Risk disclosure and its consequences
Perspectives of asymptomatic research participants in the UK and Spain

Dr Richard Milne
Society and Ethics Research Group, Wellcome Genome Campus
Department of Public Health and Primary Care, University of Cambridge
when it comes down to what we want to use data and AI for, it is early detection and diagnosis. That’s, that’s one of the big ones for us. And [that raises] questions around, why would you want to know early?“

(digital health tech researcher, interview with RM, SPACE study 2020)
Consequences of risk communication to asymptomatic individuals

- ApoE result communication does not cause distress among the majority of people who do not have major anxiety or depressive disorders, and who display an interest in genetic testing
- REVEAL (11/14 studies)
  - Selected/non-representative populations
  - US based
- Some evidence of change in LTC uptake, behaviour change
- A small % of people did experience psychological effects
- Possible ‘nocebo’ effect
- Increased fears of employment discrimination
- Focus on short-term psychological effects (anxiety, depression)
- Over time, seen as valuable – but with lasting effects for some (Zallen 2018)
Approaches to the Communication of Alzheimer’s dementia Risk (ACAR)

1. What do older adults involved in dementia research expect would be the implications of learning Alzheimer’s dementia risk?

2. What expectations would they have of any disclosure process?
Approaches to the Communication of Alzheimer’s dementia Risk (ACAR)

Focus group based research in the UK (Milne) and Spain (Diaz) and with EWGPWD

N=61 (32 (20F/12M) in four groups in Spain, 19 (10F/9M) in four groups in the UK), 1 group of EWGPWD.

Information provided on changing approach to Alzheimer’s research

Thematic analysis around shared structured protocol
Background

Discussion influenced by family experiences

Some already felt that they were ‘at risk’ because of family history

Most people expressed interest in learning their risk status – but didn’t feel their desire to know was typical
“you’re not going to have an attack of Alzheimer’s, it’s more of a, it’s a ‘living with’ situation, which sometimes heart disease can be, obviously, but sometimes you don’t get the option of living with it!” (UK2)
The risk experience

At risk

With risk

Beyond risk
Living at risk
Reducing risk

“I think it's important to know to act. Although there is no medication, if factors such as diet, environment influence it, you can act somehow” (SP3)
Reducing risk

“What are we going to change? Do we eat better? But we already do that, or we should. Do we exercise more? We should do it. What are we going to change? . . . You will not change anything; I think, honestly.”

(SP4)
Pre-emptive suicide

“I want to know immediately, that is, even a risk of 80%, not 99%, to make my own decisions ... Bump me off before I get to be like my mother.” (SP2)
Living with risk
Informal vigilance

“It would have an impact on how I then lived my life, and how I conducted my relationships with others, and my work. I would be looking for the signs of it . . . I’m bad enough as it is.” (UK1)
“For me what is important about knowing the risk is early detection, a serious advantage is that you can monitor to diagnosis.” (SP2)
Living beyond risk
I would do many things if I knew that this was going to happen to me. I would spend more time with my family, I have a grandson of a year and a half and one of eight months. I would try to be with them as much as possible and all those things.’

(SP1)
Summary
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Similar conversations in UK and Spain

Learning one’s Alzheimer’s risk may have medium and long-term effects

These are neither clearly benefits nor harms, but disruptions that need understanding and supporting

Future relationships with families and healthcare need to be accounted for in preventative programmes
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