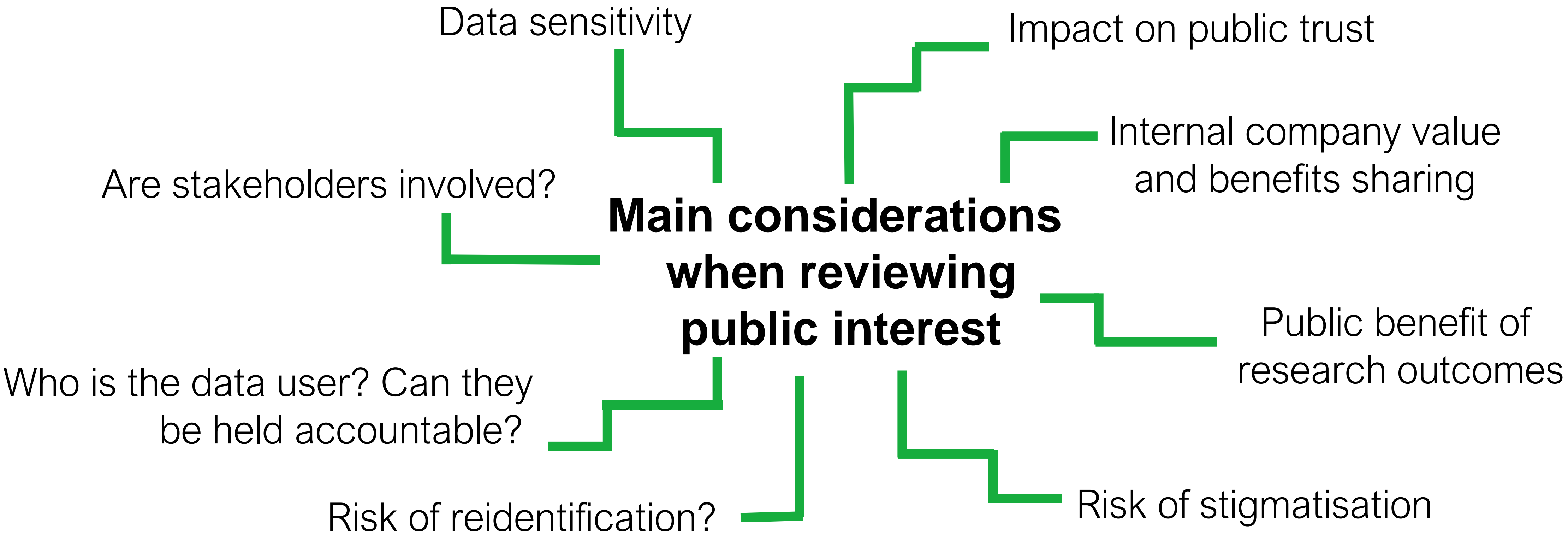
D.



DAC review depend  
on whether people  
object to research

# What is taken as relevant for deciding on public interest?

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