

# Clinical trials: the patient perspective

*and importance to  
healthcare communications*



Just

3

thoughts



NetworkPharma: Presentation, Dr Alex Wyke, PatientView  
June 19<sup>th</sup> 2014

AstraZeneca 

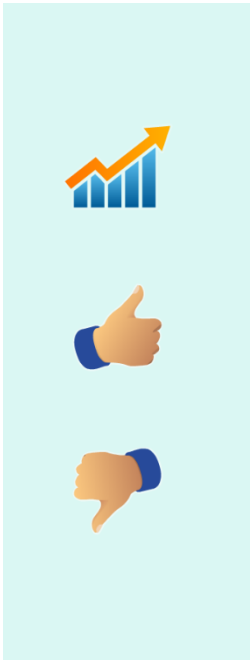


# Thought ①

Patients need to be persuaded of the **value** of the clinical trial process

... through **inclusion** in that process  
—from beginning to end





In 2011, PatientView asked patient groups to specify where they thought future NHS budget should be spent —the answer was **not on technology**



Source:  
2011 PatientView  
study of 400 UK  
patient groups,  
*Value in Healthcare*  
(conducted for Hill &  
Knowlton Strategies)

Respondents doubt  
the promise of  
healthcare technology

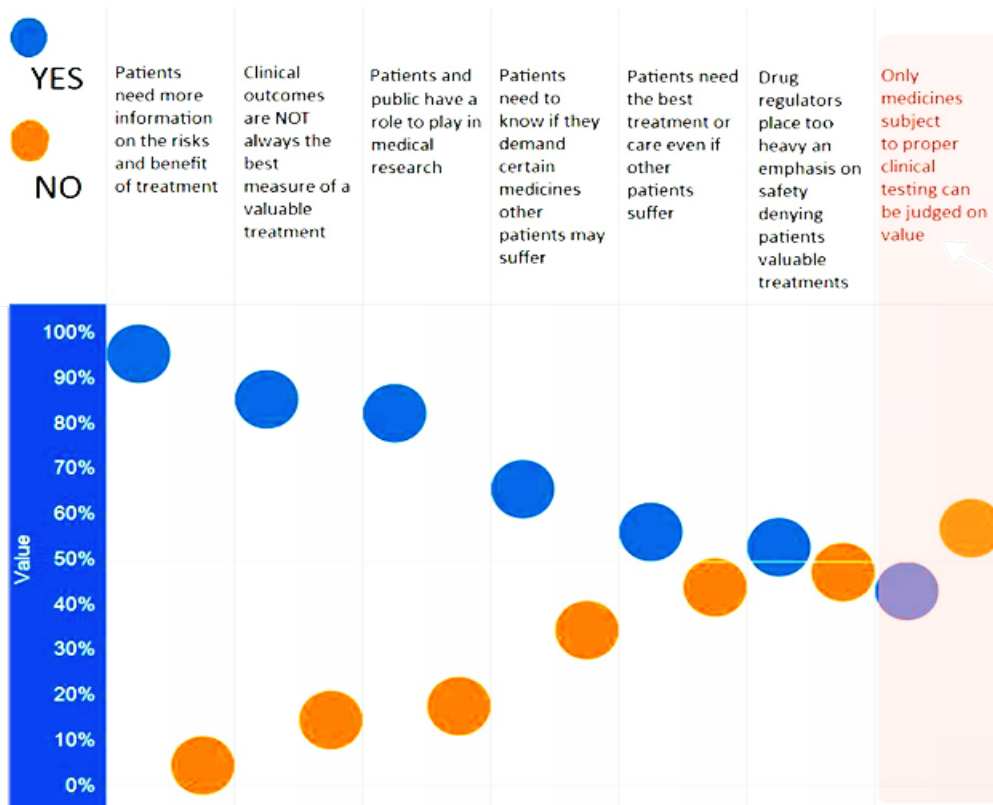
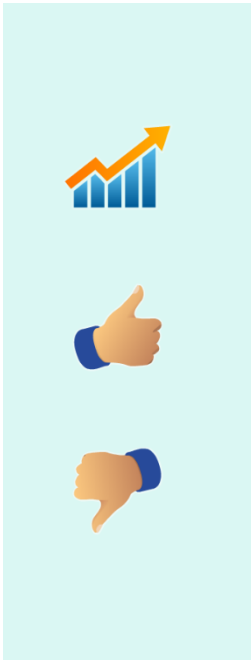


Invest more in preventive medicine, and less on treating illnesses	31%
Focus more on the healthcare needs of the most-vulnerable members of society—even if other people might experience a more poorly-funded healthcare service as a result	28%
Link the healthcare systems of neighbouring countries, so that these healthcare systems can all work more closely together—with the aim of cutting overheads, while improving standards across the board	23%
Invest more in healthcare technology (particularly drugs, medical devices, and e-technologies)—even if other parts of the healthcare system might be deprived of funds as a result	18%



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Patients are **not always persuaded** by the evidence that is provided on the efficacy and safety of drugs

Source:  
2011 PatientView  
study of 400 UK  
patient groups,  
*Value in Healthcare*  
(conducted for Hill &  
Knowlton Strategies)

- **Less than 50%** of UK patient groups agreed with the statement ...  
*“Only medicines subject to proper clinical testing can be judged on value”*
- **Just over 80%** of UK patient groups agreed that ...  
*“clinical outcomes are NOT always the best measure of a valuable treatment”*





## Patients want **a say** in health technology assessment —to make outcomes relevant to patients

*Percentage of patients who want to have a say in HTA  
to make outcomes relevant to patients*

Yes

52%

Sometimes

30%

No, this activity should be  
left to doctors

11%

I do not know

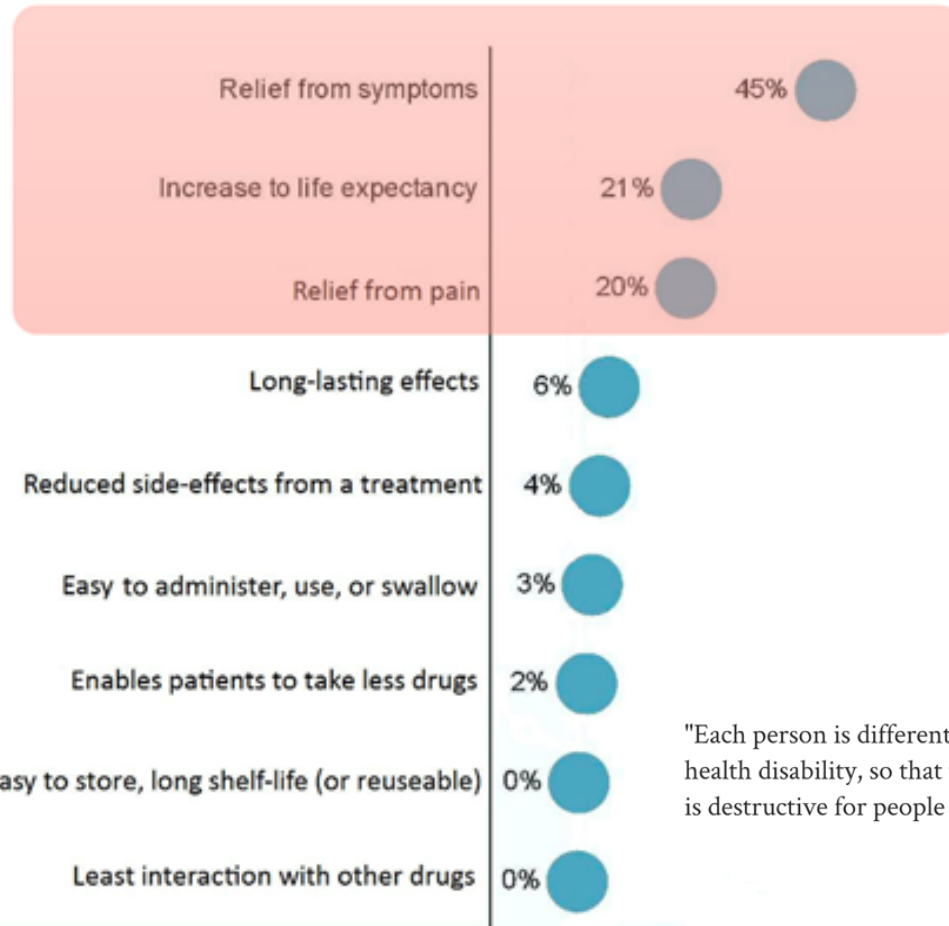
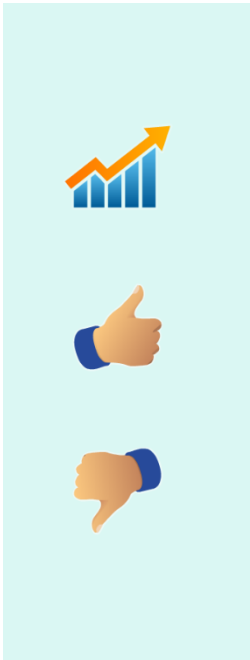
7%



Source:  
2011 PatientView  
study of 400 UK  
patient groups,  
*Value in Healthcare*  
(conducted for Hill &  
Knowlton Strategies)



# So, what do patients want from their treatments?



"Each person is different. People need education and help to study their health disability, so that they can manage it better. The 'one size fits all' is destructive for people with long-term health disabilities"

*-UK mental health group*



Source:  
2011 PatientView  
study of 400 UK  
patient groups,  
*Value in Healthcare*  
(conducted for Hill &  
Knowlton Strategies)



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## Thought ②

As active participants in the clinical-trial process, patients believe it their right to **access all** clinical-trial information ...

... in other words,  
they want **complete transparency**





## Potent advocacy on the subject



**AllTrials.net** calls for the publication of clinical study reports from **all** clinical trials since the 1990s (both positive and negative)



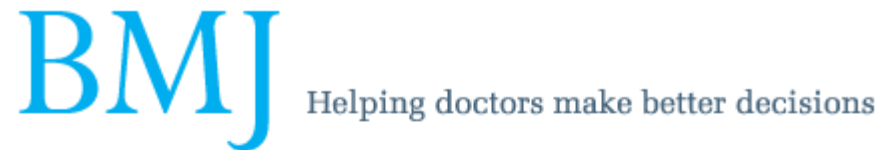
- *Signed by 476 organisations, including GSK*
- *78,689 signatures*







Potent advocacy on the subject



- *A step in the right direction, say campaigners*
- *But ... more needs to be done*



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## Thought ③

- The sharing of healthcare data, and
  - patient involvement in clinical trials (not just as subjects)
- will **both become vital**

... for big data to become viable, and  
to fuel further research





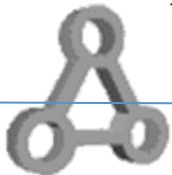
## People want their data to remain private ... unless they see the benefits of shared data

In the UK, a 2010 nationwide survey of 6,000 people by the New Economics Foundation (on behalf of the Wellcome Trust) found a majority belief that patients should be able to choose whether they are included in any digital database containing personal health data:



- 80% of adults wanted some form of consent mechanism
- 86% of young people wanted some form of consent mechanism

[http://  
www.neweconomics  
.org/sites/  
neweconomics.org/  
files/  
Who\\_Sees\\_What.pdf](http://www.neweconomics.org/sites/neweconomics.org/files/Who_Sees_What.pdf)





A growing global consumer movement dedicated to protecting individual digital privacy is now reacting to new e-technologies



**Electronic Frontiers**  
AUSTRALIA





A growing global consumer movement dedicated to protecting individual digital privacy is now reacting to new e-technologies



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So, a lot has  
to be done ...



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## Initiatives supporting **patient involvement** in the clinical trials process

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*Funded by IMI, the European Commission, the NHS*



**INVOLVE**



*Spearheaded by academics*



**The James Lind Library**

Explaining and illustrating the development of  
fair tests of treatments in health care

*Informational health apps*



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## Industry initiatives which can be used by patients

*Involving industry ... but, thus far, **only** available to researchers*

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Bayer, Boehringer Ingelheim, GSK,  
Lilly, Novartis, Roche, Sanofi  
and ViiV Healthcare ...

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Yale University  
School of Medicine

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