

# MAKING SPACE FOR HEALTH ACROSS THE EU POLICY AGENDA

CATHERINE GUINARD, SEPTEMBER 2015



**WHAT CAN THE  
PUBLIC HEALTH  
COMMUNITY  
ACHIEVE  
TOGETHER?**

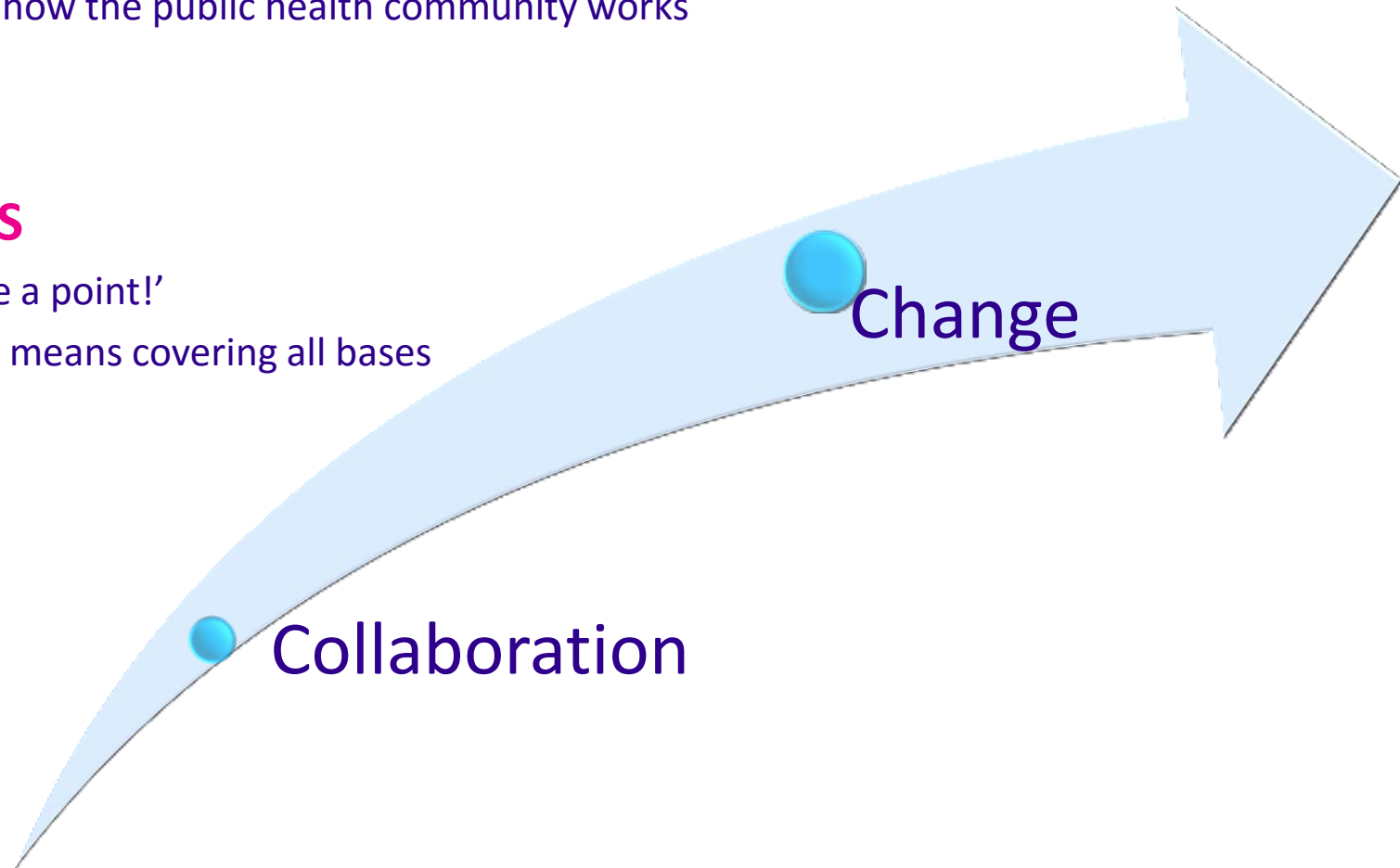
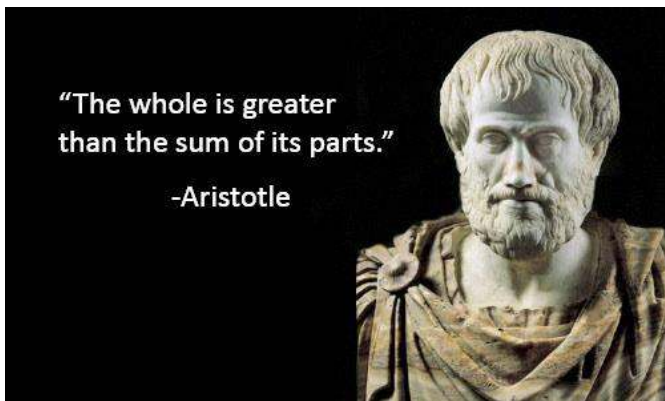
# ....AN INCREDIBLE AMOUNT!

## CHANGE NEEDS COLLABORATION

- Less well-resourced than other sectors
- Getting and keeping health on the political agenda needs concerted action
- Collaboration is ingrained into how the public health community works

## COLLABORATION WORKS

- Strategic: 'we DEFINITELY have a point!'
- Practical: genuine partnership means covering all bases



**HOW COULD WE  
MAKE CHANGE?**

# JUST ONE EXAMPLE (OF MANY)

## WHAT IT IS AND WHY IT WORKS

- Genuinely European
- Mix of patient groups and research organisations
- United around a common call to policymakers

## RESULTS

- Move the debate about personal data in research on
  - Raising profile of our issues
  - Build relationships
  - Interact with the people who matter

## EUROPEAN DATA IN HEALTH RESEARCH ALLIANCE





# Top tweets

**e!** **Ensembl** @ensembl · Feb 9  
Ensembl supports the Data saves lives campaign #datamattersEU



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**eupatientsforum** @eupatientsforum · Jan 26  
Anna from Latvia trusts health researchers to use patient data for the benefit of the society! #datamattersEU



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**EDHRA** @datamattersEU · Jun 16  
Chercheurs supportent la campagne @datamattersEU, pour une recherche adaptée #EUdataP bit.ly/1H7cEz#datasa... @GrosseteteF

YouTube



**Why The Data Protection Regulation matters to researchers**  
Researchers use personal data to make life better for all of us. Researcher Michel Coleman talks through why it is vital that the EU Data Protection Regulation is implemented.  
View on web

**Health eResearch** @HeRC\_Farr · Jun 1  
Dr Jon Read from @livuni supports the safe use of health data in conducting research #datasaveslives #datamattersEU



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**Theresa Griffin MEP** @TheresaMEP · Jun 17  
Great to meet @welcometrust @datamattersEU to discuss the upcoming general data protection regulation



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**EDHRA** @datamattersEU · Jun 16  
Vorfreude auf das Treffen mit a #EUdataP Diskussionen! #datamattersEU

**Catherine Guinard** favorited **Reumatikerförbundet** @reumatiker · Mar 25  
#datamattersEU  
datasaveslives.eu  
/Swedish Rheumatism Association



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**anna.molto** @annamolto · Mar 19  
Your data saves lives! #datamattersEU @datamattersEU



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**EDHRA** @datamattersEU · Jun 16  
Patients supportent la campagne @datamattersEU, pour une recherche adaptée #EUdataP #datasaveslives



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**Catherine Guinard** retweeted **Catherine Stinier** @C\_Stinier  
An interesting talk this morning #EUdataP with @CRUK\_F



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**EDHRA** retweeted **Glenis Willmott MEP** @GlenisWillmott · Jun 16  
Data for health and science day. Need to work together at EU level to share critical information & save lives @datamattersEU #DatamattersUK

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**...YET WE CAN'T DO IT ALONE.**



*“What does it mean for health and research?”*

**THANKS!**