

INTEGRATING PATIENT REPORTED OUTCOMES INTO REGISTRIES



INTRODUCTION

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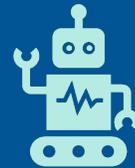
DATA DRIVEN RESEARCH WE CAN STILL DO BETTER...



Patient Reported
Outcomes are a start



Getting a richer sense
of individual
experience is essential



It adds nuance and
intelligence to the
"static" data



We are getting a grip
on representing the
static

WE NEED TO MAKE THE DATA MORE PERSONAL...

- ... which means the research and care communities know more about your experience
- Information Governance must work harder protect the data
- Regulatory Authorities need to work more with the research and patient communities to articulate the importance and benefits
- This means ensuring that basic approvals around Ethics and Data Protection are informed and established
- It also means we must balance the risk of ruining the nuance with protection measures



Questionnaires and the records you may keep are a start



They need to be reliably contributed



But you must be comfortable with what happens to the data



More than just research transparency



Requires patients and participants are informed and can engage if they want

INTEGRATING THE PERSONAL

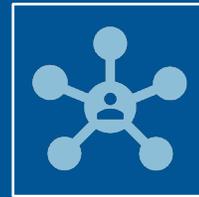
RIGHTS AND OPPORTUNITIES



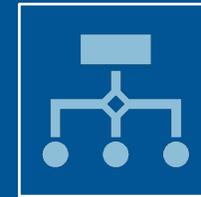
You must always have a chance to say yes please, no thank you or I have changed my mind



Your data can rarely be completely deleted, but you can require that it is no longer used



You can also join awareness networks, data access committees and indeed regulatory authority boards



FAIRVASC – after the registries are FAIRly Interoperating it will be an ongoing resource where access will be permitted by a data access committee

DATA ACCESS COMMITTEE

Should have more than one patient representative

Not the only way to be engaged

Think about the kinds of data you think would be important to share with researchers

Think about the kinds of research you want to see conducted



DISCUSSION