



# Feedback from the Patient Forum

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# Return on (patient) engagement

## 'Let's do it and not just wish it'

- Patient input can make a huge difference, often in simple ways
- We have come a long way, but we need to do more, including patients from e.g. vulnerable groups, throughout the whole medicine life cycle
- Communication – between researchers & patients, & between projects, programmes on best practice
- We all need to step outside our comfort zone
- Willingness to take risks
- Who leads research agenda development?
- Education is important – for patients and for others
- Need to change incentives, especially in academia

# Big data and digital health

## 'My data are mine'

- Caveat – this is a huge, complex area! And there are no easy answers
- Trust essential
- Who owns the data?
- What is the purpose of the research? Who develops the agenda?
- What are the benefits of the research? For participating patients, for other (future) patients, other stakeholders...
- Big data = a means to an end, not an end in itself
- Challenge: speed of change in technology
- Collaboration essential for progress
- Data quality important (rubbish in – rubbish out!)

# Innovative models of engagement

## ‘Make science more fun’

- Returning themes – reciprocity, data, trust, transparency, education, openness
- Representativeness, including vulnerable groups
- Citizen involvement also important & complements patient engagement
- There is variation from country to country (one size doesn’t fit all)
- How to compensate patients fairly
- Patient involvement is a science and we need to share what we learn
- Success breeds success (media can help spread the good news)
- Create an environment where everyone feels valued
- Time is of the essence!

**Key words from today...**

**Trust**

**Communication**

**Collaboration**

**Let's do it!**



**Thank you**

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